

FOREWORD.....	3
INTRODUCTION	4
ACKNOWLEDGEMENTS	5
SECTION 1 – COMMUNICATION AND SUPPORT	6
1.1 – Communication.....	6
1.2 – Difficulties With Communication.....	10
1.3 – Psychosocial Issues In Palliative Care	11
SECTION 2 – CONTROL SYMPTOMS	14
2.1 – Anorexia.....	14
2.2 – Ascites	17
2.3 – Bleeding.....	20
2.4 – Bowel Obstruction	23
2.5 – Breathlessness	26
2.6 – Confusion and Delirium.....	29
2.7 – Constipation	32
2.8 – Cough.....	35
2.9 – Depression	37
2.10 – Diarrhoea	41
2.11 – Emergencies in Palliative Care	43
2.12 – Hiccups	49
2.13 – Hypercalcaemia.....	51
2.14 – Insomnia	54
2.15 – Lymphoedema.....	56
2.16 – Nausea and Vomiting.....	59
2.17 – Oral Care.....	63
2.18 – Pain	69
2.19 – Pleural Effusion.....	78
2.20 – Pruritus/Itch.....	80
2.21 – Thrombosis	82
2.22 – Weakness and Fatigue	86
SECTION 3 – SYRINGE DRIVERS	90
3.1 – Obtaining a Syringe Driver from a Store.....	90
3.2 – Using a Syringe Driver.....	92
3.3 – Safety Checks and Callibration	108
SECTION 4 – CO-ORDINATION OF CARE.....	110
4.1 – Introduction & Directory of Services.....	110
4.2 – Discharge of Patients With Complex Needs.....	113
4.3 – Gold Standards Framework Out-of-Hours Handover Form.....	114
4.4 – Gold Standards Framework Homecare Paperwork.....	116
4.5 – Marie Curie Services.....	118
4.6 – Forth Valley Palliative Care Pharmacist Network.....	121
4.7 – Psychosocial Oncology, Cancer Clinical Psychology Service ...	122
4.8 – Sample DNAR Form	125
4.9 – Social Services.....	127

4.10 – Strathcarron Hospice Referral And Admission Procedures	129
4.11 – Updating A Patient Note On Taycare.....	132
SECTION 5 – CARER SUPPORT	133
5.1 – General Information	133
5.2 – Local Services	135
5.3 – Benefits Information	136
5.4 – Respite Break Information	144
5.5 – Regional and National Organisations	148
5.6 – Telephone Help Lines	150
SECTION 6 – CARE OF THE DYING	151
6.1 – Last Days of Life	151
6.2 – What To Do After A Death	156
APPENDIX A – The Grieving Process	162
APPENDIX B – Bereavement Support Assessment Tool	163
APPENDIX C – Sample of a Simple Genogram	165
APPENDIX D – Mesothelioma Proforma	166
SECTION 7 – CONTINUED LEARNING	171
7.1 – Cancer And Palliative Care Education Opportunities.....	171
SECTION 8 – OTHER USEFUL INFORMATION	174
8.1 – Adults With Incapacity.....	174
8.2 – Blood Tests in Palliative Care.....	177
8.3 – Cancer Bacup.....	178
8.4 – Complementary Therapies In Palliative Care	179
8.5 – Driving and Opioids	187
8.6 – Infection	189
8.7 – Nutrition in Palliative Care	191
8.8 – Paediatric Palliative Care	196
8.9 – Sexuality in Palliative Care.....	203
8.10 – Spiritual Care In Palliative Care	206
8.11 – Steroids In Palliative Care	208
8.12 – Travelling with Controlled Drugs.....	211
8.13 – Using Medicines Outwith their Marketing Authorisation or Without a Marketing Authorisation in Palliative Care	214
GLOSSARY OF TERMS / ABBREVIATIONS.....	216

Foreword

The NHS in Scotland is in the process of implementing a challenging programme of change which will have significant implications for those who receive palliative care, those who deliver it, and for the care settings in which it is provided.

It is widely acknowledged that all of the proven benefits of good palliative care should be extended beyond malignant disease to embrace the whole spectrum of chronic and progressive illness. This will mean that a wider range of health care professionals will be involved in providing the required care and support for patients and their families with more extensive palliative care provision and a wider range of care settings including the acute sector, intermediate care, community hospitals, hospices, care homes and other community settings.

If this care is to be delivered in a safe, effective and cohesive manner which consistently reflects best practice then it is essential that there is in place a practical framework which will guide professional staff and which will command their confidence and respect.

The Local Managed Clinical Network in Palliative Care in Forth Valley is therefore to be commended for all the hard work which has gone into the production of just such a tool – The Palliative Care Manual. Quite apart from the professional satisfaction which staff will derive from the knowledge that their practices are at the “leading edge” the real beneficiaries will be patients and their families who will be able to enjoy the quality of care and support to which they are entitled.

This is an excellent piece of work which will not only guide practice but will also inform supporting education programmes. Critical to its continued relevance is the commitment which the Local Managed Clinical Network has given to maintaining its quality and currency.



Professor Frank Clark, CBE
Scottish Partnership for Palliative Care

Introduction

At its inception, one of the objectives of the Forth Valley Local Managed Clinical Network (MCN) in Palliative Care was to produce a Palliative Care Manual for use in all care settings. The aim of the guidance was to facilitate consistent delivery of care and support to patients and relatives and to allow professionals and carers to anticipate problems and avert potential crises.

Members of the MCN agreed that the manual should be accurate, easily accessible (both on paper and electronically), informative, organised and user-friendly and that the sections should correspond to the Gold Standards Framework and allow incorporation of the Liverpool Care Pathway for End of Life Care. In addition, it was felt that the contents of the manual should be referable to patients with chronic and progressive disease as well as those with malignancies. A questionnaire to representative staff in Forth Valley confirmed our thoughts.

The development of this manual is a demonstration of altruistic collaboration and excellent multi-disciplinary teamwork and I wish to record my personal thanks to all the contributors – authors, peer reviewers, MCN manager, chair and members. I also wish to acknowledge the contributions from those outside Forth Valley. In particular, I am indebted to Dr Kirsty Boyd, Co-ordinator of the Lothian Palliative Care Guidelines, Dr J. Adams, author of “ABC of Palliative Care - The Last 48 Hours” and Dr Nicola Pease, author of “Driving and Opioids – Patient Information Leaflet” for permission to use or adapt their documents in the present guidance.

In addition to the core manual, various stand-alone documents have been included as appendices or as additional material in the pack folders. Where indicated, these may be reproduced; where bound by copyright, further copies may be obtained by request.

Guidance is most comprehensive if it can be reinforced and integrated easily into day-to-day practice. To this end, various education strategies are proposed to coincide with the launch of the Manual. It is recommended that each Gold Standard Framework practice meeting incorporates an educational topic and we hope the Manual will provide a suitable foundation.



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Section 1 – Communication and support

1.1 – Communication

Communication is always a fundamental component of the management of palliative care with both patients and relatives.

Speech and language therapists (SLTs) are a useful resource to advise on communication and give ideas on ways to maximise and enhance communication.

Communication includes :

- listening with care
- clarifying questions
- responding with openness
- considering the need for alternative or augmented communication
- monitoring, reviewing and adapting your own communication to meet the needs of the person you are communicating with.

Communication is enhanced by :

- the environment
- availability of the practitioner
- sufficient time of the practitioner
- attitude of the practitioner
- using any alternative or augmentative methods of communication in place
- seeking the advice of an SLT if communication impairment is causing communication breakdown.

Function of communication is :

- to identify patients/relatives problems and concerns
- to encourage the patient's capacity of coping
- increase patient's sense of inner strength
- to establish and maintain relationships.

There is a close relationship between good communication and the provision of emotional support.

Key tasks in communication with patients

- Eliciting:
 - the patient's main problems
 - the patient's perception of these
 - the physical, emotional, and social impact of the patient's problems on the patient and family
- Tailoring information to what the patients want to know, checking his/her understanding.

- Eliciting the patient's reactions to the information given and his/her main concerns.
- Determining how much the patient wants to participate in decision making (when treatment options are available).
- Discussing treatment options so that the patient understands the implications.
- Maximising the chance that the patients will follow agreed decisions about treatment and advice about changes in lifestyle.

Sharing difficult information

Sharing difficult information consists of :

- verbal component
- responding to the patient's emotional needs
- involving the patient in the decision making
- dealing with the stress the situation causes
- involvement of family, friends
- dealing with the dilemma of giving hope when the situation is bleak
- issues of clarity and understanding of what is communicated.

Goals of sharing difficult information

- Ethical/legal aspect of patient's rights (autonomy/informed consent).
- Foster level of hopefulness.
- Foster psychological adjustment.
- Avoid unnecessary and possible harmful treatment.

Preparing to share difficult information

- Prepare yourself mentally that the information the patient will receive might emotionally upset him/her.
- Arrange for the meeting to happen in privacy and protect against interruption.
- Involve significant others with regard to the patient's wishes.
- Ensure you have all relevant information.

Giving difficult information (tailored to the individual)

- Establish the information needs by gathering information from the patient. Avoid making summations of what the patient knows.
- Find out what the patient is already aware of (e.g. can you tell me what you understand about your illness?).
- Find out what the patients want to know (e.g. are you the sort of person that likes to know exactly what is happening?).
- Clarify understanding of current situation and provide information in accordance with the patient's needs and desires.

Coping with patient's/relative's reaction/or distress

- Support the patient by acknowledging the distress the information might cause him/her.
- Observe and feedback how you see the information affecting the patients. Ask, "how has the news left you feeling?"
- Develop a strategy in the form of a treatment plan with the input and cooperation of the patient.

Avoid using blocking behaviour such as:

- offering advice and reassurance before the main problems have been identified
- explaining away distress as normal
- attending to physical aspects only
- switching the topic
- 'jollyng' the patient along.

Collusion (adapted from Faulkner A 1998)

What is it?

- Collusion is most often seen between relatives but may also occur between professionals.
- Relatives may ask health care professionals to withhold information from the patient.
- Collusion is generally an act of love or a need to protect another from pain.
- Colluders will often argue that they know the patient better than the health care professionals do and know 'what they can take.' They may also hold the view that telling the truth to the patient would take away hope.

Explore and explain

- Explore reasons for collusion.
- Explain to the relatives the patient's need for an explanation, that will enhance the patient's understanding of own situation, must be met.
- Negotiate access to the patient to check his/her understanding of situation.
- Promise not to give unwanted information to the patient.
- Explain to the relatives that once the reality of the situation has been accepted hope can be more meaningful and based on short term achievable goals.
- Check cost to colluder of keeping secret. Highlight the emotional cost of collusion, explore with the relatives the likelihood that the patient may be colluding as well and may be aware of or at least suspicious of the truth and is ready to discuss important issues.
- Explain that honest discussion allows the patient to be reassured about many points of concern and helps them to be calmer and to plan and readjust hopes and aims.
- Arrange to talk again and raise possibility of seeing relatives and patient together if both are aware of reality.

If collusion can be broken this can greatly enhance the quality of the patient's life and foster a more open relationship between patient and relatives.

Openness can avoid problems in bereavement 'if only' when loved one wishes they had talked more openly.

Health care professionals (adapted from Faulkner A 1998)

- Common problems in communication between colleagues include defining roles, boundaries, and differing philosophies of care.
- Attempting to see problems from a colleague's point of view can enhance relationship between team and lead to effective peer support
- Regular team meetings where problems are discussed and potential solutions explored, should lead to enhanced shared understanding between staff and a resulting improvement in concerted patient care.

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[Contents Page](#)

1.2 – Difficulties with communication

Speech and language therapists (SLTs) work with adults and children who have communication impairment and with the people who live and care for them. The difficulties which SLTs diagnose, treat and manage can be due to a wide range of causes.

The following examples are provided to indicate some of the many ways communication impairment presents and some strategies to support them. This is not an exhaustive list and the SLT service welcomes enquiries about how to help in individual situations.

Congenital difficulties

People born with a learning disability or cerebral palsy, may have established communication support mechanisms which they and their families or carers use routinely, e.g. communication passport, lightwriter or a sign and or symbol system.

There may also be well established advice about the rate and complexity of language with which the person copes best.

It may be necessary, therefore, to seek help from the SLT to ensure that palliative care is communicated in the most appropriate way for that person, for example :

- new symbols around pain management in a communication passport
- Information about any palliative care intervention provided in a clear simple format that can be discussed later by the person and the people who care for them.

Acquired difficulties

Higher cognitive problems following stroke or head injury may result in aphasia, dysarthria or dyspraxia.

If required, seek SLT support to make communication as effective as possible. Make sure any comprehension problems are identified.

Degenerative conditions such MND, PD or MS all often bring communication issues. An approach such as 'talking mats' can be crucial in helping establish quality of life issues and help decision making.

Cancer of the head and neck and laryngectomy cause difficulty with voice and articulation, but there is an expectation that reading and writing skills will be intact. Writing or using a lightwriter may become the preferred method for the person to express themselves and extra time will be required in the interview.

However, people with poor literacy skills need extra support and you should :

- ensure all information they need is explained fully to them verbally
- ensure sufficient time for them to indicate their views via gesture, answering Yes / No questions etc.

For more information and advice about these or other communication issues please use the following telephone numbers :

- Stirling Royal Infirmary - 01786 434078
- Falkirk & District Royal Infirmary - 01786 616154
- Alloa Health Centre - 01259 222477
- Stirling Learning Disability Team, Drummond House, Stirling - 01786 443722

[Contents Page](#)

1.3 – Psychosocial issues in palliative care

General psychosocial care involves the creation of a supportive, non-judgemental environment enabling patients and their families to express their thoughts, concerns and choices in relation to the illness. It involves the encouragement of open and empathic communication and a focus on, and respect for, the patient as a unique and autonomous individual.

It is widely recognised that distress associated with psychological and social factors is common in palliative care patients, and that palliative care should encompass the psychological, social and spiritual needs of the patient and family.

Psychosocial distress adds to the burden suffered by patients and families and disrupts the process of adjusting to a terminal condition. Much of the psychosocial support for patients with palliative care needs is provided by the health and social care staff involved in the day to day care of the palliative care patient. For some patients this will be supplemented by services provided by the voluntary sector in the form of support groups, telephone helplines and written information. For those patients who experience more extreme degrees of distress, referral to specialist services may be appropriate. A small number will require input from professionals such as psychologists, psychiatrists, social workers and chaplaincy services.

The psychosocial concerns of carers and families should also be addressed by health and social care staff. Research has shown that the levels of distress in families who are caring for patients with advanced disease, is often as high as for the patients themselves. For many families bereavement support will also be helpful. For the minority of families who suffer an abnormal bereavement reaction referral to specialist services may be appropriate.

A psychosocial oncology service has been set up in NHS Forth Valley which provides clinical psychology services for patients and families in addition to supporting, advising and training staff.

See psychosocial oncology service information in Section 4.7 of the manual.

Some of the most common psychosocial problems experienced by patients include :

- depression and low mood
- anxiety problems
- feelings of anger
- issues around dependency and loss of control
- relationship difficulties
- sexual dysfunction
- problems with drug and alcohol use
- body image problems
- fears about death and dying
- spiritual crisis
- worries about finances, housing and placement issues.

Some patients may also raise issues such as suicide or euthanasia and these should be fully addressed by staff working within the limits of their expertise. Many psychological and social problems can be addressed with appropriate psychotherapeutic, counselling and, in certain cases, psychopharmacological interventions. A holistic team approach with good inter-professional communication is vital, although this should be balanced with the need to respect patient confidentiality where indicated.

Psychosocial distress experienced by palliative care patients may be difficult to detect. Staff, in assuming that distress is an understandable reaction to news that an illness is incurable, may, for example, overlook significant levels of depression which could be treated with psychological and/or pharmacological interventions.

The somatic symptoms of the primary disease or the side effects of treatment may also be confounded with psychiatric symptoms, making assessment of psychological distress complex. It is important that staff are equipped to assess for psychosocial distress and to deal with it within the limits of their expertise. There should be adequate systems of training and support in place for staff delivering psychosocial care.

Staff should be aware that those patients with poorly controlled physical symptoms, particularly pain, and those with a past history of mood disorder and/or poor coping may be particularly at risk. Similarly those with minimal social support and/or additional concurrent social and personal problems may be particularly vulnerable. In those patients suffering severe distress access to specialist palliative care support services may be indicated.

Recommendations :

- All staff working with palliative care patients should be aware of the increased levels of psychosocial distress in this patient group.
- Staff should be aware of the impact of advanced disease on the patient's social and psychological functioning and the potential impact of psychosocial distress on physical functioning.
- All staff should be in a position to assess for psychosocial distress at regular intervals throughout the patient journey. In addition to general assessment by interview, consideration can be given to the use of standardised screening measures. This topic can be discussed with Psychosocial Oncology staff.
- All staff should be able to provide psychological support for those patients and families experiencing mild levels of distress. A listening ear and companionship may be enough for many patients and families.
- Staff involved in providing psychosocial care for palliative care patients should be adequately trained, supervised and supported.
- Staff should have an awareness of the risk factors for significant psychosocial distress as outlined above.
- Patients experiencing moderate levels of psychosocial distress may require assessment by staff in specialist palliative care services with a view to specialist counselling, welfare advice, family support etc.
- Staff should be aware of how, and when to refer those patients experiencing severe levels of distress to specialist services in mental health such as clinical psychology and psychiatry. (See section 4.7 for information on referral to psychosocial oncology service).
- Consideration should be given to the appropriate use of medication, such as anti-depressant medication. This is especially important in patients for whom a psychological approach to therapy is precluded by the patient's physical condition. (See sections 2.6 and 2.9 of the manual – confusion & delirium and depression).

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[Contents Page](#)

Section 2 – Control Symptoms

Control of symptoms is fundamental to good palliative care.

This section provides advice on the commonest symptoms and emergency situations. Additional advice regarding driving, travelling with controlled drugs, the use of steroids and using drugs out with licence can be found in the other helpful information section (section 8).

2.1 – Anorexia

What is it?

Anorexia (poor appetite) and associated cachexia (weight loss) occur in 80-90% of patients with advanced cancer. They are believed to be both the cause and the consequence of various metabolic changes which occur as a malignancy progresses and are often accompanied by muscle wasting, lethargy and fatigue, producing the anorexia-cachexia-asthenia syndrome.

What causes it?

- Biochemical abnormalities, perhaps mediated by tumour by-products such as Tumour Necrosis Factor (TNF) and host cytokines
 - hypercalcaemia
 - hyponatraemia
 - uraemia
- Cognitive failure
- Constipation
- Delayed gastric emptying
- Depression/stress
- Dyspnoea
- Fatigue
- Nausea and vomiting
- Odours
 - fungating lesions
 - fistulae,
 - cooking smells
 - incontinence – urinary or faecal
- Oral problems
 - Altered taste
 - Candidiasis
 - Dry mouth
 - Dysphagia / obstruction
 - Ill fitting dentures
 - Ulcers / inflammation
- Pain
- Unappetising/too much food

What are the effects?

- Can cause anxiety in both patient and carer.
- Can create tension between patient and carer – ‘Food Is Life’.
- Denies carer an important aspect of care – ‘Food is love’.
- Loss of the social aspects of eating may cause withdrawal and isolation.
- Ongoing reminder of illness.
- Reduces
 - Quality of life
 - Energy
 - Ability to tolerate treatment.
- Associated cachexia may cause body image difficulties.

How is it treated?

The aim is to increase the patient’s comfort and reduce anxiety in both patient and carer.

- Treat reversible biochemical causes if appropriate.
- Treat other reversible causes.
- Offer explanation and practical advice regarding nutrition to family. Written advice is likely to be welcome and CANCER BACUP booklets may be helpful. See website address www.cancerbacup.org.uk/ResourceSupport/Eatingwell for more information.
- Consider referral to a dietician.
- Medication.

Practical advice about nutrition (see section 8.7 of the manual for more information)

- Increase nutritional value of food by adding sugar, honey, cream, butter
- Gently encourage what the patient can manage
- Give permission to eat less. Use small portions on small plates, attractively presented.
- Tastes may change. Try tart foods, strong flavours or seasonings, marinate meats. Eat food cold or at room temperature.
- Alcohol may be beneficial.
- Nutritious drinks and snacks or supplementary drinks (if advised by dietician) may be of benefit.
- Encourage participation in the social aspects of meals.
- Try not to talk about food all the time.

Medication

- Corticosteroids
 - Short term improvement in appetite.
 - Temporary improvement in energy and sense of well-being.
 - No significant effect on nutritional status.
 - Side effects
 - Water and fat retention
 - Myopathy
 - Thrush
 - Gastric irritation
 - Response limited to 3-4 weeks

- **Starting dose:** Dexamethasone 4 mg, once daily in the morning or Prednisolone 30mg in the morning
- Try for 1 week. If no response, stop.
- If beneficial, reduce to lowest effective dose.

- Progestogens
 - May improve appetite, calorific intake and nutritional status.
 - Shown to reduce fatigue and give a sensation of well-being.
 - May take a few weeks to obtain benefit and so more appropriate for patients with a longer prognosis. Effect more prolonged than corticosteroids.
 - Side effects mild
 - Nausea
 - Fluid retention
 - Can increase risk of thromboembolism
 - **Starting dose:** Megestrol acetate 160mg daily.
 - Increase dose weekly up to a maximum of 160mg tid.
 - Maintain on lowest effective dose. Stop if no benefit.
- Prokinetics
 - Helpful if patients with anorexia also have early satiety or nausea.
 - Indicated in gastroparesis due to autonomic failure or tumour infiltration.
 - **Dose:** Metoclopramide 10 -20mg tid or Domperidone 10-20mg tid half an hour before meals.

Gold Nuggets

- **Relatives should be made aware that anorexia is an expected part of the dying process and that as the patient becomes weaker his energy requirements diminish. If they can acknowledge the complex aetiology of anorexia they may be less likely to force feed the patient**
- **Written information e.g. CANCERBACUP leaflets should be provided.**

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[Contents Page](#)

2.2 – Ascites

What is it?

Ascites is the abnormal presence of fluid in the peritoneal cavity.

When caused by cancer it generally implies advanced disease and prognosis of 8-20 weeks. Ovarian carcinoma is the commonest primary in malignant ascites but stomach, colon and pancreas also feature prominently. Ovarian carcinoma is unusual in that ascites presents earlier in the disease and survival figures of 20-50 weeks have been quoted.

What causes it?

Ascites is caused by increased influx of fluid into the peritoneum or impairment of drainage of fluid from the peritoneum. Normally 50 ml of fluid are contained in the peritoneal cavity with a turnover of 4-5 ml / hr.

Peritoneal carcinomatosis

Some tumour types secrete vascular permeability factor (VPF) which enlarges the normally tiny gaps between the endothelial cells that line blood vessels allowing the passage of protein rich fluid from blood into the peritoneum. Drainage may be impaired if tumour blocks the draining lymphatic vessels in the diaphragm.

Massive liver metastases

A tumour may obstruct hepatic or portal veins and cause portal hypertension. This increases hydrostatic pressure, driving fluid out of the blood vessels into the peritoneum. As cancer cachexia may also have reduced the level of plasma albumen the oncotic pressure in the blood vessels is insufficient to retain fluid in the vascular space.

(the above two may co-exist)

Chylous ascites

Lymphatics behind the peritoneum are blocked by tumour or radiotherapy which blocks the major route for drainage of peritoneal fluid causing an overspill of white lymph into the peritoneum.

Non malignant causes

Ascites may be secondary to cirrhosis of the liver or heart failure. The mechanism is similar to that of massive liver metastases causing portal hypertension.

What are the effects?

- Abdominal discomfort but severe pain is uncommon.
- Anorexia, nausea and vomiting - Squashed stomach syndrome.
- Dyspnoea
 - splinting of the diaphragm by abdominal fluid
 - may be co-existing pleural effusion
- Increased abdominal girth
 - bulging flanks, 'shifting dullness', 'fluid thrill'
 - ultrasound will detect as little as 100ml fluid

- Peripheral oedema / Lymphoedema
 - from venous and lymphatic compression
 - may develop lymphorrhoea
- Body image and quality of life issues.
- Fatigue.

How is it treated?

Even with ascites ovarian cancer patients may respond to chemotherapy and debulking surgery. However in advanced disease treatments are palliative. Interventions should be minimally invasive, should not add to the patient's burdens and should be aimed at relieving symptoms.

Non invasive management

Chemotherapy

- Ascites due to ovarian cancer may respond to systemic intra peritoneal treatment and oncological options should be considered, particularly in early disease.

Diuretics

- Research is limited regarding dose and type of diuretic.
 - Suggested starting doses are Furosemide 40mg and Spironolactone 100mg
 - Titrate up to a maximum of 160mg Furosemide and 400mg Spironolactone
- Effective only in cirrhotic-type ascites (Liver metastases) which activates the renin-angiotensin system and causes sodium and water retention.
- May take several days.
- May cause fall in BP, electrolyte disturbance and renal impairment.
- Not effective in ascites due to peritoneal carcinomatosis alone but often given on a trial basis.

Invasive Management

Paracentesis

- Immediate relief if symptomatic.
- 2 litres over 1 hour, slowly to dryness over 12 hours.
- May need to be repeated regularly.
- Complications
 - Hypovolaemia (The use of albumen is controversial and more relevant to ascites from cirrhosis. Dextran may be helpful.)
 - Haemorrhage
 - Pulmonary emboli
 - Peritonitis

Peritoneovenous shunt

- Consider if long prognosis and frequent paracenteses.
- Peritoneal cavity to internal jugular vein.
- Conserves albumin.
- Considerable hazards
 - Shunt blockages
 - DIC
 - Pulmonary emboli
 - Accelerated metastases
 - Fluid overload peritonitis

Non-specific treatment for ascites, though ensuring general comfort care

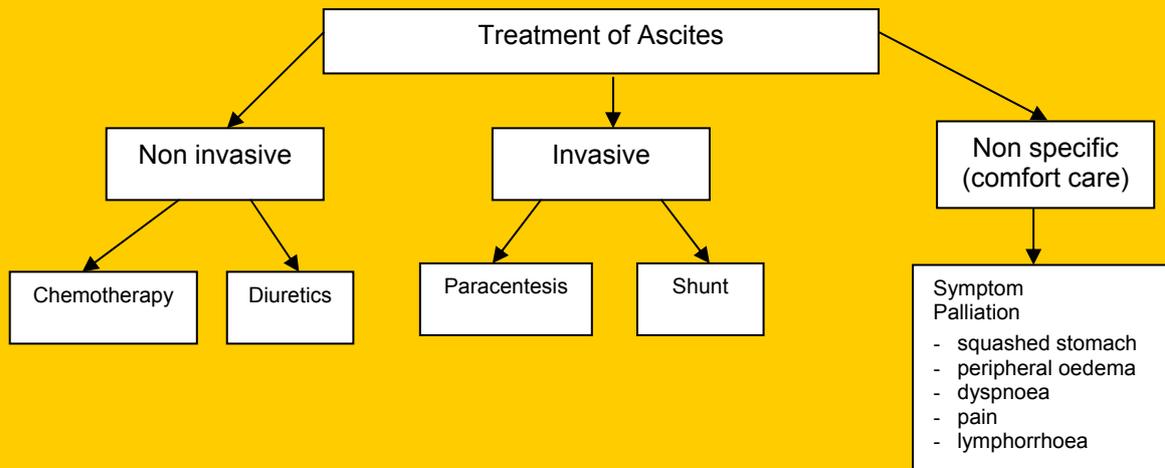
If patient choice, aggressive management inappropriate, patient asymptomatic, death imminent. May need palliation of :

- squashed stomach – Metoclopramide 10mg t.i.d. orally before food or 30-40mg subcutaneously via a syringe driver (unless malignant bowel obstruction co-exists)
- peripheral oedema - trunclal massage and stockings
- dyspnoea – regular small dose of opiate if very distressed e.g. – Oramorph 2.5mg q.i.d. and p.r.n.
- pain – treat according to analgesic ladder
- lymphorrhoea - gentle bandaging.

May need psychological support for body image issues and social / professional support for improving quality of life e.g. assistance with ADL.

Gold Nuggets

- Patients may require reassurance that their abdomens will not “burst open”
- Flow chart summary



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[Contents page](#)

2.3 – Bleeding

What is it?

Bleeding or haemorrhage is the escape of blood from any part of the vascular system. It may be obvious or occult. Bleeding occurs in about 20% of patients with advanced cancer.

What causes it?

In the palliative care situation bleeding may have a single cause or be multi-factorial.

Examples are :

- direct tumour erosion of artery
- persistent or intermittent ooze from tumour bed
- thrombocytopenia from
 - marrow invasion
 - chemotherapy
 - increased destruction of platelets (sepsis, Heparin [HIT], DIC)
- coagulation defect from
 - liver involvement (though paradoxically the risk of venous thrombosis can be increased in hepatic failure)
 - vitamin K deficiency due to
 - malnourishment
 - fat malabsorption
 - prolonged courses of antibiotics
- drug-induced haemorrhage (NSAIDS).

What are the effects?

- Bleeding at any time can be a distressing and frightening experience for patient and carer.
- External catastrophic bleeding is less common than internal occult bleeding.
- Minor bleeding may herald a fatal bleed.
- Fear of major bleed may preclude continuing care at home.
- Warning haemorrhages may permit discussion regarding resuscitation/allow natural death.
- Hypotension from even minor haemorrhage may precipitate falls.
- Clothing, bedding and furnishings may be unsalvageable in the event of a major bleed.
- Particular care is required if the patient is known to be HIV or Hep B positive.

How is it treated?

Minor bleed

Is this a local or systemic problem?

- Check coagulation and LFTs.
- Check FBC.

- Discontinue any offending drugs.
- Prescribe antibiotics if sepsis present.
- Consider Vitamin K orally or IV if obstructive jaundice present.
- Identify site of bleed and treat appropriately.

Skin & mucus membranes - local pressure

- Consider topical gauze soaks with Tranexamic acid (500mg in 5ml) or Adrenaline (Epinephrine) 1 in 1000
- Haemostatic alginate dressings such as Kaltostat
- Diathermy, laser
- Systemic antifibrinolytic drug e.g. Tranexamic Acid 0.5 - 1.5mg tid (Reduce or discontinue 1 week after bleeding has stopped but restart if bleeding recurs.)
- Systemic haemostatic drug e.g. Etamsylate 500mg qid

Haemoptysis

Occurs in 33% of lung cancer patients. 3% of bleeds are fatal. May be caused by lung cancer (especially central, cavitating squamous cell tumours), metastatic lung disease, chest infection or pulmonary embolus.

Management

- Maintain the airway.
- Lay the patient on the bleeding side, if the site of bleeding is known, to reduce the effect on the other lung. Alternatively, a head down position may help.
- Use Oxygen or suction as necessary.
- Treat infection/PTE as appropriate
- Consider XRT/laser treatment
- Oral tranexamic acid as above

Haematemesis/melaena

Bleeding from the gastroduodenum is uncommon in advanced cancer. Incidence is 2%. Melaena occurs more frequently than haematemesis but both may be present, particularly in patients with liver cancer or hepatic metastases.

Management

- Administer H2-receptor antagonist or PPI
- Consider transfusion/endoscopic therapies
- Oral Tranexamic Acid as above

Rectal or vaginal haemorrhage

If due to acute inflammatory radiotherapy damage to the rectal mucosa, a Predsol retention enema administered bd may help. If chronic ischaemic radiation proctocolitis, oral or rectal Tranexamic acid will help. If due to bleeding from tumour, consider radiotherapy.

Haematuria

- Exclude infection
- Try Tranexamic acid (Though risk of clot retention until bleeding stops completely)
- Consider Etamsylate 500mg qid
- Bladder instillations and irrigations - saline 0.9%, Alum 1% may help
- Cystoscopy/diathermy

Major haemorrhage

Defined as loss of 1.5 litres in 30 seconds in a patient for whom active treatment is neither appropriate nor possible.

- Likely to be fatal within minutes in the palliative situation.
- If predictable arrange to have red/green towels/blankets available to mask extent of haemorrhage and drugs (see below) available by the bedside.
- If due to erosion of a major artery apply local pressure with adequate packing.
- Give stat dose of S/C diamorphine for its hypotensive effect - 10mg if opiate-naïve, 2-4 times normal breakthrough dose if on regular opiates.
- Give stat dose of S/C or buccal Midazolam 10mg for anxiolytic effect.
- If the patient is peripherally constricted use IV/IM routes.
- If the patient wishes to be at home to die, ensure the risks have been explained to the relatives and they are prepared to cope.
- Ensure NHS 24/OOH Service aware of potential haemorrhage.
- Significant family support may be required.

ENSURE A DOCTOR OR NURSE REMAINS WITH THE PATIENT UNTIL DEATH OR RESOLUTION OF THE ACUTE EVENT

Gold Nuggets

- **Bleeding can be a distressing and frightening experience for patient and carer.**
- **Make appropriate preparations for predictable haemorrhage.**

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[Contents page](#)

2.4 - Bowel obstruction

What is it?

Bowel obstruction is the occlusion to the lumen of any part of the small or large bowel. There may be partial or complete obstruction. Bowel obstruction also occurs when there is lack of normal propulsion of intestinal contents.

What causes it?

- Intraluminal occlusion – from annular or polypoid tumours.
- Intramural occlusion – from infiltration of intestinal muscles resulting in ineffective peristalsis.
- Extrinsic occlusion of lumen – from a primary or secondary tumour mass, omental masses, from abdominal or pelvic adhesions, or from post radiation fibrosis.
- Intestinal motility disorders – infiltration of mesentery affecting bowel muscle or nerves, or infiltration of coeliac plexus; rarely paraneoplastic neuropathy.

What are the effects?

The onset of symptoms is often gradual. They include nausea and vomiting, abdominal colic, continuous abdominal pain, constipation or diarrhoea (faecal incontinence from overflow of liquid faeces proximal to the obstruction).

Symptoms may depend on the site of the obstruction:

- Duodenal obstruction – often no pain or distension, but characterised by large-volume vomiting of undigested food.
- Small bowel obstruction – colic in upper to central abdomen with moderate to severe vomiting and distension.
- Large bowel obstruction – colic in central to lower abdomen and large abdominal distension.

Episodes of obstruction may resolve spontaneously.

Investigations

Radiological investigations may be required if the diagnosis is in doubt. They can help differentiate between constipation and obstruction. The site and nature of the obstruction can be determined if surgery is being considered.

How is it treated?

Initial management includes deciding whether surgery is appropriate. For many patients with advanced malignancy this is not an option. Their general condition may be too poor or there are multiple levels of obstruction.

It is possible to relieve the symptoms without the need for iv fluids or naso-gastric tubes.

Exclude constipation or faecal impaction or treat accordingly.

If partial obstruction suspected:

- Stop drugs that reduce peristalsis, e.g. cyclizine.
- Consider a pro-kinetic antiemetic, e.g. metoclopramide – but stop if colic worsens.
- Give rectal intervention (e.g. phosphate enema) and an osmotic laxative, e.g. Movicol or a stimulant laxative, e.g. co-danthramer. Again, stop if colic worsens.

In complete obstruction:

- Do not give pro-kinetic anti-emetics if complete obstruction, e.g. metoclopramide, as they will worsen colic and can lead to bowel perforation.
- Drugs should be given via a syringe driver (SD) as oral route unreliable.
- Stop laxatives.

symptom	drug	dose	comments
Nausea and vomiting	cyclizine and/or haloperidol levomepromazine octreotide	100-150mg/24hr via SD 5-10mg/24 hr via SD 12.5 – 25mg/24hr via SD 300microg/24 hr via SD initially	See cyclizine notes below For large volume vomits, seek specialist advice & see octreotide notes below
Intestinal colic	hyoscine butylbromide	60 – 120mg/24hr via SD	
Tumour pain	morphine diamorphine	Convert from oral 24 hr dose of opiate to appropriate sub. cut. dose given via SD	
In partial obstruction consider:	dexamethasone	4 -8 mg/24 hr via SD	May reduce peritumour oedema and relieve obstruction temporarily. NB significant risk of bowel perforation.

Prescribing notes

- **Octreotide** – is a synthetic analogue of somatostatin that stimulates the intestinal absorption of water and electrolytes and decreases gut peristalsis. It is diluted in normal saline rather than water. It is incompatible with many other drugs used in syringe drivers, therefore seek specialist advice.
- **Cyclizine** at higher doses may crystallise when combined with other drugs in a syringe driver.

Gold Nuggets

- Relief from pain and nausea is usually possible. Complete relief from vomiting may not always be achieved, however if reduced to just once a day this may be acceptable to the patient.
- Small amounts of fluid orally may still be tolerated.
- Attention to oral hygiene cannot be overemphasised.

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[Contents page](#)

2.5 – Breathlessness

What is it?

Breathlessness (dyspnoea) is the subjective experience of breathing discomfort. It is common in advanced disease, being present in 94% of chronic lung disease, 83% of heart failure patients and up to 70% of cancer patients.

The symptom of breathlessness is often multi factorial, associated with physiological and psychological factors.

What causes it?

Breathlessness might be attributable to the presence of a primary tumour within the respiratory system, metastatic spread to the lungs, pleural effusion, advanced respiratory disease etc. It could also result from the administration of anti-cancer therapy.

The causes of breathlessness can be described as :

- mechanical –airway obstruction or lung compression
- biochemical-anaemia, hypoxaemia
- psychological-anxiety.

Some patients suffer from breathlessness as a result of reversible or partially reversible conditions. However, for others breathlessness is a non-reversible result of the disease process although this does not mean that symptoms cannot be improved.

What are the effects?

Breathlessness can cause significant distress, fear and disability. Supportive care is integral to breathlessness management.

- Multidisciplinary assessment of the patient/family is essential e.g. physiotherapist, occupational therapist, social worker, specialist nurses etc. may be needed in addition to ward staff/primary care team.
- Anxiety and panic attacks. Anxiety and fear are common with breathlessness.
 - Explore anxieties/fears (e.g. suffocation) and allay where possible.
 - Simple breathing exercises and relaxation techniques.
 - Discuss possible drug management with the patient/family e.g. benzodiazepines Lorazepam 0.5mg SL, prn for panic attacks. Diazepam 5mgs PO at night, if more chronic anxiety (increase dose gradually, as necessary and tolerated).

- Life style adaptations.
 - Discuss limitations and listen to patient and family concerns. Maximise functional ability using controlled breathing and activity pacing techniques, where possible.
 - Consider need for equipment/aids and a package of community care review benefit entitlement (may be eligible under the special rules scheme).
 - Offer written information about living with breathlessness to reinforce verbal advice and discussion.

If the patient has more severe/persistent problems with anxiety or lifestyle adjustment and has a longer prognosis, consider referral to a breathlessness support service and/or clinical psychologist, where available.

How is it treated?

The recommendations in this guidance apply equally to patients with cancer and non-malignant disease.

- Is treatment of the underlying illness appropriate? - check with specialist if in doubt.
- Are there any potentially reversible causes of breathlessness? (for example - cardiac failure, infection, anaemia, pleural or pericardial effusion, pulmonary embolus, ascites, arrhythmia, pneumothorax or airflow obstruction).

Treat below as appropriate

- Drainage of effusions, pneumothorax etc.
- Bronchodilators e.g. nebulised salbutamol 2.5 – 5mg qid + or – ipratropium bromide 250-500 mcg qid. Stop if no effect.
- Nebulised saline/Mecysteine for tenacious secretions.
- Sit well propped up.
- Do not try to hurry.
- Keep cool – consider using a fan.
- Consider Morphine Oral/SC + or – Midazolam SC.
- Diuretics if appropriate.
- Offer written information about living with breathlessness to reinforce verbal advice and discussion

If superior vena cava obstruction present or stridor :

- Seek advice-urgent referral to Oncologist or Consultant Respiratory Medicine
- Give high dose dexamethasone 16 mgs daily, IV/IM/oral or give 60mgs of prednisolone orally, before admission. Consider PPI
- Stenting and/or palliative radiotherapy or chemotherapy should be considered. Avoid giving steroids after 2pm; gradually reduce to lowest effective dose.

Gold Nuggets

- Dyspnoea often multi-factorial with physical, psychological and social components.
- Treat co-existing morbidity for example : COPD, cardiac failure, anaemia etc.
- Stridor with superior vena cava obstruction is an emergency (see section 2.11)

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[Contents page](#)

2.6 – Confusion and delirium

What is it?

Acute or sub acute confusion may develop over hours or days. It can be :

- disturbance of consciousness
- disturbance of attention
- disturbance of and disordered cognition
- disturbance of and altered perceptions
- usually accompanied by disturbance in psychomotor behaviour e.g., hyper or hypoactive.

What causes it?

It is essential to consider the cause(s) as many :

- may be reversible or irreversible
- may be multi factorial
- may be complex
- can be common in last few days of life (see section 6 of the manual).

The following represent the main causes of confusion/ delirium in the palliative care patient :

- Metabolic e.g., infection, hypoxia, uraemia, liver failure, hypercalcemia, hypo/ hyperglycaemia, low sodium or magnesium, dehydration
- Physical e.g., uncontrolled pain, urinary retention, bleeding, severe constipation, sensory deprivation
- Drug related e.g., corticosteroids, anticholinergics, neuroleptics, benzodiazepines, opioid toxicity (see section 2.18), acute withdrawal of many drugs including nicotine and alcohol
- Previous history, e.g., dementias, CVA, primary brain tumour or metastatic cerebral involvement, alcohol or drug misuse and or withdrawal, depression, end stage AIDS

What are the effects?

Delirium may have profound effects for the individual patient as well as for family and staff. It is often misdiagnosed and mismanaged. Effects may include the following :

- restlessness and agitation
- aggressive behaviour
- personality change
- lethargy or stupor
- poor concentration
- irritability
- disturbance of sleep wake cycle
- disorientation to time, place and person
- impaired memory
- altered perception inc. illusions, hallucinations and delusions.

The above can be very difficult for family to cope with and unsuccessful or unsatisfactory management of confusion may have negative effects for family eg - poor bereavement outcome.

How is it treated?

- assess each patient on an individual basis.
- consider underlying cause(s) and treat those that are possible and appropriate

Skilled nursing management is essential as well as the following :

- maintain quiet environment
- ensure well lit environment
- provide a night light
- provide a clock to improve orientation in time
- adopt a calm and reassuring manner
- use short and simple sentences when communicating
- use of name to orientate
- ensure personal effects are within environment
- ensure continuity of staff in daily care
- involve family members in care if appropriate
- provide daily routine similar to home if possible
- maintain continuity of surroundings as far as possible

Medication

- Use of neuroleptics to manage perceptual disturbance including hallucinations and to clear sensorium e.g. Haloperidol, starting at 0.5 to 1.5mg nocte and or lorazepam 0-5mg sublingually PRN 4 hourly.
- For urgent treatment of acute delirium consider subcutaneous injection of Haloperidol 5-10 mg per dose which can be repeated after one hour
- Other neuroleptics may be suitable but will require specialist advice from psychiatrist or Palliative care team
- Benzodiazepines may compound confusion and cause sedation, but will be necessary in acute confusion related to alcohol and drug withdrawal e.g. Lorazepam (as above) or diazepam 2- 5mg PRN 6 hourly
- Consider Midazolam via subcutaneous infusion e.g. Midazolam 10 mg / 24 hours. Titrate future requirements by noting extra doses required for control of symptoms.
- Consider nicotine patch if appropriate
- Review all medication
- Discontinue or reduce as appropriate unnecessary drugs
- Maintain effective symptom control
- Maintain hydration, if appropriate
- For terminal delirium, see end of life care (see section 6)
- Opioid toxicity (see section 2.18)

Gold Nuggets

- **Confusion/delirium is common in palliative patients and at end of life.**
- **Cause(s) may be reversible.**
- **Cause(s) may be multiple and complex.**
- **Can be distressing to patient, family and staff.**

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[Contents page](#)

2.7 – Constipation

What is it?

Constipation is the difficulty in passing stools. It includes straining at stool, infrequent bowel movements or passing small, dry or hard stools.

What causes it?

Causes are often multifactorial.

- Tumour within or pressing on the bowel wall.
- Tumour damaging lumbosacral spinal cord, cauda equina or pelvic plexus.
- Hypercalcaemia.
- Dehydration.
- Diminished food intake, low fibre diet and immobility.
- Drugs – opioids, anticholinergics (hyoscine, phenothiazines, tricyclic antidepressants, antacids, diuretics, iron.)
- Concurrent disease – hypothyroidism, diabetes, hypokalaemia, diverticular disease, anal fissure or stenosis.

What are the effects?

Abdominal pain, bloating, flatulence, nausea, vomiting, malaise, anorexia, headache, altered taste, overflow diarrhoea (faecal impaction with biodegradation of faeces proximal to stool resulting in passage of liquid faeces only), urinary retention.

Investigations

Ask the patient:

- What is the usual pattern of defecation?
- When was the last bowel movement?
- What laxatives have been tried?
 - Have they been taken prn or regularly?
- Are the stools hard or soft?
- Is there any pain/mucous/blood on defecation?

Abdominal and rectal examinations are essential to exclude intestinal obstruction, to diagnose faecal impaction and to determine the consistency of the stools. An empty, ballooned rectum is indicative of high impaction of faeces.

Abdominal x-rays are rarely required unless there is concern that there is intestinal obstruction.

How is it treated?

- Eliminate or modify causes listed above.
- Encourage fluid intake – 2-3 litres per day if able.
- Improve dietary fibre content – dietician referral may be appropriate.
- Identify and treat hypercalcaemia (iv fluids and pamidronate).
- Choice of laxative depends on whether the faeces requires softening or the bowel requires stimulating. Often a combination is needed.
- Rectal laxatives may be necessary in the first instance to resolve established constipation.
- Encourage regular use of laxatives, not prn.

	Mode of action	Preparation/dose	comments
Acute constipation or Hard impaction	Osmotic	Micro enema 1 at night	Maximum of 3 days therapy
	Osmotic	Phosphate enema 1 in the morning	
	Osmotic	Movicol 8 sachets in 1 litre of water over 6 hours	
Soft impaction	Stimulant	Senna 2 – 4 tablets at night	
High Impaction	Stimulant	Sodium picosulphate (Picolax) half to one sachet as required	
Chronic constipation	Stimulant	Senna 2 - 4 tablets at night	
	Osmotic	Movicol 1-2 sachets daily	
Opioid induced constipation	Softener and stimulant	Codanthramer 5 – 10ml (1-2 caps) at night titrated up to 20ml qid	
	Stimulant	Senna 2 – 4 tablets at night	

Prescribing notes

- Laxatives should be titrated up until constipation is controlled.
- Co-danthramer is only licensed for use in the terminally ill. Co-danthramer may colour the urine red. It can cause a characteristic red rash over the buttocks/perineum. The risk is increased if incontinent of urine or faeces.
- Avoid bulk-forming laxatives, eg Fybogel, as not suitable for patients with poor fluid intake, or when opioids have reduced bowel motility.

Other commonly used laxatives or suppositories :

Arachis oil enema – derived from peanuts so avoid in patients with nut allergies. Oily retention enema used in severe impaction to soften faeces, usually administered at night. This is followed by a phosphate enema in the morning to stimulate evacuation.

Glycerin suppositories – rectally administered softener for hard impaction.

Bisacodyl suppositories – rectally administered stimulant for hard impaction when given in combination with glycerin suppository or for soft impaction when given alone.

Lactulose – osmotic laxative which may take up to 48 hours to act and is therefore unsuitable for relief of acute symptoms or “prn” prescribing. Can be associated with abdominal cramping, bloating and flatulence. Needs a high fluid intake to be effective.

Bisacodyl tablets – a stimulant. Dose 5 – 10 mg nocte.

Gold Nuggets

- **Prevention is easier than cure. Prescribe laxatives prophylactically in all patients receiving opioids.**
- **For patients with spinal cord compression or other neurological conditions, it may be appropriate to keep the stools firm and use rectal intervention three times a week to prevent undignified episodes of faecal incontinence.**

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[Contents page](#)

2.8 – Cough

What is it?

Useful protective function in maintaining patency and cleanliness of the airways.

Symptomatic treatment needed when cough is distressing or affecting sleep/activity. Reversible causes should be identified and treated.

What causes it?

- Cigarette smoking.
- Cancer related - airway obstruction or distortion; pulmonary infiltration; pleural infiltration; mucous secretion and retention; tracheo-oesophageal fistula; ineffective cough e.g. due to vocal cord palsy, pain, weakness.
- Treatment related - cancer treatment e.g. pulmonary fibrosis related to radiotherapy, chemotherapy; medications e.g. ACE inhibitors, beta-blockers.
- Others - Infection; COPD; bronchiectasis; post nasal drip; gastro-oesophageal reflux; pulmonary oedema; recurrent aspiration; pleural effusion; candida.

What are the effects?

- Chest wall pain or muscle strain.
- Dyspnoea.
- Nausea.
- Fatigue.
- Sleep disturbance.
- Urinary incontinence.
- Dizziness or syncope.

How is it treated?

- Careful assessment, establish cause, where possible.
- Review medications.
- If cancer related, consider specific treatments (e.g. radiotherapy, chemotherapy, drainage of pleural effusion etc.)
- Treat, or maximise therapies for other underlying cause.

Infection	→	Antibiotics (if purulent sputum) Physiotherapy (if appropriate) Nebulised saline
Airway obstruction	→	Bronchodilator Physiotherapy Corticosteroids
Malignant obstruction	→	Dexamethasone 16mg Oral IV & PPI Seek specialist advice
Cardiac Failure	→	Diuretic
Drug induced	→	E.g. ACE inhibitor Stop or change drug
Oesophageal reflux	→	Upright position Anti reflux medication
Aspiration of saliva	→	Anticholinergic to reduce saliva Hyoscine Butylbormide (non sedating)
To encourage expectoration	→	Simple linctus Nebulised saline Carbocystine
To suppress cough	→	Codeine linctus 10ml 4 hourly PO Oramorph 2.5 - 5 mg 4 hourly PO Consider laxative as well

There is no evidence for the use of nebulised agents apart from saline and bronchodilators

Gold Nuggets

- Stop smoking.
- Treat underlying cardiac or respiratory disease.
- Consider oral morphine with a laxative.

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[Contents page](#)

2.9 – Depression

Introduction

Up to 80% of the psychological and psychiatric morbidity that develops in cancer patients goes unnoticed and depression is the most frequent psychiatric illness in patients with terminal cancer.

Depression impairs the quality of life for these patients and their carers and is often associated with physical symptoms that are difficult to control. 70% of depressed patients with end-stage illness may respond to antidepressant treatment but only a minority of patients are prescribed them.

Assessment

All patients should be assessed for the presence or risk of depression. Staff should be aware that a past history of psychiatric problems, particularly depression is a risk factor for depression in the context of a cancer diagnosis.

There are no universally accepted diagnostic criteria for depression in palliative care patients. Some biological symptoms associated with depression may be also be symptoms of the illness making diagnosis difficult on occasion.

Depressive symptoms with particular weight in palliative care patients are :

- loss of pleasure in day to day activities, social withdrawal
- excessive feelings of guilt or worthlessness
- desire for hastened death
- a positive response to the question 'Do you think you may be depressed?'

Screening tools may be useful but should be chosen carefully and used selectively. The Edinburgh Postnatal Depression Scale is the most sensitive and specific scale for a palliative care population. The Hospital Anxiety and Depression Scale is widely available but less sensitive and specific for these patients. No scale is a substitute for clinical assessment. A score suggesting depression should not automatically lead to treatment, but indicates that the patient should be assessed in more detail.

All patients with depressed mood should be :

- assessed to establish the persistence and duration of the low mood (less than 2 weeks may be an adjustment reaction which will resolve spontaneously)
- offered psychological support services, where available
- assessed for active suicidal ideas
- screened for confusion; delirium may mimic depressed mood.

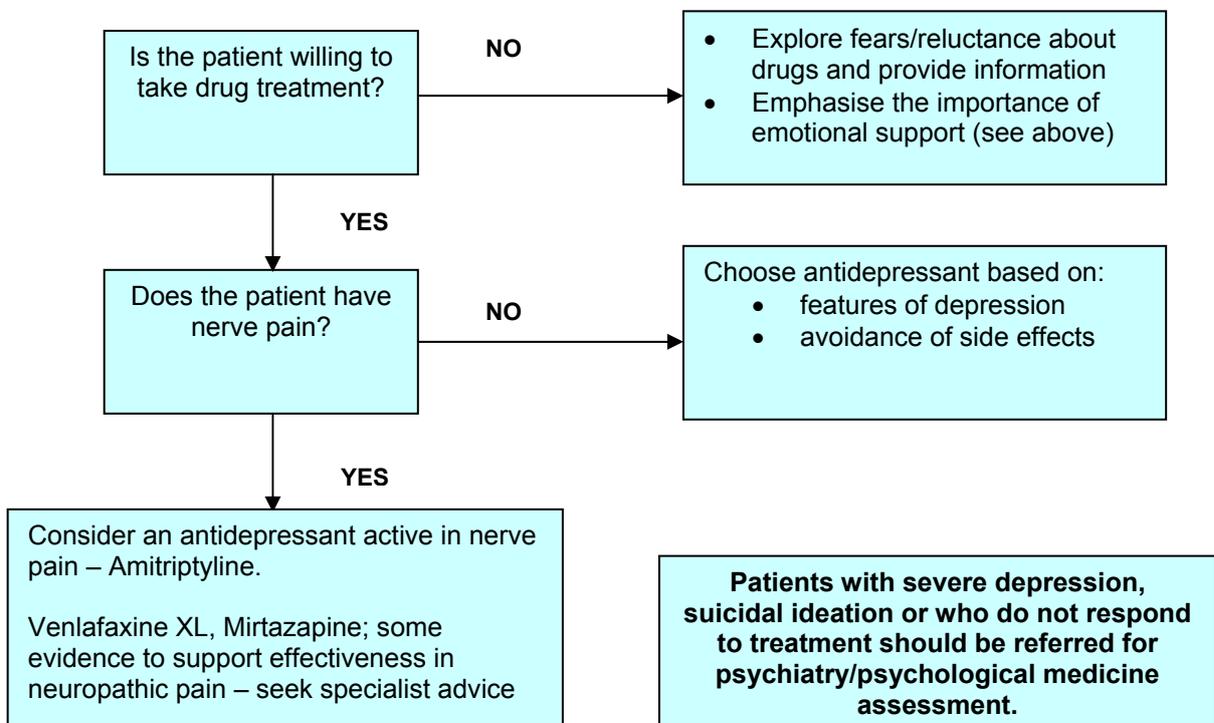
Clinical features of acute confusion (delirium) are :

- acute onset and fluctuating course
- inattention – easily distracted
- disorientated to time/place/person
- disorganised thinking – rambling or irrelevant conversation, switching topics
- altered level of consciousness – hyperactive or hypoactive.

Management of depression

- All patients with depressive symptoms should be offered emotional and/or psychological support, ideally from one or two key people to ensure continuity. Practice based counsellors, clinical psychologists, community psychiatric nurses, and other healthcare workers with training in counselling skills or adjuvant psychological therapy may be available (see other useful information section for information about local services).
- Many patients find complementary therapies helpful and if they are available they should be offered. Some therapies (e.g. massage and acupuncture) have measurable benefits on the neuro-chemical features of depression and a variety of therapies may be helpful for general psychological wellbeing.

After diagnosis of depression made: -



Choosing an antidepressant

Refer to the Forth Valley Formulary (FVF) and local guidance when selecting an antidepressant. Note that some antidepressants included in FVF may not be appropriate for a palliative care patient.

Note also that anti-depressants may take at least three weeks to become effective.

- Fluoxetine is not recommended for use in palliative care patients due to significant drug interactions, side-effects and a long half-life which may exacerbate these problems.
- Paroxetine is not recommended in FVF. It should be avoided in palliative care patients with advanced disease due to the frequency and severity of withdrawal reactions.
- All antidepressants should be withdrawn slowly, where possible.

Serotonin specific reuptake inhibitors (SSRI)

Citalopram: starting dose, 20mg, once daily. Tablets and liquid preparation (note different dose)

- Non-sedating antidepressants.
- Few drug interactions.
- Safer in patients with cardiac disease.

Side-effects include :

- nausea, diarrhoea
- insomnia
- sweating
- impaired sexual function
- hyponatraemia
- vivid dreams/nightmares, agitation
- risk of GI bleeding; especially in the elderly and patients with GI bleeding history. (due to impaired platelet aggregation).

Tricyclic Antidepressants

Amitriptyline: starting dose, 75mg nocte (25mg in elderly or frail patients)

Lofepamine: starting dose, 70mg twice daily (70mg daily in elderly patients)
(Tablets and liquid preparation are available for both drugs)

- Sedation and secretion-drying effects may be useful in some patients but may be problematic with others.
- Less likely to cause nausea than SSRIs.

Avoid in patients with cardiac disease; caution if risk of seizures.

Non-formulary drugs which may be indicated in palliative care patients (seek specialist advice).

Venlafaxine: starting dose, 75mg controlled release, once daily
Tablets only (controlled release preparation causes less nausea)

- Non-sedating antidepressant.
- Side-effects same as SSRIs; avoid if SSRI not tolerated.
- Caution in hepatic or renal impairment. Some drug interactions.
- Withdrawal effects are common; less suitable for advanced illness.
- Unsuitable for patients with pre-existing cardiac disease, electrolyte imbalance and hypertension.

NB - Venlafaxine should be initiated by specialist practitioners only. ECG and BP monitoring is required

Mirtazapine: starting dose, 15mg nocte dispersible tablet

- Sedating (but less sedation at higher doses).
- Appetite stimulant; may produce weight gain.

Gold Nuggets

- Depression is the most frequent psychiatric illness in palliative care patients.
- Depression is frequently undetected and untreated in palliative care.
- All patients in palliative care should be assessed for the presence of depression.
- Psychological and pharmacological treatments should be available as and when appropriate.
- 70% of depressed patients with end-stage illness may respond to antidepressant treatment but only a minority of patients are prescribed them.
- Some depressed patients will require referral to specialists such as clinical psychologists and psychiatrists.
- If in doubt, refer for specialist opinion.

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[Contents page](#)

2.10 – Diarrhoea

What is it?

Diarrhoea is the increase in frequency and/or fluidity of stools.

What causes it?

- Laxative overdose.
- Faecal impaction with overflow – often opiate induced.
- Partial bowel obstruction with overflow.
- Shortened bowel – resection, ileostomy, colostomy.
- Enhanced motility
 - High fibre diet
 - Steatorrhoea – pancreatic cancer, obstructive jaundice
 - Visceral neuropathy – diabetes
 - Nerve blocks – coeliac plexus, lumbar sympathectomy
 - Hyperthyroidism
- Drugs – commonly antibiotics, NSAIDs, laxatives, chemotherapy agents, iron, SSRIs.
- Infection
 - Gastro-enteritis
 - Pseudomembranous colitis – colonisation of bowel by clostridium difficile
- Cholegenic – non-absorbed bile acids from bacterial invasion of small bowel (rare).
- Radiotherapy.

What are the effects?

Physical - dehydration, fatigue, hyponatraemia, hypokalaemia and renal failure.
Psychological - anxiety and embarrassment about soiling.
Social - being confined to home or readily accessible toilets.

How is it treated?

Assess need for rehydration with iv fluids.

Identify and treat any reversible cause

- Reduce or withdraw laxatives
 - Encourage use of regular laxatives rather than erratic use of high dose laxatives once constipation established.
- Relieve constipation with rectal intervention and/or laxatives.
- Review need for antibiotics or other drugs.
- Send stool for culture and treat infection accordingly e.g. clostridium difficile, with appropriate antibiotics (according to current microbiology recommendations)
- Blood tests to exclude hyperthyroidism and electrolyte disturbances.

Specific treatments

Cause	Drug	Dose	Comments
Non-specific	loperamide	Initially, 4–8 mg daily in divided doses, adjust according to response. Max. 16 mg/day.	Avoid in antibiotic-associated colitis.
	codeine phosphate	30 mg tid or qid, adjust according to response.	May cause sedation especially in the elderly.
Acute radiation enteritis	ibuprofen octreotide	400 mg tid. 50 micrograms od or bd subcut, gradually increasing up to 200 micrograms tid.	Or other NSAID. May also be given as a continuous infusion via a syringe driver.
Zollinger-Ellison syndrome	ranitidine	150 mg tid	
Fat malabsorption	Creon 10 000	1–2 capsules with meals	Take whole or mix contents with fluid or soft food (then swallow immediately without chewing).
Carcinoid syndrome	octreotide	50 micrograms od or bd subcut, gradually increasing up to 200 micrograms tid	May also be given as a continuous infusion via a syringe driver.
Chologenic diarrhoea	colestyramine	12-24g daily in 1 - 4 divided doses	Take other drugs 1 hour before or 6 hours after as their absorption may be interfered.

If diarrhoea persists despite the above measures, and is causing faecal incontinence then an anal plug could be considered. They are inserted per rectum and can remain in situ for up to 12 hours. They can be obtained via surgical supplies : telephone 01786 450010. "Conveen Anal Plugs" available in small and large sizes.

Gold Nuggets

- Many patients who report "diarrhoea" whilst taking opiates are found to be constipated with faecal overflow: perform a rectal examination to exclude this.

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[Contents page](#)

2.11 – Emergencies in palliative care

What is an emergency?

Good palliative care is planned and not crisis intervention, as many situations can be anticipated and strategies considered in advance. However, emergencies do happen and prompt assessment and treatment decisions are required. In addition to the nature of the emergency, it is important to consider :

- the patient
 - general condition
 - symptoms
 - comorbidities
 - disease state and likely prognosis
 - wishes
- the carers
 - abilities
 - wishes
- the treatment
 - benefits
 - toxicity

Physical emergencies in palliative care are considered below but it is important to be aware that social, psychological and spiritual emergencies also occur.

Fear, anxiety and depression may present unexpectedly. Suicide and para-suicide may be significant risks if controlled drugs are available. The patient may need an opportunity to ventilate feelings and be listened to, more than medication.

When confronted with a terminal illness, patients may choose to ignore signs of impending death but may suddenly feel they have to “set their affairs in order” before it’s too late. They may question the meaning of life, their inherent worth, value or legacy. Wills and funeral requests may need to be dealt with as emergency discussions if time becomes short, as may custody of children if there is dispute between interested parties. Emergency care of pets may be problematic.

Urgent air travel for relatives can be facilitated by appropriate letters, faxes or e-mails and finance recovered through legitimate claims. Requests for prisoners to see loved ones are usually treated sympathetically.

Physical emergencies :

- Fracture
- Haemorrhage (see bleeding section 2.3)
- Hypercalcaemia (see hypercalcaemia section 2.13)
- Sepsis in the neutropenic patient (see infection section 8.6)
- Malignant spinal cord compression
- Superior vena cava obstruction

Fracture

What is it?

A fracture is a break or interruption in the continuity of a bone.

What causes it?

Bone metastases are common in advanced cancer and can cause marked thinning of bones. Consequently, even trivial injuries can result in pathological fractures of the diseased bone. Non-pathological fractures may occur as a result of falls in patients whose mobility is impaired or whose gait is ataxic.

What are the effects?

Fractures are usually painful and cause reduction in movement and function of the affected bone or limb. However some fractures may not be painful and may present as an acute confusional state.

How can it be treated?

- **Prevention**
 - if cortical thinning is present consider prophylactic internal fixation
 - irradiate painful bony metastases
 - use regular bisphosphonates – monthly IV infusion especially in myeloma, breast
- **Treatment** of established fracture is dependent on the site of fracture and condition of the patient. In addition to oral or parenteral analgesia, options include :
 - internal fixation +/- XRT
 - external immobilisation
 - topical Lidocaine patches over the fracture site to reduce pain

Malignant Spinal Cord Compression

What is it?

This is pathological pressure on the spinal cord at one or multiple levels, from the medulla oblongata to the filum terminale.

In the early stages, the presentation of spinal cord compression may be very subtle. It is important to have a high index of suspicion as the neurological damage may be reversible if treatment is started within 24-48 hours of the onset of symptoms. The neurological status at the start of treatment is the most important factor influencing outcome. Delay in diagnosis may lead to permanent loss of motor power and care at home may become impossible.

Spinal cord compression occurs in 3-5% of patients with cancer and 10% of patients with spinal metastases. Malignancies of bronchus, breast and prostate and myeloma are the commonest culprits.

What causes it?

Spinal cord compression is caused by :

- extradural compression (80%) – vertebral body metastases
- intramedullary metastases
- intradural metastases
- vertebral collapse
- tumour spread through intervertebral foramen (lymphoma and testicular tumours)
- interruption of blood supply.

What are the effects?

Symptoms and signs include :

- pain 90%
 - tenderness over the affected vertebrae
 - radicular pain, particularly on coughing or sneezing
- stiffness
- weakness
- numbness/sensory level
- altered reflexes
- sphincter disturbance
 - urinary symptoms - hesitancy (occurs late)
 - bowel symptoms - constipation

Site of compression

- thoracic – 70%
- lumbosacral – 20%
- cervical – 10%

Lesions above L₁ (lower end of spinal cord) → UMN signs + Sensory level

Lesions below L₁ → LMN signs and peri-anal numbness (cauda-equina syndrome)

Multiple sites of compression can cause confusing neurological signs.

	UMNL	LMNL
POWER	Reduced/absent	Reduced/absent
TONE	Increased	Reduced
SENSATION	Sensory loss	Sensory loss
REFLEXES	Increased	Absent/reduced
PLANTAR RESPONSE	Upgoing	Downgoing

How can it be treated?

Assessment and examination

- identify risk factors
- evaluate pain
- evaluate sensory and motor function
 - walking
 - established cord compression
- assess bowel and bladder function
- ascertain patient's wishes and prognosis as these may direct treatment

Give high dose Dexamethasone

- dose is 16mg/day oral or IV with gastric protection
- reduces peri-tumour oedema

Admit to local hospital if patient agreeable and clinical condition permits for urgent discussion with the oncology team.

Refer urgently for MRI or Multidetector row-CT (MDCT) scan and radiotherapy

Consider surgical decompression and stabilization/cementoplasty if appropriate. Nurse flat until assessment by spinal surgeon.

- Indications for surgical decompression
 - unknown cause – for histology
 - XRT ineffective
 - radio-resistant tumour – melanoma
 - unstable spine
 - major structural compression
 - cervical cord lesion
 - solitary vertebral metastasis

The results of treatment are tabled below.

State on initial assessment	Retain/regain ability to walk
Ambulatory	70%
Paraparetic	35%
Paraplegic	5%

Challenges are significant and in hospital the SPCT should be involved to ensure multi-disciplinary management of the patient and family and to facilitate future care.

Difficulties include:

- immobility – risk of DVT → consider LMWH
(if mobile maximise potential with physiotherapy and use of appropriate aids)
- skin – risk of pressure sores → obtain appropriate bed and mattress
- bowel – constipation → use paraplegic bowel treatment regime
- urinary system – retention → catheterise
- psychological – distress → promote readjustment to new (possibly paraplegic) life style

Superior Vena Cava Obstruction (SVCO)

What is it?

This is obstruction to the superior vena cava blood flow by external compression, thrombosis or direct tumour invasion. It may present acutely but may also present more insidiously as chronic dyspnoea.

What causes it?

SVCO is most commonly caused by tumour involving mediastinal lymph nodes or those in the area of the right main bronchus.

The most common tumours are :

- | | |
|-------------------------------------|-----|
| • bronchial carcinoma | 75% |
| • lymphoma | 15% |
| • breast, colon, oesophagus, testis | 10% |

Approximately 3 % of lung cancer and 8% of lymphoma patients develop SVCO.

What are the effects?

Symptoms are those of venous hypertension :

- breathlessness – airway oedema or laryngeal/tracheal/bronchial obstruction.
- visual changes.
- dizziness.
- headache worse on stooping – cerebral oedema.
- swelling of face, neck, arms.

Signs include :

- conjunctival oedema
- peri-orbital oedema
- papilloedema – late
- dilated neck veins – non-pulsatile
- dilated collateral veins – arms and anterior chest wall
- oedema of hands and arms
- stridor
- cyanosis
- increased respiratory rate

How is it treated?

- Discuss with or refer urgently to oncologist/radiotherapist/respiratory physician
- Prescribe Dexamethasone 8-16mg daily orally or IV
Discontinue promptly if no benefit and reduce gradually in responders.
- Arrange radiotherapy or chemotherapy if patient's condition permits
- Consider referral for intraluminal stents +/- thrombolysis +/- anticoagulation
- Offer benzodiazepines, opiates and supportive care for all patients, in addition to the above measures.

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[Contents page](#)

2.12 – Hiccups

What is it?

Hiccup is a pathological respiratory reflex characterised by spasm of the diaphragm, resulting in sudden inspiration followed by abrupt closure of the glottis.

It occurs more commonly in males than in females and can be transient or chronic. Chronic hiccup is defined as hiccup lasting more than 48 hours and is not unusual in patients with advanced cancer.

What causes it?

There are many potential causes of hiccup. In patients with advanced cancer the causative factor is likely to be one of the following:

- Gastric distension (most common)
- Gastro-oesophageal reflux
- Uraemia
- Infection
- Diaphragmatic irritation
- Phrenic nerve irritation
- CNS tumour

What are the effects?

Prolonged hiccup interferes significantly with a patient's daily living.

It affects eating, talking and sleeping resulting in fatigue, weight loss and depression.

How is it treated?

Various therapies are available for the management of chronic hiccup. Treatment will depend on the most likely cause.

Gastric distension	→	<ol style="list-style-type: none">1. Antiflatulent e.g. Kolanticon <i>If symptoms persist</i> <ol style="list-style-type: none">2. Add a prokinetic agent e.g. metoclopramide
Gastro-oesophageal reflux	→	<ol style="list-style-type: none">1. Prokinetic e.g. metoclopramide <i>If symptoms persist</i> <ol style="list-style-type: none">2. Add a Proton Pump Inhibitor e.g. omeprazole
Diaphragmatic irritation or other cause	→	<ol style="list-style-type: none">1. Haloperidol 1.5-3mg nocte2. Nifedipine 10-20mg tds3. Baclofen 5-20mg tds <i>If symptoms persist consider:</i> <ol style="list-style-type: none">4. Midazolam 10-60mg/24hr by CSCI

Gold Nuggets

- Chronic hiccup is not unusual in advanced cancer
- Treatment will depend on the most likely cause

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[Contents page](#)

2.13 – Hypercalcaemia

What is it?

Hypercalcaemia is a common metabolic complication of cancer. Its causes are complex and it is frequently associated with high tumour burden and end stage disease. It can be seen in any cancer and it is estimated that 10 - 20% of all patients with cancer will develop hypercalcaemia at some point during the course of their illness. It occurs primarily in end stage disease with survival often being less than 3 months.

It is particularly common in squamous cell lung tumours, breast cancer, multiple myeloma, squamous cell head and neck, renal, cervix and uterine tumours.

Normal calcium levels range from 2.15 – 2.60 mmol/l. Hypercalcaemia is any result above 2.60 mmol/l.

Patients may present as a medical emergency. It is essential that clinicians identify those patients at risk by recognising the signs and symptoms of hypercalcaemia.

What causes it?

There are three mechanisms :

- Increased osteoclastic bone reabsorption
- Increased renal calcium reabsorption
- Increased gastrointestinal absorption of dietary calcium

Three related mechanisms may contribute to hypercalcaemia. All 3 processes occur in malignancy.

What are the effects?

Signs and symptoms can be vague and non-specific and can mimic advancing disease. The severity of symptoms is not correlated with the degree of serum calcium elevation, but most patients initially develop lethargy and malaise, followed by thirst, nausea and constipation before neurological and cardiological symptoms appear.

Symptoms therefore, can range from mild to severe and become progressively worse if the condition is left untreated.

MILD

Anorexia
Lethargy and muscle weakness
Constipation
Nausea and vomiting
Thirst
Polyuria
Polydipsia
Bony Pain

SEVERE

Dehydration
Ileus
Confusion
Drowsiness
Coma
Cardiac Arrhythmias

Definitive diagnosis requires a blood test to measure serum calcium.

99% of body calcium is found in bone combined with phosphate. The remaining 1% is divided evenly in the plasma between protein (albumin) bound and ionised or free calcium. A correction formula is applied to calcium measurements to take account of low albumin levels, something commonly found in patients with advanced cancer.

Corrected calcium = measured serum calcium + [0.022 x (42 – albumin level)]

Corrected calcium measurements are given with biochemistry reports.

How is it treated?

Treatment is palliative unless the primary tumour or bone metastases can be controlled. Many patients will require several treatments for hypercalcaemia in their last few months of life.

Indications for treatment :

- Corrected calcium greater than 2.6mmol/l.
- Cymptomatic.
- First episode.
- Previous good quality of life.
- Acceptance of IV therapy and routine blood tests.

Aims of treatment :

- To improve renal calcium secretion.
- To correct factors impairing renal function i.e. dehydration.
- To stop bone reabsorption of calcium.

Treatment/Medical Management

- Usually require rehydration with 2 – 4 litres of normal saline 0.9% over 24hour period. 0.9% normal saline aids the diuresis of calcium by excreting calcium ions along with sodium. This alone will result in a small decrease in the measurement of corrected calcium and may be sufficient to treat very mild hypercalcaemia.
- Bisphosphonates are the mainstay of treatment (pamidronate, zoledronate, clodronate) and can be effective in 80% of patients
- A bisphosphonate infusion (PAMIDRONATE) in 0.9% normal saline is administered at a rate not greater than 1mg/min and a concentration not greater than 60mg in 250mls. The dose required will depend on the level of hypercalcaemia.

Calcium Level	Pamidronate	Minimum Infusion Time
< 3.0	30mg in 250mls	30 minutes
3.0 – 3.5	60mg in 250mls	60 minutes
> 3.5	90mg in 500mls	90 minutes

Pamidronate has a rapid onset of action and results in a reduction in hypercalcaemia within 24 hours. However, it does not reach a nadir until day seven. Repeat infusions of pamidronate would not be administered during this period and daily blood tests are not necessary. It is suggested that a repeat calcium level is measured at day five.

In recurrent hypercalcaemia pamidronate infusions can be repeated at three to four weekly intervals if required.

Gold Nuggets

- **Not all symptoms respond equally well to treatment and this may be due to the underlying malignancy and advanced nature of the disease. Symptoms of malaise, fatigue and anorexia may be less responsive to treatment.**
- **Oral biphosphonates can be used for maintenance but they have a low bio availability and have considerable gastric side effects. There is no real benefit for their use in the palliative care setting.**
- **In patients with advanced disease and a very poor prognosis (in the last week or days of life), it may be a more humane approach to not treat the hypercalcaemia.**

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[Contents page](#)

2.14 – Insomnia

What is it?

- A complaint that may involve difficulties falling asleep (initial or sleep onset).
- Trouble staying asleep with prolonged awakenings (middle or maintenance).
- Early morning awakenings with inability to resume sleep (terminal or late).
- A complaint of non-restorative sleep.

Insomnia may occur as a single episode, but more frequently, it is a recurrent problem.

What causes it?

- Anxiety and fear.
- Depression delirium/dementia.
- Poorly controlled pain.
- Physical symptoms e.g. breathlessness, itch, sweating, leg cramps, nocturia, heartburn.
- Cardiac failure.
- Advanced respiratory disease.
- Disordered sleep-wake cycle.
- Sleep disorders e.g. Sleep apnoea, restless leg syndrome.

What are the effects?

- Disease related symptoms may worsen, such as pain fatigue and anxiety.
- Can decrease a person's ability to cope and cause feelings of isolation.
- May cause memory and concentration problems and mood disturbances.
- May have physical, psychological and economic effects on the individual.

How is it treated?

- Address underlying cause(s) if possible.
- Sleep hygiene plan, consider the following :
 - optimise sleep environment
 - avoid napping especially during the day
 - regular bedtime/wake time
 - avoid caffeine and alcohol late in the day
 - reduce evening fluid intake
 - exercise regularly, if possible
 - relaxation techniques/breathing exercises/consider complementary therapies
 - education about sleep
 - psychological support.

Medication

Medication should be reviewed :

- Diuretics.
- Steroids (give before 2pm).
- Sedative/hypnotic/acute withdrawal.
- Theophylline.
- Opioid side effects.
- Medications may also be the cause of excessive daytime drowsiness.

If the patient's current regimen is working well, do not change. Hypnotics should be withdrawn gradually.

Drug	Comments
Temazepam (10-20mgs nocte)	Short to intermediate acting benzodiazepine
Zopiclone (3.75-7.5 mgs nocte)	Second line, short acting hypnotic
Haloperidol (1.5-3mgs daily)	Management of acute delirium
Resperidone (0.25-1mg nocte)	Management of chronic confusion (avoid long term use; caution if history of CVA or TIA)
Amitriptyline (10-50mg nocte)	Sedative antidepressant-use low dose, may cause confusion
Trazodone (50-100mg nocte)	Sedative antidepressant-less risk of worsening chronic confusion

Gold Nuggets

- Patients may present with other symptoms such as pain, fatigue or anxiety and it is therefore important to consider insomnia as part of any diagnosis.

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[Contents page](#)

2.15 – Lymphoedema

What is it?

Lymphoedema is a chronic, progressive and often debilitating condition, caused mainly by an abnormality of, or trauma to the lymphatic system.

Lymphoedema affects mainly arms and legs but can affect any part of the body causing profound physical and psychological morbidity.

What causes it?

Any reduction in the capacity of the Lymphatics to draw the fluid from the interstitium and return it to the vascular circulation will result in the build up of protein-rich fluid in the affected part of the body.

The main causes of Lymphoedema are:

- Cancer and its treatments – secondary lymphoedema
- Congenital abnormalities of lymphatic system – primary lymphoedema
- Chronic venous insufficiency – lympho-venous/chronic oedema.

What are the effects?

Clinical signs and symptoms

- Increase in fluid volume and size of the affected area.
- Distortion of limb shape.
- Progressive changes in skin and subcutaneous tissue.
- Lymphorrhoea – leakage of lymph through the skin surface.
- Cellulitis.
- Pain associated with lymphoedema eg Throbbing, heaviness, tingling.
- Sensory changes e.g. “bursting” sensation, paraesthesia.
- Impaired function.
- Psychological distress and altered body image.

General Advice for healthcare professionals in managing Lymphoedema patients

- It is important not to puncture or traumatise any limb affected by lymphoedema with needles (this includes venflons, phlebotomy, BMs, injections etc).
- Blood pressure measurements should never be carried out on an affected arm.
- Daily skin hygiene is important. Skin should be cleansed, thoroughly dried and moisturised daily with aqueous cream to maintain skin integrity.
- Skin should be examined carefully for any signs of trauma, lymphorrhoea or infection. Each should be treated promptly and in line with local wound management and antibiotic guidelines for patients with lymphoedema.
- Fungal infections - treat problems such as athlete's foot promptly.
- Effective positioning of an affected limb can help reduce oedema. Where possible during frequent rest periods the affected limb should be supported by pillows and elevated - not above shoulder height for arms or waist height for legs.
- It is important that compression garments (sleeves or hosiery) used to minimise and maintain lymphoedema, are well-fitting. Some patients may require help to apply garments, and assessment for new or replacement garments can be made through lymphoedema key workers.
- Normal activity and use of the limb is encouraged but over-exertion or strenuous exercise can exacerbate limb swelling. Patients should be encouraged where possible to follow exercise routines as advised by lymphoedema key workers or physiotherapists. Compression garments should be worn when patient is exercising.
- Educate patients to recognise signs of infection and to seek medical advice immediately.
- Patients should be advised to avoid tight and restrictive clothing, footwear or jewellery on an affected limb.
- Patients should be advised not to carry heavy weights (including handbags) with an affected arm.
- Patients should be advised to wear protective gloves when using harsh detergents or carrying out any chores where there is a risk of skin damage.

Lymphoedema service - contact information

Full details of the lymphoedema care pathway from referral to treatment, how to access the service, and contact telephone numbers for the lymphoedema nurse specialist and the key workers can be found on the Forth Valley Intranet at

http://intranet.fv.scot.nhs.uk/web/site/Clinical/Lymphoedema/Lymph_Intro.asp

For specialist advice, please contact Strathcarron Hospice on 01324 826222

Gold Nuggets

- It is important not to puncture or traumatise any limb affected by lymphoedema with needles (this includes venflons, phlebotomy, BMs, injections etc).
- Blood pressure measurements should never be carried out on an affected arm.
- Daily skin hygiene is important. Skin should be cleansed, thoroughly dried and moisturised daily with aqueous cream to maintain skin integrity.
- Skin should be examined carefully for any signs of trauma, lymphorrhoea or infection. Each should be treated promptly and in line with local guidelines.
- Fungal infections of affected limb e.g. Athlete's foot require prompt treatment.
- Contact telephone numbers for the lymphoedema nurse specialist and the key workers can be found on the Forth Valley intranet.

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[Contents page](#)

2.16 – Nausea and vomiting

What is it?

Nausea is an unpleasant feeling of sickness that often precedes vomiting. Autonomic symptoms e.g. cold sweat, pallor, diarrhoea, tachycardia are often present.

Vomiting is the involuntary upward expulsion of gastric contents through the mouth.

What causes it?

There are many causative factors in advanced cancer (see table). The most common are drugs, metabolic disorders, gastrointestinal obstruction and gastric stasis.

What are the effects?

Nausea and vomiting are symptoms that are highly distressing for patients, adversely affecting their quality of life. Prolonged vomiting can result in various metabolic effects, including hyponatraemia, hypokalaemia and dehydration.

How is it treated?

Treatment will depend on the likely cause. If the cause is reversible, treatment should be directed at the underlying cause, if appropriate. If the cause is irreversible, treatment should be given according to the likely cause and clinical picture.

Reversible Cause	Irreversible Cause
Hypercalcaemia Constipation Drugs Infection Raised intracranial pressure Anxiety Gastric irritation Ascites	May be related to site of disease or other factors and complications
Treat underlying cause	Treat according to likely cause and mechanism

Likely causes	Clinical picture	Treatment (see table below for drug doses)
Drugs (incl opioids) Carcinomatosis Uraemia/hypercalcaemia Infection	Chemical/metabolic Persistent, often severe nausea. Little relief from vomiting/retching	1.Haloperidol ² 2.Metoclopramide ^{4,5} 2.Levomepromazine ³
Opioids, anticholinergics Local tumour Autonomic failure Hepatomegaly Peptic ulceration	Gastric stasis/outlet obstruction Intermittent nausea, often relieved by vomiting	Prokinetic 1. Metoclopramide ^{4,5} 2. Domperidone ^{5,6} If colic/ no response, seek advice Liver metastases or extrinsic compression ⁷ consider dexamethasone 4-6 mg/day Gastritis -proton pump inhibitor (e.g.lansoprazole)
Oesophageal or mediastinal disease	Regurgitation Dysphagia. Little nausea. Relief after food regurgitated	Stents/laser Radio/chemotherapy Dexamethasone 6-8 mg/day ⁷ Antiemetics often ineffective
Abdominal carcinomas Autonomic neuropathy Exclude constipation	Bowel obstruction May be partial/intermittent initially. Nausea often improved after vomiting. ↑ nausea, +/- colic, +/- faeculent vomiting in advanced/complete obstruction	Medical management if surgery inappropriate. Seek specialist advice early. 2 main types:- peristaltic failure metoclopramide ^{4,5} mechanical obstruction 1. hyoscine butylbromide (if colic) 2. Levomepromazine ³ 3.Cyclizine +/- Haloperidol 4.Octreotide SC (seek advice)
↑ Intracranial pressure Radiotherapy Brainstem/meningeal disease	Cranial disease/treatment Headache +/- cranial nerve signs	1. Cyclizine + Dexamethasone 8-16mg/day (if raised intracranial pressure) ⁷
Vestibular disease Base of skull tumour Motion sickness	Movement related	1. Cyclizine 2. Levomepromazine ³ 3. Hyoscine hydrobromide patch
	Causes unclear or multiple causes	1. Levomepromazine ³ 2. Metoclopramide (if no colic) ^{4,5} 3. Cyclizine + Haloperidol 4. Trial of Dexamethasone ⁷

If chemotherapy/radio therapy induced then seek specialist advice

NB – 5HT3 antagonists (e.g. – ondansetron) are of proven value in chemotherapy / radiotherapy induced nausea and vomiting but otherwise are not recommended

Prescribing notes (numbers refer to table above)

1. Long term antiemetic use should be reviewed regularly. Stop if the underlying cause has resolved.
2. Haloperidol may cause extrapyramidal side effects (e.g. – apathy, withdrawal) at higher doses or if use is prolonged.
3. Levomepromazine is a potent, broad-spectrum antiemetic. Use low doses to avoid sedation and hypotension. A 6mg, scored tablet is available on a named patient basis.
4. Metoclopramide may cause extrapyramidal side effects (e.g. tremor) with prolonged use. Caution in patients aged 20 years and under.
5. Prokinetic action is blocked by anticholinergics e.g. – cyclizine, buscopan, amitriptyline.
6. Domperidone is not as useful a prokinetic agent as metoclopramide but is less likely to cause extrapyramidal side effects.
7. Corticosteroids are best given before 2pm. Review and reduce to lowest effective dose. Withdraw once ineffective. Oral dexamethasone 1mg is approximately equivalent to oral prednisolone 7.5mg. Parental dose of dexamethasone is the same as the oral; prescribed as dexamethasone sodium phosphate SC or IM.

Prescribing guidance

- It is important to prescribe the same antiemetic regularly and when required. Review the situation every 24 hours.
- Avoid the oral route if the patient is vomiting or if oral absorption is likely to be compromised.
- Skin irritation with sc infusions of cyclizine or levomepromazine may be reduced by using a more dilute concentration in a 20ml syringe.
- Octreotide should be diluted in sodium chloride 0.9% rather than in water.

Drug Doses

Drug	Oral dose	Stat dose / prn dose	Subcutaneous syringe driver 24 hrs
Cyclizine	50mg, 8 hourly	50mg, oral SC	100-150mg
Domperidone	10-20mg, 6-8 hourly rectal preparation available	N/A	N/A
Haloperidol	1.5mg - 3mg, nocte	1.5mg, oral 1.5-2.5mg, SC	2.5-10 mg
Levomopromazine	6mg, nocte or bd	6mg, oral 6.25mg, SC	6.25-25mg
Metoclopramide	10-20mg 6-8 hourly	10mg, oral or SC	30-40mg (up to 80mg)
Hyoscine butylbromide (buscopan)	20mg, 4-6 hourly	20mg, 4 hourly, SC	40-120mg
Hyoscine hydrobromide	Topical patch, 1mg / 72 hours	0.4-0.6 mg, 2-4 hourly SC	0.8-2.4mg
Octreotide	N/A	N/A	0.3-0.6mg

Non-pharmacological measures

- Avoid exposure to foods that may precipitate nausea
- Ensure that the patient is in a calm environment away from the sight and smell of food
- Advise frequent snacks rather than large meals
- Have someone else prepare meals
- Use a mouthwash to rinse the mouth after vomiting
- Control malodour from wounds etc
- Use acupuncture wristbands

Assessment and investigations

It is important to assess nausea and vomiting independently.

- Establish the frequency, volume, nature of vomitus, precipitating factors and whether or not there is ongoing nausea between vomits.
- Review the drug regimen.
- Examine the abdomen.
- Perform a rectal examination.
- Perform blood tests to exclude metabolic causes or drug toxicity (e.g. digoxin).
- Examine the fundi for papilloedema.
- Evaluate associated symptoms.

Radiological investigations may be required if there is significant doubt over the cause.

Gold Nuggets

- **Assess nausea and vomiting independently**
- **Treatment is dependent on the likely cause**
- **Consider parenteral administration if continuous nausea or frequent vomits**

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[Contents page](#)

2.17 – Oral care

Introduction

The consequences of an unhealthy or painful oral cavity are significant. Not only are there physical implications of reduced oral intake and weight loss but, in addition, there may be psychological effects due to impaired communication and feelings of exclusion and social isolation. Patients who are at particular risk of developing oral problems and who will require scrupulous oral care include :

- patients aged 75 and over
- dysphagic patients
- patients with NG or PEG tubes
- patients receiving high volumes of O₂ therapy
- terminally ill patients
- endotracheal intubated/ventilated patients
- patients with acute oral or oro-pharyngeal conditions or requiring oro-pharyngeal suction
- patients receiving chemotherapy or XRT, especially to head and neck (seek specialist advice)
- immunosuppressed / immunocompromised patients
- children.

What is oral care?

The aim of Oral care is to :

- preserve a clean and healthy mouth
- remove plaque and debris
- prevent complications such as
 - Candidiasis or other infections
 - Xerostomia – subjective feeling of mouth dryness
 - Sialorrhoea – excessive salivation
 - Stomatitis
 - Halitosis – unpleasant or bad breath
 - Haemorrhage
- treat complications if they arise

How is this achieved?

Assessment and prompt treatment are essential.

Assessment

An assessment should be performed on admission to hospital or hospice (and should be repeated daily) and as regularly as possible at home. It entails :

- History
 - Mouth pain
 - Mouth dryness
 - Anorexia
 - Dysmastia (difficulty in chewing)
 - Dysphagia
 - Dysphonia (difficulty in talking)
 - Altered taste
 - Drug history
- Examination
 - Use a recognised oral assessment guide, torch and tongue depressor and wear disposable non-sterile non-powdered gloves.
 - Lips – clean and moisten before assessing oral cavity as dry cracked lips will be painful when the mouth is opened. Check for angular stomatitis
 - Mouth – examine hard palate, tongue and mucosal surfaces for evidence of coating, ulceration or infection. Retract upper and lower lips and cheeks. Ask patient to protrude tongue and lift upwards. Swab affected areas with a microbiological oral swab to identify any infection. Assess mouth dryness and pain.
 - Dentures – all dentures should be removed to permit a thorough assessment. Ensure privacy to avoid embarrassment.
- Documentation
 - Findings should be accurately recorded on a daily basis. Diagrams may help assess response to treatment.

Treatment

If able, patients may prefer to perform their own oral care but most palliative care patients are likely to require some assistance. It is a duty of carers to carry out oral hygiene in dependent patients.

Treatment can be considered as follows

- General treatment (for all patients)
- Treatment of specific problems
- Dental referral

General treatment

- Offer oral care x4 daily (after meals and at bedtime).
- Wear disposable gloves.
- For patients with natural teeth :
 - Clean with soft toothbrush and fluoridated toothpaste
 - Use water for rinsing to ensure all food debris is removed
 - Clean lips gently with gauze swab or foam stick soaked in water
 - Apply water soluble lubricating jelly to lips
 - If mouth is dry, also use artificial saliva (aerosol) and give frequent sips of water or crushed ice. Sucking sugar-free mints or gum may be helpful.
- For patients with dentures :
 - Remove dentures and clean with a soft toothbrush under running water over a sink or bowl to avoid damage.
 - Use water or denture cream in accordance with patient's wishes.
 - Remove full and partial dentures at night, clean and soak overnight in Chlorhexidine solution. Rinse after soaking.
 - Thoroughly rinse dentures after use.
 - Check dentures regularly for cracks , sharp edges or missing teeth.
 - Mark dentures with patient's name.
 - When dentures are removed, rinse the mouth with Chlorhexidine solution morning and night and water at other times.
 - Remove food debris with disposable foam sticks moistened with water.
 - If necessary, clean the tongue and oral mucosa with a soft toothbrush or foam stick soaked in water.
 - For heavy coating, dissolve ¼ tablet of effervescent ascorbic acid on the tongue.
 - If mouth is dry, also use artificial saliva (aerosol) and give frequent sips of water or crushed ice.
- For patients whose condition is poor or who are unconscious :
 - Brush teeth with fluoridated toothpaste and a small soft toothbrush or foam stick moistened with water (or dilute Chlorhexidine morning and night).
 - Remove excess toothpaste with a moistened foam stick.
 - Clean oral mucosa with foam sticks moistened with water.
 - Increase frequency of oral care as tolerated.
 - If mouth is very dry apply a thin film of water soluble lubricating jelly to the oral mucosa with a foam stick.

Treatment for specific problems – may be required singly or in combinations

- Bacterial infections :
 - Chlorhexidine mouthwash has antibacterial, antifungal and antiplaque properties and is used to treat oral infections in palliative care. It can be used on a foam stick but may be unpalatable and can cause alteration of taste. It is astringent and may cause pain but this can be reduced by diluting with equal volumes of water. It should only be used 12 hourly and the patient should not eat for 1 hour after use.
 - Flucloxacillin 250 - 500mg qid should be considered for Staphylococcal Mucositis

- Candidal infection :
 - Nystatin 1-5 ml q.i.d. is a topical used to treat thrush but should be given 1 hour before or after Chlorhexidine as they compete for the same receptors. Its action is limited to time of contact with the mucosa.
 - Fluconazole 50 mg orally daily for 7-14 days is a systemic treatment and is available as a capsule or liquid.
 - Itraconazole may be helpful in resistant infection but sensitivities would be required before prescription.

- Viral infections :
 - Herpes Simplex may be present on the mucosa (yellowish lesions) or on the lips as vesicles (cold sores) and oral or topical Aciclovir should be prescribed – oral dose is 200mg x5 daily for 5 days, topical dose is 1 smear x5 daily for 5-10 days.

- Xerostomia :

The causes of xerostomia are myriad but can be considered in 3 groups :

- Decreased saliva secretion.
- Extensive erosion of oral mucosa.
- Dehydration and reduced mastication.

Treatment of xerostomia includes :

- Two hourly oral hygiene.
- Ice cubes /crushed ice.
- Sugarless chewing gum, acid substances – salivary stimulants.
- Saliva substitutes.
 - mucin-based artificial saliva is more effective and better tolerated than cellulose-based preparations
 - pH should be neutral
- Water soluble lubricating gel.
- Dentures with a substitute saliva reservoir.
- Saliva stimulating tablets (SST) or pastilles (Salivix).
- Pilocarpine hydrochloride 5mg tid with meals (only for xerostomia following irradiation for head and neck cancer) N.B. Contraindicated in uncontrolled asthma and COPD, hepatic and renal impairment and angle-closure glaucoma.

- Sialorrhoea :

- Excessive salivation is unusual in cancer patients but may occur in patients with neurological conditions associated with swallowing problems.
Amitriptyline 10-25mg nocte may help as may the application of a Hyoscine Hydrobromide (Scopoderm TTS) Patch which releases 1mg/72 hours.

- Stomatitis (or mucositis) :

This may be chemotherapy or radiation induced and can be extremely painful. Chemotherapy inhibits mitosis in the rapidly dividing cells of the oral epithelium causing atrophic changes and ulceration usually about 7 days after treatment. Radiotherapy can cause erythema and ulceration usually about 2 weeks after treatment.

Palliative treatment is aimed at controlling pain and reducing mucosal trauma :

- Oral hygiene is vital.
- Ice chips can be soothing.
- Spicy foods should be avoided.
- Topical corticosteroids (Hydrocortisone oromucosal pellets or Triamcinolone dental paste) may reduce inflammation.
- Topical analgesics such as choline salicylate oral gel 8.7% (Bonjela) may lessen discomfort.
- Topical Gelclair (which covers the affected area with a film of povidone and sodium hyaluronidase) may allow the patient to eat.
- Care should be taken with topical local anaesthetics to avoid anaesthesia of the pharynx before meals as this may cause choking.
- Systemic analgesia may be required.
- Angular stomatitis (chelitis) presents as inflammation and cracking at the corners of the mouth. Consider haematinic deficiencies, bacterial or candidal infection and treat accordingly.
Topical miconazole or sodium fusidate ointment can be tried and evidence is emerging that topical tea tree oil may be beneficial.

- Halitosis :

This is a combination of exhaled air and foul-smelling substance from the upper digestive or respiratory tracts but most cases result from disease of the oral cavity. Treatment includes :

- Oral hygiene
- Dietary advice
- Systemic or topical antibiotics
- Prokinetic drugs e.g. Metoclopramide

In addition, odour absorbing or odour masking substances e.g. aromatherapy essential oils may be required in the patient's room.

- Haemorrhage (Please also refer to section 2.3 – Bleeding)

Consider topical sucralfate suspension 2g in 10ml bd or Silver nitrate sticks applied to bleeding points.

Dental referral

If new problems are identified or complex dental work is present a dental referral should be considered.

Poorly fitting dentures can be improved with denture soft lining or denture tissue conditioner eg Ivoclar Elite Soft Relining Kit or Coe Soft Relining Kit to prevent irritation of atrophic mucosa.

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[Contents page](#)

2.18 – Pain

What is it?

Pain is one of the most common symptoms experienced by patients receiving palliative care and for many the most feared. If not treated effectively, pain can have a detrimental effect of many aspects of the patient's life.

Pain is 'what the patient says it is' and can be described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

What causes it?

Pain can be caused by many different factors :

- For patients with cancer, the primary tumour itself may be pressing on surrounding tissues and or nerves.
- Secondary tumours or metastases can often cause pain, especially in the bones.
- Inflammation caused by infection.
- Tissue damage due to therapies e.g. – chemotherapy or radiotherapy
- Pain can be exacerbated by the psychosocial and spiritual impact of the person's illness.

What are the effects?

Unresolved pain may have an effect on :

- mood
- general enjoyment of life
- sleep
- the patient's general activity
- mobility
- normal working
- relationships with others

Psychological pain

Pain can reduce the quality of life, lead to fear, anxiety and depression which in turn can effect the patient's perception of pain creating a vicious cycle (see section 2.9).

Social pain

Pain may limit the contribution the person makes socially. They may be unable to work and become socially isolated and withdrawn, leading to depression. Financial problems due to loss of earnings may also impact on the person's wellbeing.

Spiritual pain

Pain can have a major spiritual component (see section 8.10). This is not always related to religion or culture. Pain can cause people to lose hope or ask 'why me' or think that 'pain means death'.

Factors that increase the perception of pain :

- Insomnia
- Tiredness/exhaustion
- Anxiety
- Fear or anger
- Isolation
- Depression
- Boredom
- Financial/family concerns
- Uncommunicative staff/carers
- Therapeutic failure

Factors that decrease the perception of pain :

- Sleep
- Comprehension
- Calmness
- Companionship
- Elevation of mood
- Occupation of time
- Forward planning
- Communication
- Control of other symptoms

Pain assessment

The purpose of assessment is :

- to identify and describe the patient's experience of pain
- its location and intensity
- to diagnose its cause and any factors which make the pain better or worse. This then enables appropriate treatments to be tailored for the individual.

How to assess pain

The most effective way to assess a patient's pain is through dialogue with the patient. The use of the Forth Valley Pain Assessment Tools (see the control symptoms resource folder for samples) will allow the patient the opportunity to express the physical characteristics of their pain and also the effect it has on their life.

The assessment tool incorporates a visual analogue scale, a body diagram to pinpoint where the patient's pain(s) are as well as specific questions to ask. Assessment must include sensitive and careful questioning to allow the patients to open up and discuss their pain.

How is it treated?

All aspects of a patient's pain (spiritual, physical, social, psychosocial) should be addressed. See section 8.10 for information on spiritual care, and sections 1.3 and 4.7 for information on psychosocial care.

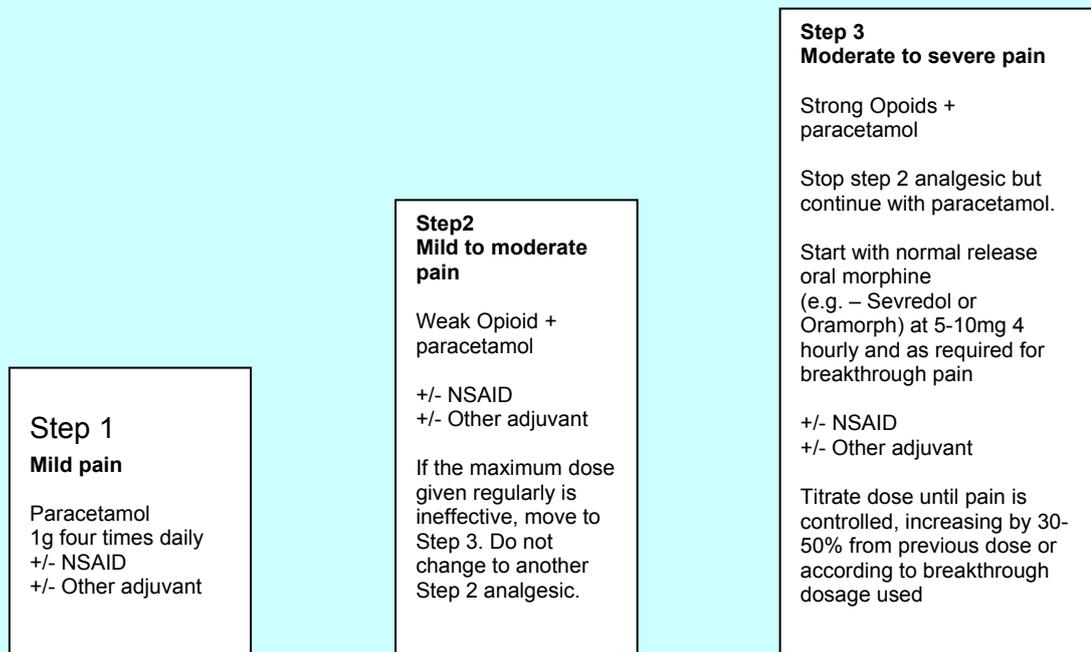
Physical pain

The World Health Organisation (WHO) has produced a helpful “analgesic ladder” which suggests treatment for varying levels of pain and allows analgesics to be tailored for the individual patient.

The WHO analgesic ladder

The following WHO ladder has been extracted from the Scottish Intercollegiate Guidelines Network (SIGN) Publication 44 (Control of Pain in Patients with Cancer). A quick reference guide for SIGN 44 is available in the control symptoms resource folder.

Pain is graded from mild to severe and the analgesic ladder is a useful means of tailoring analgesia. Start at an appropriate step of the ladder and move up or down as needed.



Notes

- All patients on step 2 or 3 of the ladder must have access to regular prophylactic laxatives
- Patients on step 3 of the ladder should have access to a prophylactic antiemetic to take when required.

If pain is controlled on step 3

- Convert to a 12 hourly release preparation of controlled release oral morphine: Calculate 24 hour dose of normal release morphine and divide by 2. Prescribe this dose as controlled release morphine (e.g. MST continuous) 12 hourly.
- Prescribe breakthrough analgesia (section below).
- Review regularly.
- If oral route is inappropriate, for some patients fentanyl patch may be appropriate (refer to Fentanyl section for appropriate indications and guidance).

If pain is not controlled (or side effects intervene) on step 3

- Review diagnosis.
- Consider adjuvant therapy.
- Consider other treatment.

- Seek specialist advice. Oxycodone may be a suitable alternative if patient has opioid responsive pain and is unable to tolerate morphine at an adequate dose to control their pain.

Example of conversion to controlled release morphine.

- Sevredol 20 mg 4 hourly = 120mg in 24 hours (no breakthrough doses used in 24 hours)
- Dose of MST = $120\text{mg} / 2 = 60\text{mg}$ every 12 hours.
- Dose of Sevredol for breakthrough = $120\text{mg} / 6 = 20\text{mg}$ as required.

Moderate to severe uncontrolled pain (Step 3) – parenteral diamorphine (please be aware of the current shortage of diamorphine.)

- Parenteral opioids will not give better analgesia than the oral route unless there is a problem with absorption (e.g. – persistent nausea/vomiting or bowel obstruction) or with administration (e.g. – unable to swallow or very weak).
- Diamorphine is opioid of choice in syringe drivers due to its high solubility.

Patients who are not currently on any opioids

- For a patient who has not previously been on any opioids, i.e. – opioid naïve, a suitable starting dose of SC diamorphine would be 5-10mg over 24 hours given via a syringe driver.

Patients already on oral morphine

- When transferring from oral morphine, 3:1 is the usual conversion:- 3mg oral morphine = 1 mg subcutaneous diamorphine.
- Breakthrough analgesia : Prescribe a bolus dose of SC diamorphine: $1/6^{\text{th}}$ of the 24 hour diamorphine dose.
- Titrate dose until pain is controlled increasing by 30-50% from previous dose or add up total of 24 hour infusion and breakthrough doses given, and use this total as the new 24 infusion dose.

Example of conversion from controlled release oral morphine

- Patient has MST 30mg twice daily + 3 doses of Sevredol 10mg in previous 24 hours. Total oral morphine therefore equals 90mg over 24 hours.
- Diamorphine dose = $90\text{mg} / 3 = 30\text{mg}$ by SC infusion over 24 hours.
- Diamorphine breakthrough dosage = $30\text{mg} / 6 = 5\text{mg}$ as required.

If pain is controlled

- Reassess regularly.

If pain is not controlled (or side effects intervene)

- Review diagnosis.
- Consider adjuvant therapy.
- Consider other treatment.
- Seek specialist advice. An alternative opioid may be appropriate if patient has pain which is opioid responsive and is unable to tolerate diamorphine at an adequate dose to control their pain : seek advice on choice and dose conversion.

Breakthrough Analgesia

- Every patient on step 3 should have access to breakthrough analgesia.
- The same principles apply for oral morphine and subcutaneous diamorphine.
- Prescribe normal release oral morphine (Sevredol/Oramorph) at 1/6th of the total daily dose or prescribe SC bolus dose of diamorphine at 1/6th of the 24 diamorphine infusion dose.
- If more than 1 or 2 breakthrough doses required on a regular basis, consider increasing dose of controlled release morphine or SC diamorphine infusion; then calculate new breakthrough dose.
- **Caution** – In a patient who has movement related pain or incident pain, and whose background is satisfactorily controlled, do not keep titrating upwards the regular 24 dose as toxicity may ensue. Give breakthrough doses in anticipation of movement related pain or incident pain.

Practical points

- Remember to increase/decrease the breakthrough dosage when the 24 hour dose is changed.
- Advise the patient to wait 30 minutes after taking breakthrough medication to assess the effect. If pain persists take a further dose and wait 30 minutes. If pain persists, ask the nurse, doctor or pharmacist for advice.

Opioid Toxicity

There is wide individual variation in the dose of opioid which causes toxicity. Prompt recognition and action is essential. Patients may not volunteer information regarding dreams or hallucinations.

Toxicity can present as :

- Subtle agitation or confusion
- Pinpoint pupils
- Muscle twitching/myoclonus/jerking
- Vivid dreams/ hallucinations
- Abnormal skin sensitivity to touch
- Seeing shadows at periphery of visual field

Actions

- Reduce opioid dose by 1/3rd and ensure patient well hydrated.
- Consider checking urea, electrolytes & calcium. Give SC/IV fluids if necessary.
- Consider adjuvant therapies and/or seek advice on alternative opioids if toxicity precludes control of pain.
- If side effects are distressing or symptoms do not settle, seek advice promptly.

Practical points

- Agitated confusion may be misinterpreted as uncontrolled pain, and further opioids given making it worse.
- Patients with excessive sedation may become dehydrated, with resultant renal impairment and increased toxicity. Ensure adequate oral fluids are taken.

Adjuvant therapies and co-analgesics for pain management

Practical points

- Assess fully the type of pain and likely cause before commencing a co-analgesic.
- Reassess regularly.
- Review effectiveness of any medication prescribed and discontinue if no benefit after appropriate trial period.
- Remember that the side effects of some of the co-analgesics are additive to opioid side effects e.g. – drowsiness and dry mouth.

Drug Class	Drug	Start dose	Titration	Useful points
Tricyclic antidepressants	Amitriptyline	10-25mg at night	Titrate up slowly	Watch for sedation, confusion, dry mouth
Anti-convulsants	Gabapentin	300mg at night	Increase by 300mg on day 2 and again on day 3 depending on tolerance. Maximum of 2.4g daily in divided doses	100mg at night + slow titration essential in frail or elderly patients and in renal impairment.
	Carbamazepine	100-200mg twice daily	Titrate up slowly	Use lower end of dose range in elderly
	Sodium valproate	100-200mg twice daily	Titrate up slowly	

Description	Co-analgesics	Non-drug methods
Nerve pain (shooting, lightning, shock like, burning, tingling, pins & needles, throbbing, jaggy, radiating)	Trial of steroids (e.g. – dexamethasone) Tricyclic anti-depressants Anti-convulsants	Hot/cold packs TENS Acupuncture Nerve blocks
Bone metastases (worse on movement relieved by rest, grinding, hot spot, tenderness over bone, definite location)	NSAIDS Trial of steroids (e.g. – dexamethasone) Consider bisphosphonates	Hot/cold packs Radiotherapy Nerve blocks
Intestinal colic (comes and goes, spasm like, gripping, gripey)	Anti-spasmodics (e.g. hyoscine Butylbromide)	Hot/cold packs Relaxation therapy TENS
Liver capsule pain (right sided, dull ache, continuous, deep, tight)	Trial of steroids (e.g. – dexamethasone) NSAIDS	Advice on change of position (e.g. – sleeping propped up)
Headache (related to raised intracranial pressure)	Trial of steroids NSAIDS / Paracetamol	Radiotherapy Relaxation techniques
Muscular pain	NSAIDS Muscle relaxant (e.g. – diazepam 2mg)	Heat pad Massage Relaxation exercises Acupuncture

Please refer to section 8.11 of the palliative care manual for more information on the use of steroids in palliative care.

Fentanyl patches

Indications

- Stable, opioid responsive pain. **Do not use for unstable pain (i.e.- pain that is not controlled).**
- Intolerable adverse effects with oral morphine which do not resolve with appropriate intervention.
- Oral route inappropriate e.g.- difficulty swallowing, ileostomy, administration of medicines via enteral feeding tube.
- Poor compliance with oral medication but supervised patch application is possible.

Initiation of patches

From full therapeutic dose of oral/weak opioid (step 2 of WHO analgesic ladder)

- Not normally advised.
- Start with regular oral strong opioid (step 3 of WHO analgesic ladder) first if possible
- Extreme caution required particularly in frail and elderly. The lowest patch strength may be too high

From oral strong opioid (step 3 of WHO analgesic ladder)

- For a 4 hourly opioid (e.g. – Oramorph) – continue for 12 hours after applying first patch
- For a 12 hourly opioid (e.g. – MST) – give last dose when first patch applied
- For a 24 hourly opioid (e.g. – MXL) – apply first patch 12 hours after last dose

From Diamorphine SC infusion

- Apply first patch and continue infusion for 12 hours. **Then stop infusion.**

General

- When applying a fentanyl patch, select a strength based on an opioid dose conversion chart or seek specialist advice. The control symptoms resources folder contains a sample conversion chart.
- Ensure that the patient/carer knows to stop the regular oral or SC opioid.
- Prescribe breakthrough morphine (either orally or via enteral tube). Use an opioid dose conversion chart for appropriate dose. If oral route is unavailable, consider alternative e.g.- morphine suppositories.

Titration

- If pain is not controlled, wait 48-72 hours until steady rate is reached before considering a dose increase. (Advise patient to use breakthrough analgesia as required.)
- If pain persists and is opioid responsive, consider dose increase by increment of 12 micrograms. (25 mcg increments if 75mcg patch or higher).
- Prescribe appropriate new dose of breakthrough analgesia.
- Review after 48-72 hours
- Incident pain or movement related pain in patients whose pain is otherwise controlled should be managed by appropriate use of breakthrough analgesia and not by increases in patch strength.
- Less constipating than morphine – halve previous laxative dose and adjust according to need.

If there are signs of opioid toxicity present (see above), remove patch and seek advice.

Practical points for patients

- Change patch every three days.
- Apply new patch to a different skin site to previous patch.
- Apply to dry, non-inflamed, non-irradiated skin, hairless skin on upper arm or trunk. Avoid bony prominences.
- Consider writing date and time patch applied on the patch.
- Avoid direct heat sources (e.g.- hot water bottle) in direct contact with patch.
- Used patches still contain active drug – dispose of safely.
- Sweating may reduce adhesion and absorption.

Changing from a fentanyl patch to oral morphine may occasionally be necessary for example, when a patient develops sensitivity to the patch adhesive or pain is not well controlled with the fentanyl patch. A reservoir of fentanyl in the skin under the patch means that significant levels persist in the blood for up to 24 hours after patch removal. Do not convert directly to a modified release oral opioid. Seek specialist advice.

Initiation of diamorphine infusion at end of life in a patient on a fentanyl patch

This can be complicated – practitioners must seek specialist advice if they are unsure or require guidance on doses.

Continue fentanyl patch at current dose and change every 3 days (conversion to equivalent dose of diamorphine is difficult due to the reservoir of fentanyl under the skin and is not normally advised). At the same time, add in and titrate diamorphine to control the increasing pain using either of the options below i.e. – bolus dose or continuous infusion as appropriate.

Bolus dose

- Prescribe diamorphine SC as required for breakthrough pain, calculated from an opioid dose conversion chart for the total patch strength of fentanyl in situ.
- If regular breakthrough required, give the amount of diamorphine required in 24 hours in a syringe driver as a continuous SC infusion. This is given in addition to the fentanyl patch.
- Calculate the new breakthrough dose of diamorphine from an opioid dose conversion chart (=diamorphine SC breakthrough dose for fentanyl patch + diamorphine SC breakthrough dose for 24 hour diamorphine infusion).

Example

Calculate breakthrough dose of diamorphine for fentanyl patch:

- a) patient on fentanyl 50 microgram patch. Conversion chart calculates diamorphine breakthrough dose = 10mg subcutaneously

Calculate breakthrough dose of diamorphine for SC infusion:

- b) patient on diamorphine SC infusion 30mg over 24 hours. Conversion chart calculates diamorphine breakthrough dose = 5mg

Calculate total breakthrough dose by adding (a) and (b) above

- c) Diamorphine breakthrough dose = 10mg + 5mg = 15mg, as required

Continuous Infusion

If 'as required' SC bolus injections are difficult (e.g. – in the community), set up a continuous SC infusion of diamorphine using the equivalent of 2 breakthrough doses of diamorphine, calculated from an opioid dose conversion chart for the patch of fentanyl in situ.

Example

Patient on fentanyl 100 microgram patch. From opioid dose conversion chart, breakthrough dose of diamorphine = 20mg subcutaneously prn

Titrate diamorphine infusion and breakthrough as per guidance above.

Gold Nuggets

- **Agitated confusion may be misinterpreted as uncontrolled pain, and further opioids given making it worse.**
- **Do not use a Fentanyl patch for unstable pain.**

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[Contents page](#)

2.19– Pleural effusion

What is it?

A small amount of fluid (20-30ml) is normally present in the pleural space for lubrication. This is produced by capillaries and removed by lymphatics at a rate of 100-200ml daily. The lymphatics drain into the mediastinal lymph nodes.

A pleural effusion forms as a result of excess production and /or reduced resorption of fluid. Almost 50% of patients with advanced cancer develop a pleural effusion. The commonest primary tumours are lung, breast, ovary or lymphoma.

The median survival for patients with a pleural effusion is 3-12 months but a low pleural fluid pH (<7.3) and/or low glucose (<3.3mmol/l) suggests extensive pleural disease and a prognosis of 2 months.

What causes it?

In most malignant effusions there is reduced resorption of fluid due to tumour obstructing lymphatic transport in the pleura or regional lymph nodes. There may also be parapneumonic effusions secondary to infection behind the tumour, empyema or cardiac failure.

Effusions may be exudates or transudates. More than 90% of malignant pleural effusions are exudates.

What are the effects?

- Breathlessness is the main symptom and is caused by :
 - chest wall and diaphragm displacement, weakening respiratory muscles
 - lung compression causing ventilation-perfusion mismatch
 - hypoxia.
- Cough
- Chest pain

How is it treated?

Investigations include :

- chest X-Ray
- ultrasound
- CT scan thorax
- cytological, bacteriological and biochemical examination.

Management depends on severity of symptoms and prognosis and it is important to exclude reversible causes. Small asymptomatic effusions require monitoring only. Symptomatic effusions should be drained.

Short prognosis (<8weeks)

- Aspiration (thoracocentesis) – even removal of 500ml may provide relief. The effusion is likely to recur and repeat aspirations may be necessary.
- Aspiration of loculated effusions may be aided by intrapleural streptokinase or urokinase which degrade fibrin but the evidence for this is poor.

Longer prognosis (>8 weeks)

- Aspiration.
- Drainage - small bore catheters (8-14F) can be inserted under ultrasound guidance. A chest X-ray should be performed after insertion of a chest drain.
- Pleurodesis – medical pleurodesis involves the instillation of an irritant agent into the pleural cavity to induce inflammation. This causes adhesion of the pleural layers which obliterates the pleural space. Talc is the recommended agent and is added with 50ml of saline 0.9%.
- Thoracoscopy – if the patient is fit consideration should be given to thoracoscopy with drainage and pleurodesis.
- Pleuroperitoneal shunts.

Adequate analgesia (local and systemic) should be administered for the above procedures and consent should be obtained. Oxygen should be available.

Gold Nuggets

- **Pleural effusions may not always be due to tumour. Exclude reversible causes**

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[Contents page](#)

2.20 Pruritus/itch

What is it?

Pruritus or itch is an unpleasant sensation in the skin which provokes an urge to scratch.

What causes it?

There are many causes of skin itching (with or without a rash) ranging from simple allergies and primary skin diseases such as scabies through to more complicated haematological or endocrine disorders. Itch is often associated with dry skin. Virtually all patients with advanced cancer and pruritus have dry skin.

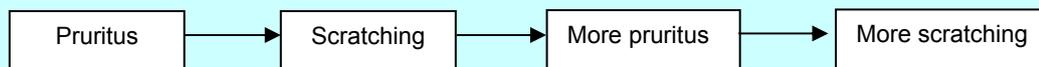
In palliative care the most common reasons for itch are listed below but this is not an exhaustive list and other causes should be considered where appropriate.

- Allergies causing contact dermatitis.
- Drug reactions.
- Cholestatic jaundice.
- Renal failure resulting in uraemia.
- Cutaneous metastatic lesions.
- Myeloma, lymphoma & polycythaemia rubra vera.

Pruritus can also be neuropathic i.e. initiated centrally by brain tumours, brain damage and multiple sclerosis.

What are the effects?

- Mild to severe discomfort/distress for patients.
- Disturbed sleep.
- There is often dry, scaling skin, which will itself cause pruritus through the itch/scratch cycle.



- Painful excoriated skin – which has the potential to become infected.

Pruritus can be increased by attention/awareness, anxiety and boredom. Similarly it can be decreased by relaxation and distraction.

How is it treated?

Always correct the correctable.

Review the patients medication :

- Is the pruritus drug-induced? (a rash may or may not be present)
- Has an opioid recently been prescribed (this side effect is more common with spinal opioids, but it can occur with systemic drugs.)
- If a drug is the likely cause, it should be stopped if possible or switch to an alternative.
- Consider biliary stenting or a percutaneous drain, if there is obstructive jaundice. Stent insertion can be very effective in relieving jaundice and the associated pruritus.
- Dry skin is frequently an important factor in advanced cancer and pruritus (or itch) is often associated with dry skin. Rehydrate the skin topically with aqueous cream or emulsifying ointment and/or emollient in the bath water, twice a day. This is an essential part of treatment and is often effective on its own.
- Menthol 1% can be added extemporaneously if aqueous cream alone is ineffective.
- Eurax (Cromamiton) has been shown to be ineffective against pruritus despite it being commonly used.
- The topical use of antihistamine creams should not be encouraged – prolonged use may lead to contact dermatitis.
- Calamine lotion has an antipruritic effect but as the water evaporates, the lotion has a drying effect, which is counterproductive. An oily lotion or aqueous cream calamine preparation is available but many people find the pink colour cosmetically unacceptable.
- General measures include the discouragement of scratching, keeping finger nails short and avoid skin contact with synthetic materials.
- Avoid agents that exacerbate skin dryness – e.g. stop using soap and use a non detergent substitute. Use aqueous cream as a soap substitute.
- Antihistamines such as chlorpheniramine are commonly used, but pruritus resulting from renal failure or cholestasis is rarely relieved by antihistamines.
 - However, the sedative effect may allow the patient to sleep at night
 - Newer non-sedating antihistamines are probably ineffective for pruritus
- Cholestyramine is not recommended for patients with advanced cancer because
 - Generally it is not effective
 - It often causes diarrhoea, is unpalatable and is poorly tolerated

Gold Nuggets

- **The most common cause in advanced malignancy is probably cholestatic jaundice although there is not a clear association between the level of bilirubin and the severity of pruritus.**
- **Biliary stenting or percutaneous drainage should be considered if cholestatic jaundice is evident.**

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[Contents page](#)

2.21 - Thrombosis

What is it?

A thrombus consists of dense layers of platelets and fibrin. Later it becomes a loose, friable, jelly-like mass of fibrin and red cells which may readily detach to form an embolus. After a few days, inflammatory changes occur in the wall of the vein. The thrombus may undergo lysis or organisation.

Thrombosis is commonest in the lower limbs but the axillary vein may be involved as a complication of tumour or radiotherapy.

What causes it?

Injury to the vein, slowing or obstruction of the blood stream and increased coagulability of the blood may all be contributory.

What are the effects?

- Pain.
- Swelling.
- Pyrexia.
- Limb discolouration :
 - Pink- dilatation of superficial veins
 - White – collaterals patent
 - Blue – collaterals occluded
- Silent.
- Pulmonary embolism.

Thrombosis may be diagnosed clinically or by US scanning. D-dimer testing may become more widely available soon.

How is it treated?

Cancer patients are at risk of venous thrombo-embolism (VTE) but control of anti-coagulation is difficult in palliative care and decisions regarding management should be made on an individual basis. Traditionally Warfarin has been the anti-coagulant of choice. However, evidence is now emerging to support the use of Low Molecular Weight Heparin (LMWH) as first-line treatment of cancer-related VTE. In addition, many patients have found LMWH to be an acceptable and simple alternative to Warfarin allowing them freedom from blood tests and optimism regarding their care.

Cancer patients will fall into one of three groups :

- Patients not on anti-coagulant and with no evidence of DVT
- Patients previously established on oral anti-coagulation
- Patients not on anti-coagulant and found to have DVT

Patients not on anticoagulant and with no evidence of DVT

These patients should not routinely be commenced on an anti-coagulant but consideration should be given to prophylactic LMWH in addition to compression hosiery or TED stockings for patients at particular risk e.g. spinal cord compression

Patients previously established on oral anti-coagulation

In general oral Warfarin may be continued unless there are significant contra-indications to continued use such as :

- Evidence of bleeding
- High INR (> 5) on repetition and for no identified reason
- Thrombocytopenia
- Hepatic failure.
- Serious risk of falls
- High alcohol intake

Consideration should be given to the use of LMWH (see below for details) if there are difficulties associated with administration such as :

- Dysphagia
- Drug interactions
- Difficulty in monitoring INR e.g. poor venous access (note, however, that finger prick monitoring of INR is becoming more widely available in the community).

Patients not on an anti-coagulant and discovered to have a DVT

- Each patient should be considered as an individual but all patients should receive symptomatic relief with leg elevation and analgesia. Possible PTEs should be treated with O₂, opioids and anxiolytics.
- Further investigation may be appropriate e.g. US scanning but need not delay the initiation of therapy.
- Initial treatment should be given with appropriate (treatment) dose LMWH once daily according to BNF guidelines. Platelets should be monitored at day 5-8. The LMWH can be reduced to maintenance/prophylactic dose or converted to oral Warfarin therapy as indicated by the clinical condition, prognosis, concomitant diagnoses etc.
- Anti-Factor Xa monitoring is not normally required for LMWH but may be considered in patients with an increased risk of bleeding or those who are actively bleeding.
- The dose of LMWH should be reduced in severe renal impairment.
- If Warfarin is commenced the INR should be monitored regularly and if interacting drugs are used the monitoring schedule should be adjusted accordingly.
- The length of treatment should be considered on an individual basis. In some situations the risks of continuing treatment may outweigh the benefits.
- For some patients Aspirin 75-150mg daily may be a more useful compromise.
- Some patients with inferior vena caval thrombosis may be well enough to have a vena caval filter inserted to prevent recurrent pulmonary emboli if anti-coagulation is contra-indicated.

Problems associated with anti-coagulant therapy

Haemorrhage (please refer to section 2.3 – Bleeding)

Reversal of Warfarin therapy may be necessary in the event of major haemorrhage using Phytomenadione (Vit K1), factor concentrate or fresh frozen plasma. (See BNF 2.8.2) If bleeding is minor (e.g. microscopic haematuria, single epistaxis of < 5 minutes duration) the Warfarin should be discontinued and re-introduced when the INR is satisfactory (< 5). Alternatively LMWH could be considered.

Heparin-induced thrombocytopenia (HIT)

LMWH can rarely cause cutaneous reactions which may be a clinical indicator of heparin-induced thrombocytopenia (HIT). Platelet counts may be stable in this condition but heparin-dependent antibodies can often be detected.

If patients develop skin lesions LMWH should be discontinued.

Potential Drug interactions with Warfarin

All changes in drug therapy should be considered (see BNF Appendix 1) but those commonly used in palliative care are listed.

Anti-coagulation effect increased by :

- Coproxamol
- NSAIDS
- Amiodarone
- Erythromycin
- Ciprofloxacin
- Metronidazole
- Fluconazole
- Miconazole gel
- Omeprazole
- Cranberry juice (CSM suggests should be avoided in patients taking Warfarin)

Anticoagulation effect decreased by :

- Rifampacin
- Carbamazepine
- Azothioprine
- Sucralfate
- Vitamin K (may be present in enteral feeds)
- St. John's Wort

Changing Clinical Situation

Changing clinical conditions can adversely affect oral anticoagulation control e.g. cardiac failure, alcohol consumption, changing thyroid function. In addition, changes in dietary intake, concurrent chemotherapy and significant constipation/diarrhoea can have detrimental effects, requiring closer monitoring.

Interfaces of care

When patients on Warfarin are transferred from one care setting to another the most recent INR should be detailed with a recommended date for rechecking. Arrangements for subsequent monitoring should be confirmed.

If a patient is discharged on Warfarin initiated during an admission the GP should be informed via the immediate discharge document. The patient should be educated about anticoagulant therapy and provided with a yellow record book and information on potential drug interactions.

If a patient has been commenced on LMWH during an admission this should be communicated to the PHCT and arrangements made for daily administration by the DN. A 7 day supply of LMWH should be provided.

Gold Nuggets

- **Death due to a thrombotic episode may be preferable to death due to uncontrolled bleeding. Prophylactic anti-coagulation should be tailored to the patient's present and future needs.**
- **Be aware of potential drug interactions with warfarin.**

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[Contents page](#)

2.22 – Weakness and Fatigue

What is it?

Fatigue is defined as a chronic form of tiredness which persists for longer than one month, which is perceived by the patient as being unusual or abnormal, absolutely disproportionate to the amount of exercise or mental activity carried out and not removed by resting or sleeping.

What causes it?

Contributory factors

Extrinsic :

- Radiotherapy.
- Chemotherapy.
- Hormone therapy.
- Biological therapy e.g. Interferon.
- Surgery.
- Drugs e.g. analgesics, antiemetics, sedatives. Corticosteroids.

Intrinsic :

- Disease progression
- Cancer cachexia
 - skeletal muscle wasting may be mediated by Tumour Necrosis Factor.
- Infection.
- Anaemia.
- Metabolic abnormalities
 - low sodium, potassium
 - high calcium, urea, glucose
- Accumulation of toxic metabolites from cell destruction may contribute.
- Poorly controlled symptoms e.g. pain.
- Psychological factors e.g. depression/anxiety/fear.
- Altered sleep pattern.
- Co-morbidity e.g. COPD, cardiac failure.
- Nutrition.

Specific causes of Muscle Weakness :

- Cancer cachexia.
- Physical inactivity.
- Focal weakness.
- Cerebral metastases.
- Spinal cord / nerve root compression.
- Brachial plexopathy.
- Proximal myopathy from corticosteroids.
- Paraneoplastic syndromes.
e.g. Lambert-Eaton myasthenic syndrome (LEMS).

What are the effects?

- Low energy, tiredness.
- Loss of independence / control.
- Muscle weakness.
- Poor concentration.
- Reduced mobility.
- Low mood / loss of self esteem.

How is it treated?

There is no generally accepted treatment for the whole fatigue syndrome.

Patients will require multi-dimensional evaluation & regular review. The impact on the quality of life should be assessed.

Treatment should be tailored to the individual & modified as necessary.

Treat the treatable - if appropriate, consider

- Medication review.
- Control of other symptoms.
- Blood transfusion.
- Correction of biochemical abnormalities.
- Treatment of infection.
- Dietetic advice +/- supplementary drinks etc.
- Trial of an appetite stimulant
 - Dexamethasone 4-6 mg daily
 - Discontinue if ineffective after 1 week
 - Reduce dose by 2mg weekly (see section 8.11 on using Steroids in Palliative care)
 - Duration of response may be limited.
 - Co-morbidities may limit use e.g.- gastro-intestinal bleeding
 - Megestrol acetate 160 mg daily
 - Increase dose weekly up to 160 mg qid
 - Maintain on lowest effective dose
 - Stop if no benefit
 - Avoid if hypertension, cardiac and renal dysfunction

Provide information

- Explore patient's understanding of condition.
- Emphasise reality of symptoms.
- Offer possible explanations.
- A fatigue diary may help.
- Offer written information e.g. Cancer Bacup.

Devise a management strategy considering physical, emotional & practical needs

Physical needs :

- graded exercise.
- physiotherapy /OT to maximise potential.
- pace self care activities.
- prioritise and delegate less important tasks.
- set realistic goals.
- schedule day time rest periods.
- ensure adequate sleep.
- consider relaxation techniques.

Emotional needs :

- allow opportunities to share feelings and concerns.
- address issues of self worth and significance.
- prescribe an antidepressant or anxiolytic if appropriate.
- enlist appropriate professionals e.g. community nurse, clinical psychologist.
- consider attendance at a community centre or day hospice.

Practical needs :

- identify key family members / carers.
- if in hospital anticipate discharge requirements.
- if at home predict patterns of decline and identify changing requirements.
- a case conference involving all agencies may be necessary.
- a home visit/environmental visit should identify equipment needs and any home adaptations required.
- social work can advise re benefits, home help for shopping, carers etc.
- voluntary agencies may provide support e.g. Crossroads, befrienders.
- consider transport needs (disability sticker, reduce hospital appointments).
- meals on wheels / Wiltshire farm foods may be helpful.

Patient pointers

- Written information from Cancer BACUP is very useful

Gold Nuggets

- **Balance exercise and rest.**
- **Good assessment is vital.**

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[Contents page](#)

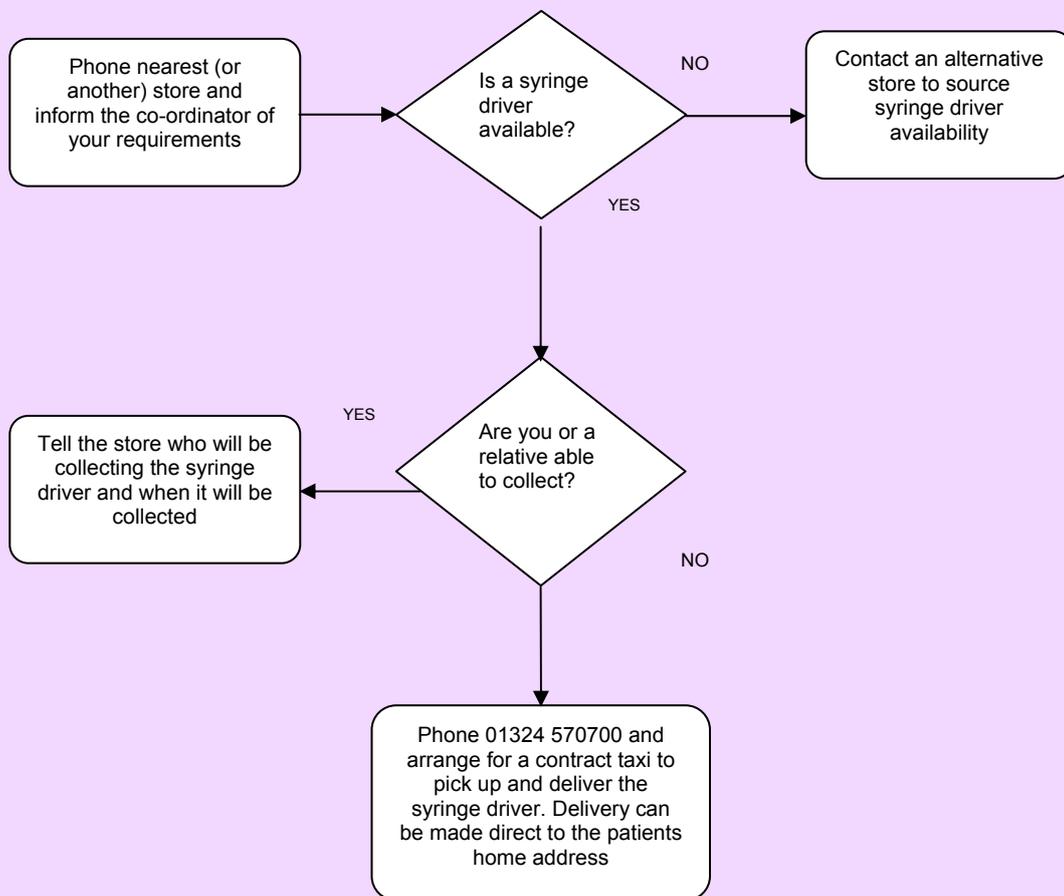
Section 3 – Syringe drivers

3.1 - Obtaining a syringe driver from a store

NHS Forth Valley operates a centralised management system for graseby ms26 syringe drivers. This section sets out the procedure to follow to access a syringe driver and the contact details of the stores holding the equipment.

24 hour access to syringe drivers is available at Falkirk & District Royal Infirmary, Stirling Royal Infirmary, Bannockburn Hospital, Bo'ness Hospital and Bonnybridge Hospital.

How to obtain a syringe driver from a store



Please note the following points after using the syringe driver :

- You should replenish the consumables in the syringe driver box.
- Please return the syringe driver to the store and include a decontamination certificate.
- If the syringe driver has been damaged, please send to medical physics in the carry box provided.
- You can obtain advice on all aspects of syringe driver use, including drug combinations, dosages etc from Strathcarron Hospice 24 hours a day on 01324 826222.

Syringe driver store details

Store location	Phone number	Type of store	No. of syringe drivers held
Stirling Royal Infirmary	01786 434000 (page 700)	24 hour	14
Falkirk Royal Infirmary	01324 624000 (page 137)	24 hour	14
Bannockburn Hospital, Ward 5	01786 483130	24 hour	3
Sauchie Hospital, Ward 4	01259 728584	24 hour	5
Bo'ness Hospital, Unit 2	01506 821930	24 hour	2
Strathcarron Hospice	01324 826222	24 hour	2
Bonnybridge Hospital	01324 811144	24 hour	4
Kildean Hospital, Ward 3	01786 458600	24 hour	1
St Ninians Health Centre	01786 479555	satellite	3
Dunblane Health Centre	01786 822115	satellite	2
Doune Health Centre	01786 841256	satellite	1
Callander Health Centre	01877 330150	satellite	2
Killin Health Centre	01567 820213	satellite	2
Balfron Health Centre	01360 440614	satellite	2
Killearn Health Centre	01360 550554	satellite	1
Camelon Clinic, Falkirk	01324 611711	satellite	4
Meadowbank Health Centre	01324 717920	satellite	4
Grangemouth Health Centre	01324 482354	satellite	1

[Contents page](#)

3.2 - Using a syringe driver

Introduction

This section of the manual extracts information from the NHS Forth Valley guidelines for good practice for using a syringe driver. These guidelines serve as a refresher to staff who have attended syringe driver training sessions in Forth Valley. They do not replace the need for formal training. Only nurses who have undertaken training should be involved in the setting up of the syringe drivers.

The aim of the guidelines is to provide a framework for the management of graseby MS26 syringe drivers.

Scope of practice

Nursing staff administering medication via a syringe driver must have current NMC registration. Nurses must use these guidelines in conjunction with the Code of Professional Practice (NMC 2004), Guidelines for the administration of medicines (NMC 2004) and guidelines for records and record keeping (NMC 2005) and all Forth Valley NHS policies relevant to the administration of medicines and the use of infusions devices.

Training and competence

Employers are responsible for ensuring that all staff using medical devices are appropriately trained. All health care professionals have a personal responsibility and accountability to ensure they receive training in the safe use and observation of any medical device they need to use.

All staff who are expected to be competent in undertaking the management and use of syringe drivers will be provided the opportunity to attend practical instruction and education. Training and update sessions will be delivered by competent trainers (key workers for syringe driver training, specialist palliative care nurses, practice development nurses). Availability of training sessions will be approximately once every month but additional sessions can be arranged by request to meet local training needs.

Following training, health care professionals will be expected to demonstrate the following competencies in the use of syringe drivers and maintain these competencies, keeping up to date with current practice.

- The ability to communicate the rationale for use effectively with patients and/or carers.
- Awareness of single model system for use of MS26 in Forth Valley and models that may be used in neighbouring health boards.
- Ability to access devices when clinical need arises.
- Knowledge of drugs used in syringe drivers and their possible side effects.
- Indications for use, advantages and disadvantages of use.
- Skin sites; selection and care.
- Identification of problems.
- Care and maintenance of equipment.

What is a syringe driver

The syringe driver is a small, portable, battery-powered device used to deliver continuous medication via the subcutaneous route. The infusion period is usually 24 hours. It is widely used in palliative care and is a valuable option for pain and symptom control of patients at various stages in their disease process. Using combinations of two or three drugs in one infusion can control multiple symptoms such as pain, nausea, vomiting or agitation.

The syringe driver provides a convenient alternative for administering medicines when the oral route is no longer available. Other alternative routes that can be considered include rectal and transdermal. The advantages of using a syringe driver include:

- Maintenance of steady plasma drug concentrations providing round the clock comfort.
- Patient comfort enhanced by avoiding the need for repeated injections.
- Control of multiple symptoms by using a combination of drugs in a single device.
- Small device can be worn discreetly by mobile patients or tucked under the bed clothing of bed bound patients.
- Usually set up and maintained by nurses.

Some indications for use :

- Persistent nausea and vomiting
- Dysphagia/swallowing difficulties
- Intestinal obstruction
- Profound weakness
- Poor absorption of oral drugs
- Unacceptable numbers of oral medications or volumes of syrups
- Reduced conscious level

Disadvantages of using a syringe driver

Because syringe drivers are strongly associated with terminal care there is a fear or myth that this is the last resort. This is not true and many people can have a syringe driver to maximise symptom control before recommencing oral therapy. Many patients or their family may have known someone who had a syringe driver at the end of their life. It is important to address any concerns and reassure where possible. A patient information leaflet 'About Your Syringe Driver' is available and is enclosed in the symptom control resource wallet.

Occasionally syringe drivers can malfunction and it is vital that a medical physics department checks them regularly. Annual maintenance checks are essential. They should also be checked if they have been dropped or there is doubt over their care whilst on loan to a different setting. Refer to section 3.3 for further information.

Other disadvantages include the need to anticipate medication requirements over the next 24-hours. There is also the potential for irritation or inflammation at the infusion site leading to poor absorption of medication.

Graseby have 2 models of syringe drivers – MS26 and MS16A.

In Forth Valley a single model system (MS26) has been adopted to minimise confusion and reduce the risk of error. However, it is possible that patients may be transferred from another health care region with an MS16A infusion device. This should be discontinued at the earliest opportunity in favour of an MS26 obtained through the central device store/ central management system.

Differences between MS26 and MS16A

MS26	MS16A
Colour coded with GREEN on the casing.	Colour coded with BLUE on the casing.
Rate setting in millimetres of travel per DAY/24-HOURS	Rate setting in millimetres of travel per HOUR
START/BOOST button	START/TEST button
Indicator light flashes every 25-seconds	Indicator light flashes every 1-second

Boost button facility on MS26

It is strongly recommended that this facility is never used for the following reasons :

- It only delivers about 1/208th of the total daily dose of drugs, which is an inadequate breakthrough dose (recommended breakthrough dose is 1/6th of total 24-hour opioid dose as a single dose, (not all routes of breakthrough are by injection, refer to sub section on breakthrough analgesia below). PRN medications should be prescribed and administered to control breakthrough symptoms in addition to the medications via the syringe driver.
- It is not only the opioid that is boosted; other drugs within the infusion are also boosted and this may be undesirable.

Each boost will reduce the overall infusion time thereby risking the early completion of infusion before replacement infusion is prepared. This may result in a period of poor symptom control or overdosing. In some cases a delivery of a bolus may cause pain at the injection site.

It is important that the plastic cover for the syringe driver is correctly applied with the circular hole over the button and plastic nipple at the rear fitting snugly over the screw recess. If it is placed the wrong way round, theoretically, the plastic nipple can constantly depress the boost button until the infusion is completed. **This has the potential to be a fatal incident.**

Formula for calculating rate settings

MS26

$$\frac{\text{Length of volume in millimeters}}{\text{Delivery time in days (24 hours = 1 day)}} = \text{mm of travel per day}$$

Example -
$$\frac{48\text{mm}}{1 \text{ day}} = 48 \text{ mm per day}$$

NB Only MS26 model is used in Forth Valley. In very exceptional circumstances a Graseby MS 16A may still be required, usually for medications out-with palliative care. In these circumstances health professionals should refer to the Graseby instruction manual.

However, if a patient presents with a need for an MS16A syringe driver the use of such a device should be explained and negotiated with the nursing team involved as the use of such a device is now out-with the training routinely provided in NHS Forth Valley.

It is good practice to aim for a volume length of 48mm + approx 1ml for priming, (depending on the giving set e.g. 48mm + approx 1ml for Microflex, 48mm + approx 1.50ml for Microbore) this will also make calculations easier. Always round up or down to the nearest whole number.

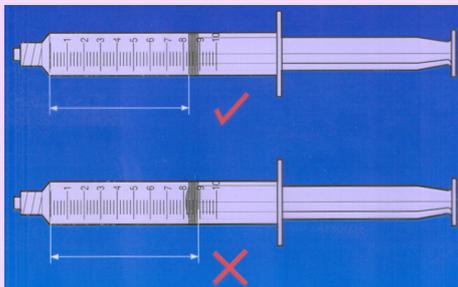
It is good practice to aim for a volume length of 48 mm + priming volume as this will make calculations much easier. i.e. 48mm per day.

Choosing a syringe

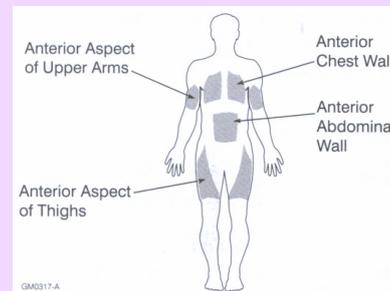
The syringe volume in millilitres (ml) is not used in calculation of rate setting – it is the length of fluid in millimetres (mm). This allows the flexibility to use different brands and sizes of syringes, 2ml–30ml syringes should be used. Larger volume syringes are not recommended. 10ml syringes are most commonly used.

In some situations where a more dilute preparation is required or reconstituted medications are used a 20 ml syringe may be desirable. Luer lock syringes are best practice as they offer security against accidental disconnection. It is strongly recommended that luer slip syringes are not used. The syringe brand and size chosen should fit properly on the syringe driver and be secured by the rubber strap.

Correct measurement of fluid length on the syringe



Infusion Sites



Acceptable subcutaneous sites include anterior aspect of thigh, anterior chest wall, anterior abdominal wall, outer aspect of upper arm and area over scapula. It is important to consider patient comfort and avoid areas of excessive pressure or excessive movement. Skin folds and breast tissue should be avoided. Also avoid oedematous skin, including the abdomen if ascites present.

Sites may last for up to seven days if there are no local reactions (redness, induration or swelling). Local reactions necessitate resiting of the needle and/or further dilution of irritant drugs using a larger volume syringe.

Resiting of infusion

It is possible that medication may not be properly absorbed from an inflamed site. Site should be checked regularly and needle replaced if inflammation occurs. Where possible, resiting should take place at the beginning of a new infusion using a fresh giving set and butterfly needle.

However, it may be necessary to 'resite' during the infusion period, and in this case, the whole giving set, needle and clear surgical dressing should be replaced at that time which will shorten the infusion time of that syringe. It is important to communicate this to whoever is responsible for the next syringe change.

Infusion sets

The infusion set should be long enough to allow the syringe driver to be comfortably worn by the mobile patient or comfortably placed around the bed bound patient. A 100cm long infusion set with a 'winged' or 'butterfly' needle attachment is required.

Infusion sets used in Forth Valley :

- MICROFLEX 100CM- routinely used.
- ABBOCATH + MICROBORE 150CM EXT SET- used if patient has a nickel allergy.

Batteries

- A nine-volt alkaline battery is required. Duracell brand is recommended.
- A fresh battery lasts for 50 full infusions.
- Indicator light ceases to flash when battery is running low.
- The syringe driver will complete delivery of current infusion when indicator light stops flashing. Replace battery at next infusion.
- Battery testing equipment may be available in some areas.

Medication prescription

Ensure that prescription is accurate and clearly written. If prescriber is unfamiliar with subcutaneous infusions, advice should be sought from palliative care team or specialist palliative care practitioner.

The prescription should contain the prescribed medications in mgs/24hours, the name of diluent used, the route of delivery and the device being used to deliver medications (example – 20mgs of diamorphine and 10mgs of midazolam over 24 hours, in water for injection, subcutaneous via syringe driver).

Ensure that breakthrough medication is also prescribed for all symptoms that potentially could be troublesome e.g. pain, agitation or restlessness, moist chest secretions, nausea. Recording sheet should indicate time when infusion commenced.

Many of the medications used for subcutaneous infusion in syringe drivers are not licensed for this route. This means that (s/c) will not be included in the package insert. It is legal for a UK doctor to prescribe out-with the license. In palliative care many indications and routes recommended fall outside the manufacturer's license but are supported by the literature and backed by extensive clinical experience. Individual clinicians should assess each patient carefully, seek specialist advice if appropriate and document all treatment decisions carefully.

Labelling of syringe

- Prepared solution must be labelled at time of preparation
- Label should be applied to syringe not syringe driver or plastic cover.
- Do not completely obscure fluid volume – stick label back on itself keeping all details visible and fluid volume visible for measurement
- Always use pre-printed labels and complete all information requested.

Documentation and checks whilst in use

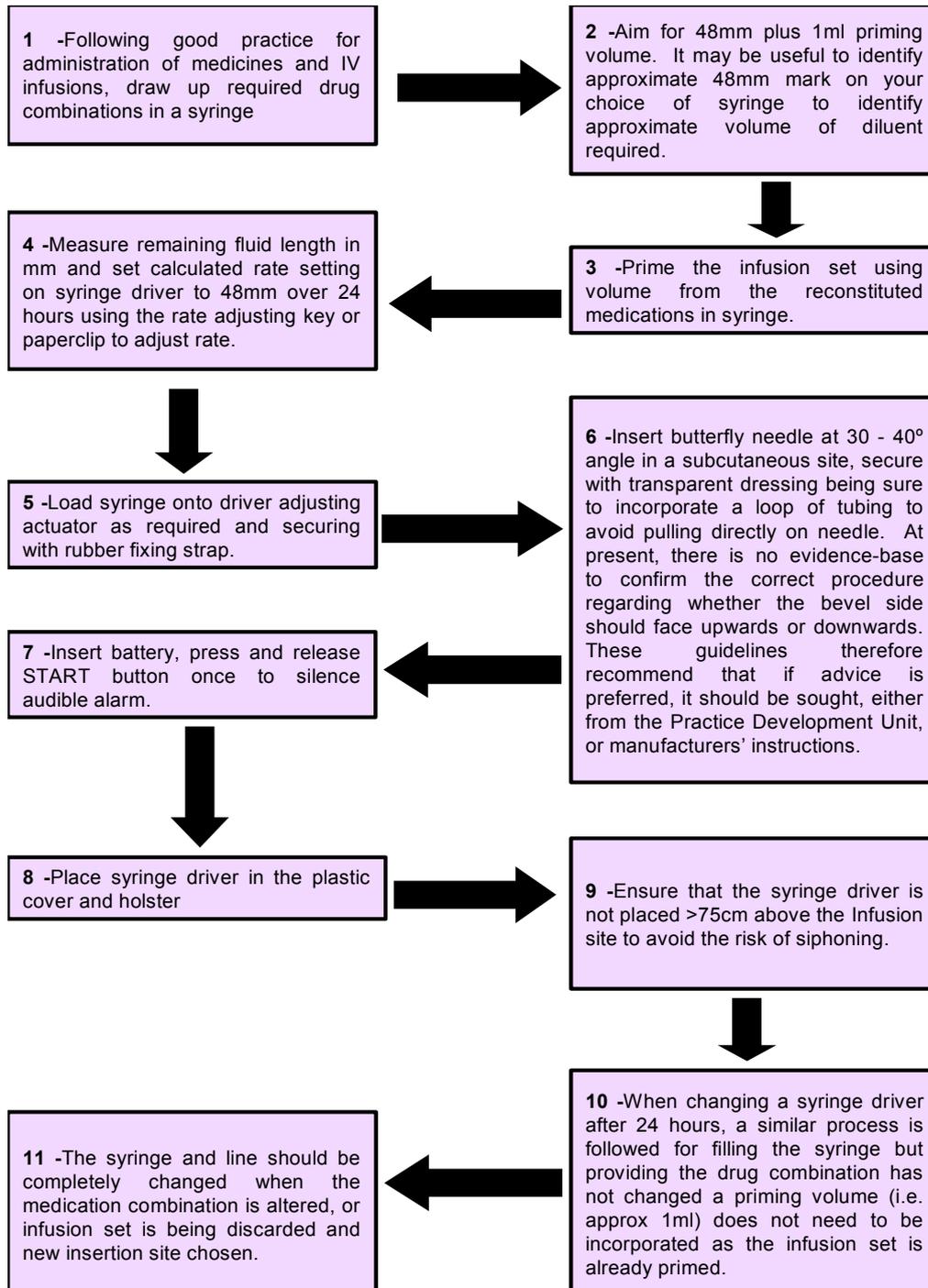
- Assess symptom control regularly.
- Check infusion site for irritation, inflammation, infection or needle displacement.
- Check syringe and infusion set for crystallization or precipitation of contents or leakage.
- Check and record rate setting.
- Measure fluid remaining in syringe at each check. (This recommendation is made on best available evidence and based on current literature)
- Monitoring infusions in the in-patient settings should be as follows :
 - Hospital / Hospice = 4 hourly
 - Community = at each visit / daily
 - Checks should be recorded on the appropriate syringe driver monitoring form/prescription sheet.

Equipment required for a syringe driver infusion

Those items marked (H) are supplied in Hospital boxes which are green.
Those items marked (C) are supplied in Community boxes which are blue.

- MS26 Syringe Driver and syringe driver cover (H) (C).
- Measurement tool with mm scale (C).
- 9 volt alkaline battery (C).
- Holster for mobile patients and to protect infusion from sunlight. (H) (C).
- Rate adjusting key or paperclip (C).
- 10ml or 20ml luer lock syringe (C).
- Infusion set with butterfly needle attached (C).
- Skin cleansing alcohol wipe (C).
- Clear surgical dressing (Opsite or Tegaderm) (C).
- Diluent – sterile water for injection (very few drugs require normal saline and all 2 or 3 drug combinations are mixed with sterile water) (C).
- Needles to draw up medications and diluents (C).
- Decontamination certificate (H) (C).
- Label for drugs added to syringe (C).
- Instruction manual (H) (C).
- Prescription/recording sheet (C).
- Guidelines for good practice (H) (C).

Setting up the syringe driver to start an infusion



Transferring care of patients with a syringe driver

Care maybe transferred between various settings – acute care, primary care, hospice, home and tertiary centres. It is important that staff ensure good communication and planning in order to maximize continuity and comfort. The following checklist may provide a useful guide to aid planning and communication.

Action	Rationale
<p>Telephone contact made by current care team to receiving care team. (Care team members include GP, District Nurse, Ward Nursing Staff or Medical Staff, Matron or Nurse in Charge of Care Homes etc.)</p>	<p>Unless circumstances are exceptional and care transfer of care is taking place on an urgent basis, contact should be made with receiving care team at least 24 hours prior to transfer. This allows forward planning of workload, equipment and drug requirements.</p>
<p>Discuss supply of syringe driver and preferred model – in Forth Valley, this will always be MS26.</p>	<p>However, in order to standardize safe practice, all patients transferred into FV with MS16A in progress must have the syringe renewed, resited and changed to MS 26 following transfer. Syringe drivers will be accessed through the Central Management System.</p>
<p>Discuss supply of drugs for continuing symptom management. Anticipate potential for changing symptoms and provide extra medication if necessary.</p>	<p>Some care settings may have a short delay before prescriptions can be issued and supplied. A supply of 3 – 5 days of current drug therapy should be negotiated to ensure ongoing care.</p>
<p>If going home, supply a fresh battery to accompany patient.</p>	<p>A battery lasts for 50 full deliveries. If indicator light on device stops flashing, the current infusion will be delivered but battery should be changed before further infusions are commenced.</p>
<p>A holster should always be used and should be transferred with the patient</p>	<p>Attempts should be made to ensure a proper holster is supplied. Makeshift holsters can look unsightly and may not be properly secured.</p>
<p>Educate patient and/or carers' about the syringe driver. Use of patient leaflets on the use of the syringe driver is recommended. Explain that reddened sites should be highlighted to nursing staff at the earliest opportunity.</p>	<p>Patients and carers' may be apprehensive about going home with a syringe driver in operation. It is important that they are familiar with the device, the reason for its' use, that it should not be dropped or immersed in water and who is responsible for ongoing care at home.</p>

Commonly used drugs in syringe drivers

This is not an exhaustive list. Further reference can be made using BNF, Palliative Care Formulary, SIGN 44 guidelines or by consulting with palliative care team, pharmacy department or palliative care network pharmacist.

Drug	Indication	Dose	Comments
Cyclizine 50mg in 1ml	Nausea and vomiting due to intestinal obstruction or intracranial disease	100–150 mg/ 24 hrs	Can cause site irritation Dilute as far as possible Incompatible with sodium chloride 0.9%.
Dexamethasone 8mg in 2ml	Intractable nausea and vomiting or raised intracranial pressure	2-16mg/24hrs	Consider gastric protection May be given as a once or twice daily SC bolus injection Insomnia at higher doses
Diamorphine 5mg 10mg 30mg 100mg, 500mg amps	Opioid responsive pain	No maximum dose limit	Incompatible with sodium chloride 0.9% at doses > 40mg/ml
Haloperidol 5mg in 1ml 10mg in 2ml	Opioid or metabolic induced nausea Agitation	2.5-10mg / 24hrs up to 30mg / 24hrs	Extrapyramidal side-effects at higher doses and in prolonged use Incompatible with sodium chloride 0.9%.
Hyoscine Butylbromide 20mg in 1ml	Intestinal obstruction (colic, vomits)	40-120mg /24 hrs	Non sedative Anticholinergic side effects
Hyoscine Hydrobromide 400mcg in 1ml 600mcg in 1ml	Noisy chest secretions	0.8–2.4mg / 24hrs.	Sedative Anticholinergic side effects Can cause agitation/ confusion
Levomepromazine 25mg in 1ml	Antiemetic Terminal restlessness	6.25-25mg / 24hrs 25-100mg / 24hrs	Can cause irritation Dilute as far as possible Sedation and postural hypotension at high doses Can be given as single SC dose Protect syringe and line from sunlight
Metoclopramide 10mg in 2ml	Nausea and vomiting especially due to gastric stasis/outlet obstruction, opioid induced nausea	30- 80 mg / 24 hrs	Prokinetic agent Avoid in complete intestinal obstruction or in colic Extrapyramidal side-effects at higher doses and in prolonged use
Midazolam 10mg in 2ml	Anxiety Terminal restlessness Seizures/myoclonus	5-30mg / 24hrs (up to 60mg may be required)	Tolerance can develop rapidly
Morphine Sulphate 10mg/ml; 15mg/ml;20mg/ml;30 mg/ml	Opioid responsive pain	No maximum dose limit	First choice alternative to diamorphine when supply problems exist
Octreotide 100mcg in 1ml 500mcg in 1ml	Vomiting due to bowel obstruction	300–600 mcg /24hrs	Antisecretory agent Does not treat nausea Expensive

Adapted from Lothian Palliative Care Guidelines 2004

Medication stability and compatibility

Drug stability and compatibility is most important when using two or three drugs in combination via the syringe driver. The drugs must be:

- suitable for subcutaneous infusion
- stable in solution for the duration of the infusion (usually 24-hours).

Water for injection is the diluent of choice in most circumstances.

When using drugs such as octreotide and dexamethasone alone, Sodium chloride 0.9% is the diluent of choice. When mixed with other medications however, water for injection should normally be used.

Compatible drug combinations along with safe concentrations are identified in the SIGN 44 Guidelines (The control of pain in patients with cancer). Shortened versions are included in the resource wallet for symptom control for your convenience.

With increasing drug concentrations, it may well be necessary to use larger volumes of diluents to prevent skin irritation at insertion site.

Your local pharmacist, specialist palliative care practitioner or locality palliative care network pharmacist can provide advice and support on any of these matters.

The tables overleaf provide details of the suitable two and three drug combinations.

Suitable two and three drug combinations

Two drug combinations for subcutaneous infusion which are stable for 24 hours

diluent: water for injections bp

DRUG	Maximum dose (in milligrams) known to be stable in:						Comments
	8ml in 10ml syringe		14ml in 20ml syringe		17ml in 30ml syringe		
Diamorphine And Cyclizine	160 * 160	If >160 Diamorphine then no more than 80 cyclizine	280 280*	If > 280 Diamorphine then no more than 140 cyclizine	340 340*	If > 340 Diamorphine then no more than 170 cyclizine	If exceed these doses then likely to get precipitate *Maximum daily dose usually 150mg
Diamorphine And Dexamethasone	400 3.2		700 5.6		850 6.8		Can prescribe if undiluted drugs are mixed during preparation
Diamorphine And Haloperidol	800 24	400 32					If exceed these doses then likely to get precipitation
Diamorphine And Hyoscine Hydrobromide	1200 3.2						
Diamorphine And Hyoscine Butylbromide (Buscopan)	1200 160						
Diamorphine And Levomopromazine (Nozinan)	400 80		700 140		850 170		Mixture can be irritant, dilute to largest possible volume.
Diamorphine And Metoclopramide	1200 40		2100 70		2550 85		Mixture can be irritant dilute to largest possible volume
Diamorphine And Midazolam	400 16		700 28		850 34		
Diamorphine And Octreotide	200 0.9		350 1.6		425 1.9		

If the table does not contain information on a particular drug combination seek specialist advice. Please note that some of these figures are in excess of clinical doses. The table serves to advise re the maximum dose in volume, to maintain stability. Morphine sulphate is visually compatible when mixed with each of the above drugs at normal doses. Observe the syringe closely for signs of incompatibility (e.g. cloudiness, precipitation).

Three drug combinations for subcutaneous infusion which are stable for 24 hours

diluent: water for injections bp

Drug Combination	Maximum dose (in milligrams) known to be stable in:			COMMENTS
	8ml in 10ml syringe	14ml in 20ml syringe	17ml in 30ml syringe	
Diamorphine And Cyclizine And Haloperidol	160 160 16	280 280 28	340 340 34	Above these doses the mixture is likely to precipitate *maximum daily dose of cyclizine usually 150mg
Diamorphine And Haloperidol And Midazolam	560 4 32	980 7 56	1190 8.5 68	
Diamorphine And Hyoscine Butylbromide (Buscopan) And Midazolam	560 4 22	980 7 39	1190 8.5 48	
Diamorphine And Levomepromazine And Metoclopramide	400 80 24	700 140 42	850 170 51	

The following combinations are not stable :

- Diamorphine, dexamethasone and levomepromazine
- Diamorphine, dexamethasone and midazolam
- Diamorphine, cyclizine and metoclopramide
- Octreotide and Levomepromazine
- Octreotide and cyclizine
- Octreotide and dexamethasone.

If the table does not contain information on a particular drug combination seek specialist advice.

The following combination is not recommended due to an increased risk of undesirable effects:

- Diamorphine, haloperidol and metoclopramide.

Converting to diamorphine

- Diamorphine is the opioid of choice for syringe drivers because it is highly soluble in small volumes. 1g of diamorphine can be dissolved in 1.6 ml of water (21 ml of water are needed to dissolve 1g of Morphine sulphate).
- Subcutaneous diamorphine is three times the strength of oral morphine.

To convert from oral morphine to subcutaneous diamorphine the total 24-hour dose of oral morphine should be divided by three.

Example:

Patient is on MST 120 mgs twice daily
Breakthrough dose is 1/6th of total 24 hour dose = 120 mgs + 120 mgs = 240 mgs
divided by 6 = 40 mgs
Patient has required 3 doses of breakthrough medication in preceding 24 hours
Total 24 hours oral morphine dose has been 120 mgs + 120 mgs + 40 mgs + 40 mgs +
40mgs = 360 mgs
360 mgs divided by 3 = 120 mgs of diamorphine subcutaneously over 24 hours

Opioid naïve patient

If a patient has not received opioids before, is now unable to swallow and has pain, consider whether rectal paracetamol +/- rectal diclofenac is appropriate analgesia OR start syringe driver at 5 mgs or 10 mgs of diamorphine over 24 hours.

Converting to other opioids

Subcutaneous morphine

If diamorphine is unavailable and a patient requires a strong opioid to be administered via a syringe driver then morphine sulphate is the alternative opioid of choice.

Conversion from oral morphine to subcutaneous morphine.

Subcutaneous morphine is two times the strength of oral morphine. To convert from oral morphine to subcutaneous morphine the total 24-hour dose of oral morphine should be divided by two.

Example 1 :

Patient is on MST 60 mg twice daily
Breakthrough dose is 1/6th of total 24 hour dose = 60 mg + 60 mg = 120 mg divided by 6
= 20 mgs
Patient has required 2 doses of breakthrough medication in preceding 24 hours
Total 24 hours oral morphine dose has been 60 mg + 60 mg + 20mg + 20 mg = 160 mg
160 mgs divided by 2 = 80 mg of morphine subcutaneously over 24 hours

Conversion from subcutaneous diamorphine to subcutaneous morphine

Subcutaneous diamorphine is 1.5 times the strength of subcutaneous morphine. To convert from subcutaneous diamorphine to subcutaneous morphine the total 24 hour dose of subcutaneous diamorphine should be multiplied by 1.5.

Example 2

Patient is on diamorphine 30mg over 24hours via a syringe driver.
Breakthrough dose is 1/6th of the total 24 hour dose = 30mg divided by 6 = 5mg
Patient has required no breakthrough over the last 24 hours

Total 24hours subcutaneous diamorphine = 30mg
30mg multiplied by 1.5 = 45mg morphine subcutaneously over 24 hours

Other alternative opioids (e.g. oxycodone or alfentanil) should only be used on specialist advice.

Note: Transdermal Fentanyl is only suitable for stable chronic pain.

Breakthrough analgesia

Morphine is the recommended first line strong opioid for oral use.

It is established practice when using morphine for cancer/chronic pain that a breakthrough dose of analgesia be available for an unexpected increase in pain.

Immediate release formulations are used. The dose is approximately 1/6th of the total 24 hour morphine dose. It can be administered at any time out-with regular analgesia if the patient is in pain. Allow 30 minutes and reassess pain.

Examples

MST 60 mg bd = 120 mg MST in 24 hours
1/6th of 120 mg = 20 mg of sevredol or oramorph for breakthrough pain

MST 40 mg bd = 80 mg MST in 24 hours
1/6th of 80 mg = 13 mg approx: this is a difficult dose to achieve so round down to 10 mg or up to 15 mg.

Breakthrough analgesia is normally prescribed subcutaneously when a syringe driver is in use. The dose is approximately 1/6th of the total 24 hour diamorphine dose. If the calculated dose is difficult to administer round up or down to the nearest easy dose to achieve.

To avoid repeated injections in frail emaciated patients, a butterfly needle can be left in situ at a subcutaneous site, secured with a clear surgical dressing and extra doses can be administered via this subcutaneous route followed by a small flush of sodium chloride 0.9% (use water for injection if medication is not compatible with sodium chloride 0.9%).

If the oral route is still available it may be more appropriate to administer breakthrough orally. In this event however, it is important to use the appropriate conversion factor.

Example

Patient is on Diamorphine 30mgs subcutaneously over 24 hours.

Breakthrough dose is $1/6^{\text{th}}$ of the total 24 hour dose = $30\text{mg} \div 6 = 5\text{mg}$ subcutaneous diamorphine.

If the oral route is more appropriate, 5mg of diamorphine is equivalent to 15mgs oral morphine. Give 15mgs oral morphine as breakthrough analgesia.

Opioid toxicity

Unlike other medicines, strong opioids have no ceiling dose. The correct dose for a patient is the dose that relieves pain without adverse effects.

Adverse effects caused by too high an opioid dose can be termed opioid toxicity.

The ability of individual patients to tolerate particular dose of opioid depends on several factors :

- Degree of opioid responsiveness of the pain
- Prior exposure to opioid
- Rate of titration of the dose
- Renal function

Signs of opioid toxicity can vary from mild to severe and include the following :

- Seeing shadows at the periphery of visual field
- Vivid dreams
- Nightmares
- Visual and auditory hallucinations
- Confusion
- Twitching and plucking at the air
- Semi-purposeful movements
- Myoclonic jerks
- Drowsiness
- Pin point pupils

The signs or symptoms may indicate that a particular dose of opioid is too high at a particular time and they may warn of developing renal dysfunction.

Appropriate action includes reducing 24 hour opioid dose by 30 – 50% and ensuring adequate hydration. In severe situations, a sedative may be necessary to manage situation until symptoms resolve.

It is recommended that advice should be sought if symptoms are severe.

Further advice

This extract of the guidelines should be used to inform practice. Information has been compiled by the Forth Valley working group for syringe driver practice and has been sourced from the list of articles in the reference list below.

Further advice and information is readily available on any matter relating to syringe drivers from members of the palliative care team, Strathcarron Hospice or clinical pharmacists.

These guidelines serve as a refresher to staff that have attended a recognised syringe driver training session. They are not intended to nor should they replace formal training.

Bibliography

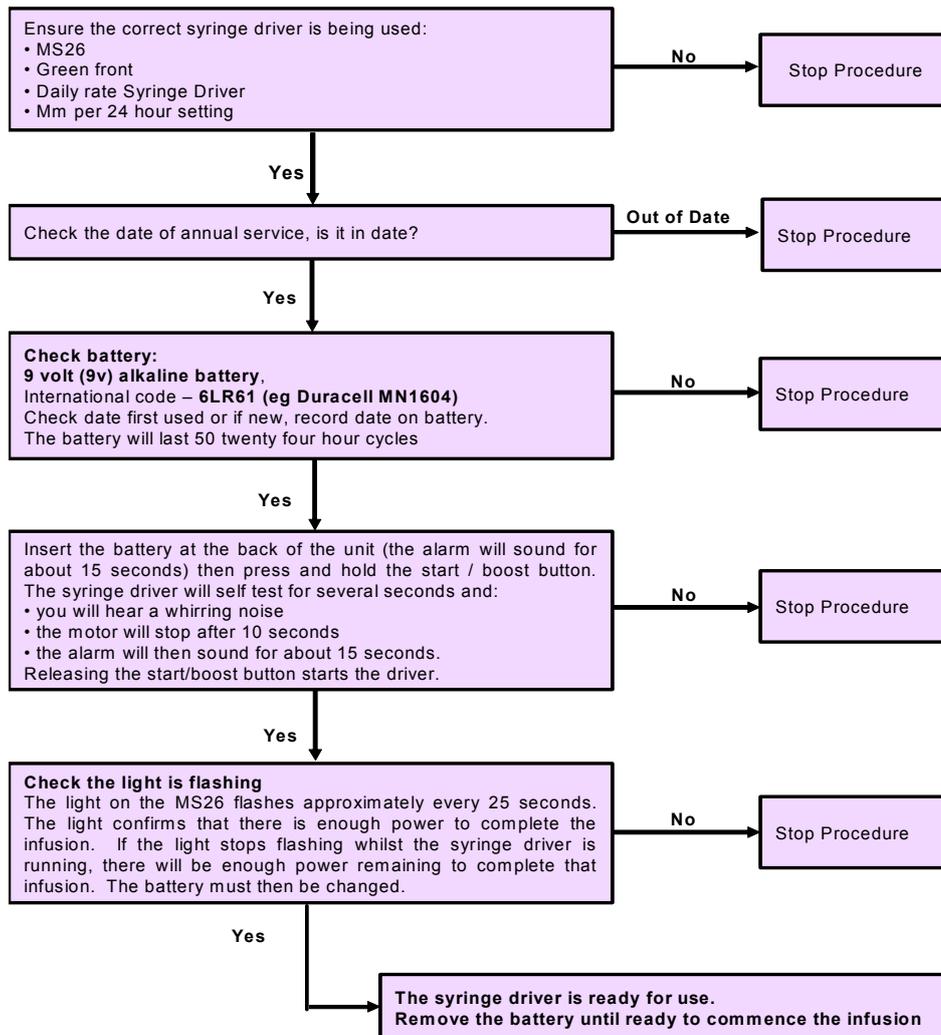
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[Contents page](#)

3.3 – Safety checks and callibration

Syringe driver safety checks prior to use

Please follow the chart below for safety checks prior to use.



Essential safety checks on the Graseby MS 26 after each patient use.

On receiving the device from a patient/relative the following questions should be asked to determine if the device has been exposed to anything that may increase the risk of failure of the device thus exposing future users to an unacceptable level of risk.

- Has the device been dropped or suffered a severe jolt particularly onto a hard surface?
- Has the unit been exposed to water e.g. used in a shower / bath?
- Has the unit been dropped into or immersed in water?

If any of these questions result in a positive response then the unit should be returned to the Medical Physics Department in Stirling Royal Infirmary.

Even although the answers to the above questions have been negative the member of staff receiving the device should thoroughly examine the device for any physical damage e.g. damage to plunger drive block.

- Examine the battery compartment firstly by removing the battery cover and the battery and look for signs of moisture; presence of moisture would suggest exposure to water.
- Examine the rate window for signs of fogging/misting; presence of fogging/misting would suggest exposure to water.
- Check the device for abnormal sounds when moved e.g. rattling from within the casing; rattling from within would suggest that the unit has been dropped or suffered a severe jolt.

Should any of the above conditions arise then the unit should be returned to the Medical Physics Department in Stirling Royal Infirmary for inspection/repair.

Please ensure that a complete account of your findings is enclosed with the device.

Calibration after Use

All servicing and calibration of the syringe drivers in Forth Valley will be carried out at the Medical Physics Department at Stirling Royal Infirmary. This should be done on an annual basis in all care settings. After every use please follow the safety checks above and if in any doubt about the safety of a syringe driver return it to Medical Physics.

Please return the carry box and the contents to the Medical Physics Department at SRI when calibration or maintenance is required. Please also ensure that the stock in the carrybox has been replenished, prior to sending the syringe driver for servicing or back to the originating store

[Contents page](#)

Section 4 – Co-ordination of care

4.1 – Introduction & directory of services

Introduction

Good palliative care requires coordination and access to a wide range of services aiming to provide care that meets the needs of the patient in the most appropriate setting. This section provides information, paperwork and contact details of services that are available in Forth Valley that would support staff in providing and coordinating that care.

Community

	Contact details	Manual section for further info
Community nursing contacts by locality – for further information, please use the community nursing pages on the Forth Valley Internet site.	Polmont - 01324 717920 Grangemouth - 01324 482354 Bo'ness - 01506 827701 Falkirk - 01324 611711 Bonnybridge - 01324 815105 Denny - 01324 827400 Stenhousemuir - 01324 554231 Clacks - contact local GP practice Stirling, North West Forth valley & West stirlingshire - contact local GP practice	N/A
Marie Curie	0845 0567899	Section 4.5
Specialist palliative care advice	Strathcarron Hospice 01324 826222	Section 4.10
Palliative care pharmacy network	Various contacts for all pharmacies in the network	Section 4.6
Gold standards framework paperwork	N/A	Sections 4.3 & 4.4
Sample DNAR form	N/A	Section 4.8
Translator service	0845 130 1170	N/A
Margarot Forrest carers	01324 692095	N/A
Independent Living Services (ILS) Ltd	01259 226300	N/A
Crossroads Carers	Falkirk - 01324 612141 Clacks - 01259 216760 Stirling – 01786 464380 West Stirlingshire - 01360 449400 www.crossroads-scotland.co.uk	Section 5 – Carer support

Hospitals

	Contact details	Manual section for further information
Admissions – bed manager	SRI – 01786 434000 FDRI - 01324 624000	N/A
Palliative care clinical nurse specialists	SRI – 01786 434000 ext 4454 or page 749 or 983 FDRI – 01324 624000 ext 8673 or bleep 234	N/A
Liverpool Care Pathway	General information at www.lcp-mariecurie.org.uk or call 0151 706 2274	Section 6 resource wallet

Community hospital contacts

	Contact details	Manual section for further information
Bannockburn Hospital	01786 814792	N/A
Bonnybridge Hospital (CMHT South)	01324 814685	N/A
Bo'ness Hospital	01506 829580	N/A
Clackmannan County Hospital	01259 727373	N/A
Kildean Hospital	01786 446615	N/A
Sauchie Hospital	01259 722060	N/A
Ward 12, FDRI	01324 616112	N/A
Ward 17, FDRI	01324 616117	N/A
Orchard House Day Hospital	01786 849721	N/A
Kildean Hospital (CMHT North)	01786 446615	N/A

Equipment

	Contact details	Manual section for further information
Joint Lending Equipment Service (JLES)	01324 508762 – range of equipment available for caring for palliative care patients in the community	N/A
Discharge Liaison co- ordinator	01786 434093 or 07881 833194 - for advice about equipment not available through JLES	N/A

Hospice

	Contact details	Manual section for further information
Strathcarron hospice	01324 826222	Section 4.10

Out-of-hours

	Contact details	Manual section for further information
NHS 24	Telephone 0845 242424 www.nhs24.com	N/A
OOH palliative care pharmacy network	01324 616195	Section 4.6
Using Taycare to update NHS 24 details	N/A	Section 4.11
OOH handover form	N/A	Section 4.3

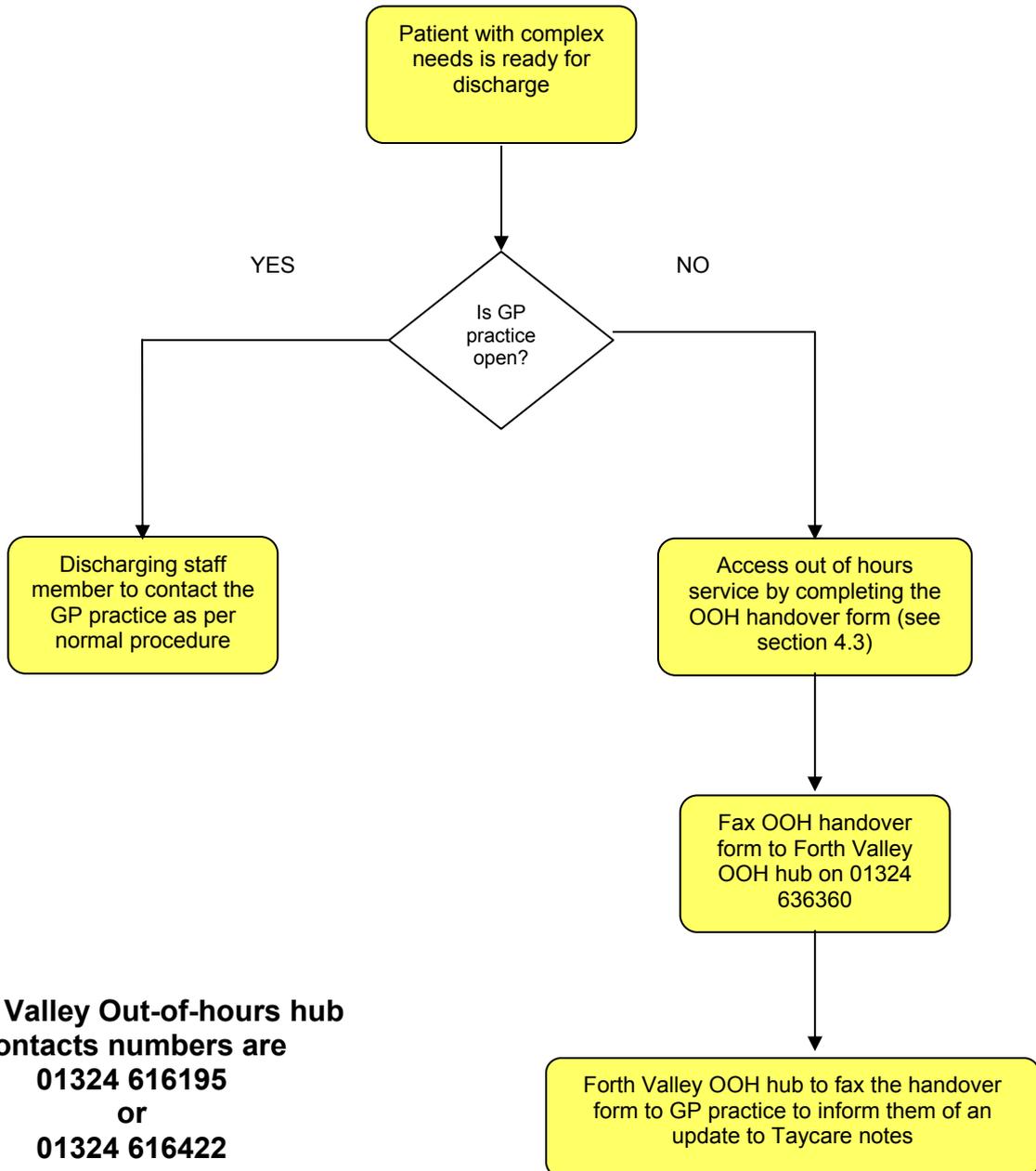
Social services

	Contact details	Manual section for further information
Clackmannanshire	01259 450000 www.clacksweb.org.uk The adult care service can be contacted as follows; <i>Outwith Hillfoots - Tel: 01259 727010</i> Hillfoots villages - Tel: 01259 452482	Section 4.9 & see Co-ordinated care resource wallet
Falkirk	Telephone 01324 506070 www.falkirk.gov.uk Home care services can be obtained at the following numbers Denny - 01324 504160 Falkirk - 01324 506400 Grangemouth - 01324 504343 Contact details for other social work offices can be found in section 4.10 of the manual.	Section 4.9
Stirling	Telephone 0845 277 7000 www.stirling.gov.uk	Section 4.9 & see Co-ordinated care resource wallet

[Contents page](#)

4.2 – Discharge of patients with complex needs

The chart below sets out the procedure for the discharge of patients with complex needs where the GP practice is closed using the out of hours service and updating Taycare notes. You can also see sections 4.3 and 4.11 of the manual for a copy of the out of hours form to use and instructions on how to update Taycare notes.



**Forth Valley Out-of-hours hub
contacts numbers are
01324 616195
or
01324 616422**

[Contents page](#)

4.3 – Gold Standards Framework Out-of-hours handover form

Name:	Diagnosis:
Comp No:	Secondaries:
DOB:	Date of Diagnosis:
CHI No:	DS 1500 registered Date/Ca:

Address:	<u>Family/carer contacts</u>
Tel No:	

<u>Personnel involved</u>	<u>Key GP</u>	<u>Key DN</u>
Oncologist:		
Other Specialists:		
Macmillan/Nurse/SPC <input type="checkbox"/>	Hospice <input type="checkbox"/>	Other conditions:
Others eg SS:		

<u>Treatment</u>		
Surgery	Radiotherapy	Chemotherapy
Current Medication:		

<u>Priorities</u> (Problems and concerns – physical, psychological, social, spiritual)
<u>Other issues</u> (incl. Care plan, out of hours, drugs left at home, before considering admission try etc)

Preferred place of care (dated)	Signature	Date

4.4 – Gold Standards Framework Homecare paperwork

Proforma to hold for local information for patients and carers.

At Home		
		Telephone Number
GP		
District Nurse		
Macmillan / Specialist Nurse		
Social Services Adviser		
Care Assistant /Home Care Team		
Local Carers Support Team		
Other links & services available		
At Hospital		
Local Hospital Consultant		
Oncologist Cancer Specialist		
Hospital Specialist Nurse		
Other links		
Hospital Links		
Hospice		
Hospice Doctor		
Hospice Day Care Nurse		
Hospice Home Care Team		
Other links		
What to do in an emergency		
If you have a problem during normal working hours:		Telephone Number
GP		
District Nurse		
Oncology Ward / Chemo Nurse		
Other		
If you have a problem outside normal working hours i.e. at a weekend or in the evening:		
Name		
Or		
Or		

General information - Who's who and what they do:

GP – your General Practitioner or Family Doctor is responsible for all aspects of your medical care at home, and can arrange help from other professionals or services.

District / community nurse – co-ordinate nursing care and give practical advice at home. In many places they are available 24 hours, and can usually be contacted via your GP Surgery or directly at their office. They have wide-ranging skills in cancer and palliative care nursing.

Primary care team – this is the team, usually based at your GP's surgery, comprising GP, District/community nurse, practice nurse, practice manager, receptionists and other associated professionals such as health visitors, etc.

Clinical nurse specialist – is a nurse who has been specially trained to help people with cancer or a certain type of cancer and is usually based in a hospital.

Macmillan nurse – is a clinical nurse specialist, skilled in pain and symptom control, who offers emotional and practical advice to people with cancer and their families from the moment of diagnosis onwards. They do not usually provide hands on care, but advise the primary health care team and can provide a link with the hospital or hospice.

Marie Curie nurse – can provide care at home through the day or night, giving the carer a chance to have a break or sleep. They can be contacted through your District Nurse.

Physician or surgeon / hospital doctor – these are the specialist (or secondary care) doctors in the hospital who specialise in a certain area of medicine.

Oncologist – this is a doctor who specialises in treating cancer. They are often based at another hospital, which is a cancer centre for an area, but may also see you at your local hospital.

Social worker – social service professional who helps you get practical, emotional and financial support.

Specialist in palliative care / hospice doctor – these are doctors who specialise in palliative medicine which concentrates on the quality of life for you and your family. They focus on improving pain and other symptoms and meeting a person's social, emotional and spiritual needs.

Hospice staff – these are doctors, nurses, physiotherapists, counsellors, volunteers and others who work in your local hospice. These are often funded independently by private donation with contributions by the NHS.

Care assistant / home care team – these are care staff who can help with personal care at home.

[Contents page](#)

4.5 – Marie Curie services

Marie Curie nursing service

Marie Curie Cancer Care provides high-quality nursing, totally free, to give terminally ill people the choice of dying at home, supported by their families.

The charity is the leading independent provider of specialist and general palliative care outside the NHS. The cost is funded on a 50/50 basis by Marie Curie Cancer Care and Forth Valley Primary Care Division. The service is free to all patients; it relies on the generosity of the charity's supporters (including many bereaved families).

Marie Curie nurses provide care mainly to cancer patients, but will also offer care for non-cancer patients. The funding for this is charged at 100 per cent to the primary care trust.

The Marie Curie nursing service is complementary to the district nursing service, and primarily provides palliative care in the terminal stages of illness (last six months of life).

Marie Curie nurses work mainly at night but as the service has developed, there is a recognised need for day and evening cover. Shifts are typically nine hours overnight, although the minimum length of any shift is three hours. However shifts are flexible to fit in with the patient's needs.

Other Marie Curie services

Marie Curie cancer care also runs 10 hospices throughout the UK; a research institute investigating the causes and treatments of cancer; palliative care research to improve the standard of care for patients and education for nurses and other healthcare professionals.

Referrals to the Marie Curie nursing service

The District Nurse is the central point for communication and coordination of the patient's care. It is the patient's District Nurse who decides, in consultation with the patient and carers:

- Whether to request a Marie Curie Nurse
- What periods of care or shifts are required
- Whether to request a Registered Nurse or a Health Care assistant, depending on the patient's nursing needs.

The District Nurse will review the patient's care at intervals and decide whether to increase or decrease the amount of care requested, depending on the patient's condition.

Referrals are made via Marie Curie cancer care referral centre and nurses are allocated by matching a patient's nursing need and postcode with an appropriately skilled and available nurse. Referrals can be phoned, faxed or emailed up to two weeks in advance of care.

The role of the Marie Curie nurse

Marie Curie nurses and care assistants are employed to provide nursing care appropriate to their grade to patients in their own homes.

Marie Curie nurses are registered nurses who will provide physical and psychological care to patients (including administration of prescribed and authorised medication) and provide support to carers.

Marie Curie care assistants provide basic nursing care and psychological support to patients and carers (administration of medicines is not part of Marie Curie care assistants' remit).

All Marie Curie nurses:

- Are registered nurses
 - Have palliative care nursing experience
- or**
- Are required to complete the accredited principles of palliative care module (Diploma in palliative care)

All Marie Curie care assistants:

- have experience in providing basic health care
 - have received additional training in the specialist needs of patients with cancer requiring palliative care
- and**
- are required to complete a two day foundation course in the principles of palliative care

If you would like more information about Marie Curie cancer care or the Marie Curie nursing service in Forth Valley please contact the Marie Curie office on 0141 531 1341 or visit the website www.mariecurie.org.uk.

Prioritisation of service provision

When district nurses refer or re-refer patients, a prioritisation category must be given: Patients should be reassessed regularly (every 48-72 hours) and categories altered to reflect changing need.

REA – Reactive

Crisis management, same day/next day service. Referrals to be made before 12 noon and will only be accessed if one of the following criteria apply:

- Life expectancy less than 72 hours
- Hospital/hospice admission will be inevitable if additional nursing support is not provided.

PRO – Proactive

Aimed at preventing crisis occurring and may include:

- Rapid and/or progressive deterioration
- Management of any poorly controlled symptoms (e.g. pain, nausea, vomiting, breathlessness)
- Increasing stress/exhaustion of family /carer.

MAIN – Maintenance

- Patient who is stable, deteriorating slowly and aim is support the family/carers to care for this person over time in their own home

How to obtain a Marie Curie nurse or healthcare assistant

You should have the following details available when calling the Marie Curie nursing referral centre;

- Patient's name and address including postcode
- Patient's telephone number
- Patient's date of birth
- Patient's diagnosis, prognosis and general condition
- Patient's medication
- Whether patient is aware of diagnosis/prognosis
- Whether there is a care plan and Moving & Handling risk assessment in house
- Any special instructions/requirements
- Grade of nurse required (registered nurse or health care assistant)
- GP's name, telephone number and CHP
- Your own name, base and telephone number.

Tel: 0845 0567 899 or Fax 0845 0567 898

(out of hours messages can also be left on these numbers)

Opening Hours 08.00-22.00

Monday to Sunday and Bank holidays

(excluding Christmas Day & New Year's Day last referral taken 21.45)

[Contents page](#)

4.6 – Forth Valley palliative care pharmacist network

The contact details for all pharmacists involved in the palliative care pharmacists network are as follows :

Pharmacy	Pharmacy Telephone no.	Oxygen Contractor?
Ian Campbell 5 Firs Entry Bannockburn	01786 816893	No
Lloyds Pharmacy Richmond Terrace Bo'ness	01506 824524	No
Bonnybridge Pharmacy Co. The Toll Bonnybridge	01324 812332	No
M Farren Ltd 45 Main Street Callander	01877 330132	Yes
Lloyds Pharmacy 55 Bridge Street Dollar	01259 742536	No
Woodside Pharmacy 3 The Cross Doone	01786 841216	Yes
Lloyds Pharmacy 334 Thornhill Road Falkirk	01324 623688	Yes
Tesco In-Store Pharmacy Central Retail Park Falkirk	01324 507649	No
Lindsay & Gilmour 16 Central Avenue Grangemouth	01324 482079	No
The Pharmacy 11 Main Street Killlearn	01360 550242	Yes
Slammanan Village Pharmacy 17 High Street Slammanan	01324 851265	Yes
Lindsay & Gilmour 81 Main Street Sauchie	01259 723155	No
Sainsbury Pharmacy Drip Road, Raploch Stirling	01786 449908	Yes

The Out-of-hours hub contact number to access this service is 01324 616195.

You will find a leaflet about the palliative care pharmacy network in the useful resources wallet for this section of the manual.

[Contents page](#)

4.7 - Psychosocial oncology, cancer clinical psychology service

Purpose of cancer clinical psychology service

The Cancer Clinical Psychology (CCP) service has been set up to provide advice, support and training for staff throughout NHS Forth Valley working with cancer patients.

Training

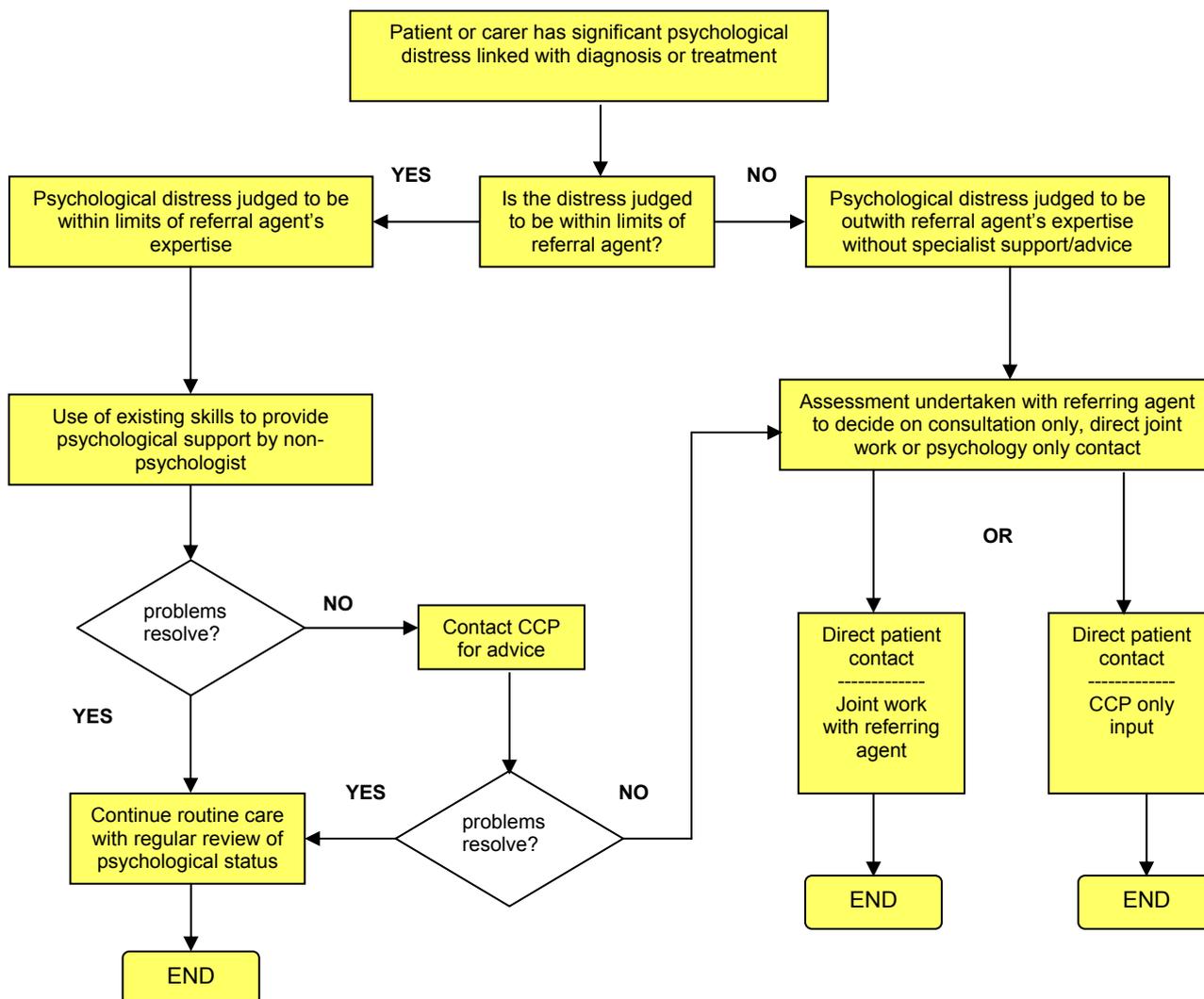
Training events covering a range of psychological topics will be offered. Events will be advertised through the normal channels, as appropriate to the training on offer.

Consultancy service

A consultancy service is available for senior members of nursing and medical staff. There are options for one-off advice, on-going consultation regarding a particular patient, general support and advice or, in the case of complex and enduring patient problems, for a referral for direct contact with clinical psychology.

Referral to clinical psychology

The following diagram shows the pathways for a referral to clinical psychology.



Being given a diagnosis of cancer is distressing for most people and it is normal to feel a range of emotions such as anxiety, low mood and anger in response to the news. These feelings may last for some time and may reappear at times of change such as the start of new treatments or the recurrence of the cancer. It is important that we do not pathologise normal human emotion and thereby add to the patient's difficulties.

For this reason the psychological support of the majority of cancer patients is best managed by the team of nurses, doctors and other clinical staff already involved in their care. The Cancer Clinical Psychology service is there to provide advice and support for you to help you fulfil this important role.

Which patients may need direct psychology contact?

Those patients with more complex and/or more enduring problems may need to be seen directly by clinical psychology staff. The following questions may help you decide whether a referral to clinical psychology is appropriate for consultation or direct contact :

- Have the patient's problems failed to respond to general counselling and support?
- Do you believe that the problems are so severe that they will not respond to general counselling and support?
- Have the problems lasted for several weeks or months?
- Are the problems affecting the patient's compliance with important aspects of their treatment?
- Are the problems having a significant impact on the patient's functioning and/or quality of life?

The following are examples of the problem areas which may be amenable to psychological intervention (Further details of these can be seen on the Cancer Clinical Psychology pages of the NHSFV Cancer Website) :

- Adjustment disorders
- Anxiety disorders
- Depression
- Traumatic stress
- Relationship problems
- Coping with treatment procedures
- Coping with pain
- Drugs and alcohol
- Cognitive difficulties
- Body image or disfigurement issues
- Coming to terms with death and/or decisions to limit treatment
- Abnormal bereavement response

Direct patient contact

Patients will be seen alone, with family members or occasionally as part of a group of patients as deemed appropriate. The initial assessment will often be undertaken in the presence of a member of staff with whom the patient is familiar, for example the clinical nurse specialist. In some cases the ongoing psychological treatment will be passed on to the clinical nurse specialist who will work under the supervision of the clinical psychologist.

The patient will be seen in a hospital clinic or occasionally within the local health centre. The number and length of therapy sessions, and the therapeutic approach will vary depending on the nature of the patient's difficulties and the stage of the treatment. See CCP pages on NHSFV Cancer Website for more information about direct patient contact.

<http://intranet.fv.scot.nhs.uk/web/site/home/intro.asp>

Who can refer?

All referrals should come through either :

- Cancer and palliative care clinical nurse specialists (CNS)
- Hospital and hospice consultants
- General practitioners.

Referrals from hospital and hospice consultants and general practitioners will be discussed, in the first instance, with the cancer or palliative care CNS, if this is deemed to be appropriate. Initial contact with the patient may be with both the CNS and the clinical psychologist.

Depending on the outcome of the psychological assessment there may then follow contact with the CNS, clinical psychology or both.

How to refer?

Please contact the CCP secretary Monday to Friday a.m on 01324 404199 and your call will be returned by psychology staff as soon as possible. Contact can be made in person or by telephone to our office in Adult Clinical Psychology, Clinical Services Building, FVPCOD.

Referrals should be made on the Cancer clinical psychology referral form or by telephone via the secretary on 01324 404199. The referral form can be accessed on-line from the cancer pages or the psychosocial oncology pages of the intranet and printed out for submission by post. <http://intranet.fv.scot.nhs.uk/web/site/home/intro.asp>

Please note that the service will be relocating to Falkirk & District Royal Infirmary in mid 2006 – contact number after the move will be 01324 624000.

[Contents page](#)

4.8 – Sample DNAR form

Please see below for a sample of the DNAR form. Hard copies of this form can be obtained via the Communications Officer at FDRI. An electronic version will be made available as part of the Verification of Death work currently ongoing (see section 6.2 for further information).

Do Not Attempt Resuscitation

Please affix label or enter patient details

Patient's Name
Unit No.....
DOB.....

Do Not Attempt Resuscitation Decision Implemented Because:-

- CPR is unlikely to be successful due to:
.....
- Successful CPR would be unlikely to result in a return of consciousness and quality of life which has been assessed as not being acceptable to sustain
- CPR is not in accord with the decision of a patient who is mentally competent
- CPR is not in accord with a valid applicable advance decision (refusal or living will)

Patient Consulted Yes

Relative/Significant Other consulted Yes /

Name & Relationship

If no view sought, please state why

.....

Doctor/GP's Name Date

(Block Capitals)

Doctor/GP's Signature Date

Please list those involved in the decision below:-

Review

Review date			
Signature			
Print name			

1. If, on review, the DNAR decision is deemed still appropriate the Consultant / GP should sign under the review date to record this as well as making a more detailed entry in the clinical record
2. If, on review, the DNAR decision is deemed no longer appropriate then this form must be scored across with a diagonal line in ink, signed and dated by the Consultant /GP along the diagonal line, removed from the "Medical Directives" section of the case record and filed in the clinical record. A "DNAR" decision and any alterations to it must be communicated to all members of the health care team involved in the patient's care and the patient and their relatives as appropriate.

SUMMARY GUIDELINES ON DECISIONS ABOUT CARDIOPULMONARY RESUSCITATION

These guidelines are a summary and must be read in conjunction with the Forth Valley Resuscitation Policy .

DECISIONS

CPR should be attempted in the event of a sudden or unexpected cardio- respiratory arrest **unless** a "Do not attempt resuscitation decision"(DNAR) has been made and documented . A DNAR decision may be made for a number of reasons which are detailed in the Forth Valley resuscitation Policy. If a DNAR decision has **not** been made and the express wishes of the patient are unknown CPR **will** be initiated if cardiac or respiratory arrest occurs **if** it appears appropriate in clinical judgement of the senior clinician present .

Overall responsibility for the decision made regarding the appropriateness of resuscitation for an individual patient rests with the consultant or general practitioner in charge of the patient's care . This decision should be made as soon as is practicably possible following admission /transfer .

DISCUSSION

There should be discussion of decision making with appropriate members of the multidisciplinary team caring for the patient . The patient, relatives or close friends may be available in forming the doctor's decision . They should be appropriately involved in the decision making process . A "Do not attempt resuscitation" decision must be made in consultation with the patient and other health care professionals involved in the patient's care and documented .

DOCUMENTATION

If a " Do not attempt resuscitation" decision is made this must be recorded on the standard " Do not attempt resuscitation" form which should be placed in the "Medical Directives" section of the patients clinical record. Detailed records of full relevant information and discussions with the patient , relatives and other members of the multidisciplinary team should be recorded in the patients clinical record (medical and nursing) dated and signed with the name and signature of the person making the entry. Reasons for not involving the patient in the decision making process should also be documented .

REVIEW

There must be a regular review of a " Do not attempt resuscitation decision" by the consultant/ GP in charge of the patient's care. A date for review , taking into account the condition of the patient, should be decided and documented . An earlier review should be initiated if the patient's condition or competently stated wishes change.

A DNAR DECISION APPLIES ONLY TO THE APPROPRIATENESS OF PERFORMING CPR AND NOT TO OTHER FORMS OF TREATMENT OR CARE

[Contents page](#)

4.9 – Social services

Background information

The local authorities can provide a wide variety of support services for patients with palliative care needs. Examples of the services that can be provided are as follows :

- Homecare and home help
- Equipment and adaptations
- Mobile Emergency Care Services (MECS)
- Respite care

Please note that there may be a charge for some of these services. Contact details for further information are provided below. You will also find helpful leaflets for each local authority in the co-ordinated care resource wallet.

Clackmannanshire

The adult care service can be contacted as follows :

Living in Alva, Cambus, Coalsnaughton, Devonside, Dollar, Menstrie, Muckart, Tillicoultry or Tullibody contact the Hillfoots and Tullibody Community Care Team at Limetree House, Castle Street Alloa FK10 1EX. **Tel. 01259 452498 or fax 01259 452473.**

Living in Alloa, Clackmannan, Fishcross, Kennet or Sauchie contact Alloa Community Care Team The Whins Office, 7/8 Miller Court Alloa Fk10 3SA **Tel 01259 727010 or fax 01259 720143.**

Further information can be found at www.clacksweb.org.uk/social/adultcare and in the leaflet contained in the co-ordinated care resource wallet.

Falkirk

Home care services can be accessed at the following sites :

Denny – Carronbank house, Carronbank road, Denny, FK6 6DG Tel 01324 504160

Falkirk – Brockville, Hope Street, Falkirk, FK1 5RW Tel 01324 506400

Grangemouth - Oxgang Road, Grangemouth, FK3 9EF Tel : 01324 504343.

Other social work offices :

Larbert sub office – 130 King Street, Stenhousemuir, FK5 4 HD Tel 01324 503504.

Grahamston sub office – 155 Grahams Road, Falkirk, FK1 5RW Tel 01324 506595.

Bo'ness sub office – Kinglass Centre, Gauze Road, Bo'ness, EH51 9UE Tel 01506 778668.

Meadowbank sub office – 1 Salmon Inn Road, Polmont, FK2 0XS Tel 01324 503883.

Camelon sub office – 108b Glasgow Road, Camelon, Falkirk, FK1 4HS Tel 01324 501200.

FDRI Unit – Falkirk & District Royal Infirmary, Majors Loan, Falkirk Fk1 5QE Tel 01324 616039.

Further information can be found at www.falkirk.gov.uk.

Stirling

Community Services, Stirling Council, Viewforth, Stirling FK8 2ET Tel – 08457 277 7000.

Further information can be found at www.stirling.gov.uk. You will also find a directory of community care services available in the co-ordinated care resource wallet.

[Contents page](#)

4.10 – Strathcarron hospice referral and admission procedures

Service Provision

- The Specialist Palliative Care Service based at Strathcarron Hospice is available to patients with active, progressive malignant disease (90%) or neurological /other disease (10%). Patients will be accepted from Forth Valley and from Cumbernauld or Kilsyth in North Lanarkshire.
- The service aims to support and supplement mainstream health care and adopts a multidisciplinary and collaborative ethos when involved in patient care. The range of presenting needs/concerns appropriate for referral include symptom control, end of life care, psychosocial and emotional support, family support, respite care, rehabilitation and bereavement support.
- In addition to end of life care, the In-patient unit (24 beds) provides supportive care with the aim of maximising the potential of the individual and their family, and where appropriate facilitating discharge back into the community. Strathcarron Hospice are unable to offer long term care.
- The hospice can also provide day care at the hospice, support to individuals and their families in the Community and advice to the primary care teams and advice through the hospital palliative care support teams.
- The situation may arise where, as a finite resource, the hospice are unable to accept patients for in patient care despite identified need. In this event, they will continue to provide specialist support to other professionals and maximise other available resources until such time as the service can be accessed directly.

Accessing the service

- Referrals are accepted from Consultants, GPs, or from nurses who have the consent of the appropriate doctor. Referrals may originate in primary care, acute care, care homes, community hospitals or tertiary sites.
- Referrals to any aspect of the Specialist Palliative Care Service should be agreed by the patient, the carer and the GP/Consultant.
- If the patient satisfies the referral criteria for a particular aspect of the Specialist Palliative Care Service, it should be accessed via a referral form. This is available electronically via the SCI Gateway, by e-mail or fax from the hospice medical secretary or via the hospice web-site – www.strathcarronhospice.org [Click on professional resources).
- Completed referrals (non SCI gateway) can be submitted by post or fax (safe haven fax no 01324 826119). The hard copy of a faxed referral should be forwarded by post.
- Only urgent referrals may be made by telephone. These calls should be taken by the medical secretary and referred to medical staff for a decision that same day. A completed referral form should be faxed to the hospice within 24 hours.
- All patients who meet the eligibility criteria will be considered, irrespective of race, creed, disability, age, gender or ethnic group.

- A waiting list and priority rating system is in operation for admission to the in patient unit. It is for this reason that the referral form should be completed accurately throughout, with particular emphasis on the sections detailing 'current care issues' and 'family/social/psychological/spiritual' issues.

Referral criteria for Strathcarron Hospice

1. Referral criteria to any component of specialist palliative care service

- Active progressive disease (see page 1 for scope)
- Complex physical, psychosocial, emotional, spiritual or bereavement issues
- Patient living within Forth Valley / Cumbernauld / Kilsyth
- Patient / family / GP / consultant agreement to referral
- Referrer identifies a clear need for input of specialist palliative care services
- Care cannot be offered more appropriately elsewhere

2. Additional criteria for admission to in patient service

- Need for symptom control :
 - Pain
 - Constipation / diarrhoea / intestinal obstruction
 - Breathlessness, cough, other respiratory symptoms
 - Nausea, vomiting
 - Anorexia, cachexia and nutrition
 - Depression, anxiety and confusion
 - Emergencies in palliative care e.g. hypercalcaemia
- End of life care
- Co-morbidity of carer / family
- Respite care
- Maximising potential quality of life
- Social circumstances e.g. living alone, young family
- Availability of a bed
- Able to tolerate a smoke free environment, using nicotine replacement or other available support when needed.

3. Additional criteria for admission to in patient service

- Need for symptom control :
 - Pain
 - Constipation / diarrhoea / intestinal obstruction
 - Breathlessness, cough, other respiratory symptoms
 - Nausea, vomiting
 - Anorexia, cachexia and nutrition
 - Depression, anxiety and confusion
 - Emergencies in palliative care e.g. hypercalcaemia

- End of life care
- Co-morbidity of carer / family
- Respite care
- Maximising potential quality of life
- Social circumstances e.g. living alone, young family
- Availability of a bed
- Able to tolerate a smoke free environment, using nicotine replacement or other available support when needed

4. Additional criteria for admission to day care service

- Patient able and willing to attend day care
- Patient aware that a process of regular review will determine duration of attendance
- Suitable transport available – either with volunteer driver provided by the hospice or dial-a-journey
- Ongoing need for specialist advice on pain, symptom control or psychosocial support
- Maximising of function / quality of life
- Co-morbidity of family / carer
- Help with physical care e.g. use of specialised bath
- Availability of a place
- Able to tolerate a smoke free environment, using nicotine replacement or other available support when needed

5. Additional criteria for admission to home care service

- Be able and willing to receive care at home
- Patient aware that a process of regular review will determine duration of input
- Require advice or management of pain and/or other symptoms
- Co-morbidity of family/carer
- Actual/Potential bereavement needs

Decision-making and communication re referral

- Once a completed referral form is received, it will be reviewed by a member of the medical staff / senior nursing team for appropriateness and urgency. Outcome of decisions regarding the referral will normally recommend access to one or more aspects of our service. This decision will be communicated to the patient and referrer within two working days of receipt. Urgent referrals will be passed onto medical staff for decision on the same day.
- In addition to this service, health care professionals will be able to obtain advice from a member of the specialist palliative care team at Strathcarron Hospice 24 hours a day by telephoning 01324 826222.
- Complex issues regarding access should be discussed with consultant or senior member of the medical/nursing team.

[Contents page](#)

4.11 – Updating a patient note on Taycare

Patient details

- To view the patient details for a patient – with the patient record open, click on patient details on the menu on the left hand side of the screen.
- The patient details shows the patient’s demographic information:

You have chosen the following patient

Proceeding further will be logged.

Identifier: 69 **Address:** FLAT
1 CAMERON SQUARE
FORT WILLIAM

Name: TESTTHIRTY LOCHABER

Date of Birth: 08/10/1955

Age : 48

Sex: M **PostCode:** PH33 6AJ

Registered GP: Borders Gp Unregistered
Registered Practice: Borders Unregistered Surgery

[New Search.](#)

LOCHABER, TESTTHIRTY (M)
Local: 69
Age: 48

? The system has highlighted this patient as a potential match for another.
! The system has matched this patient to a call from NHS24.

Patient notes

To view patient notes - with the patient record open, click on the link in the menu on the left hand side of the screen, the view patient notes screen will be displayed:

View Patient Notes [Add Note](#)

Name	Review Date	Note Text	Edit	Remove
LOCHABER, TESTTHIRTY	12/12/2004	test	e	X

LOCHABER, TESTTHIRTY (M)
Local: 69
Age: 48

? The system has highlighted this patient as a potential match for another.
! The system has matched this patient to a call from NHS24.

- If there are any patient notes they will be displayed. Click on the green “e” to edit or the red “x” to delete.
- To add a new note, click on the add note hyperlink at the top right of the screen.
- Enter a review date, note text and tick the box if you wish NHS24 to view the note. NHS 24 can view up to five patient notes for a patient.

[Contents page](#)

Section 5 – Carer support

5.1 - General information

Introduction

A carer is someone who, unpaid, provides help and support to a relative, friend or neighbour who could not manage without that help due to frailty, long-term illness or disability.

Many carers do not see themselves as carers but primarily as a parent, child, wife, husband, partner, friend or neighbour. Many carers tend to be hidden in our communities and are not aware that help and support is available. Carers may live with the person they care for but many do not. Some carers will be balancing caring responsibilities with paid employment. Many give up paid employment to care. There is no such thing as a typical carer. Caring impacts not only on individual carers but also on whole family units.

The majority of carers take on this role willingly, out of a sense of love and commitment; others become carer's because they feel there is no choice. Caring can be very rewarding but it can also be exhausting and can cause difficulties for the carer - financial problems, stress, loneliness, isolation, health problems - and trying to obtain information can be frustrating.

Becoming a carer can gradually happen through the course of a progressive illness but can sometimes happen overnight and the carer may have to face dramatic changes to life by learning new skills, accepting major disruption to routines, social life, employment and relationships.

There is help and support available for carer's and those for whom they care. However, it can be difficult and confusing trying to find out where to go and who to approach for different kinds of assistance.

Since the legislation that formalised community care was introduced in 1993, there has been a steadily increasing awareness of the contribution that informal / unpaid carers make in supporting people at home. This contribution is increasingly important as the percentage of the population in Scotland that is older and dependent continues to increase.

Following devolution in 1996, the Scottish Executive required each local authority to prepare a carers strategy for their area.

As the joint future initiative (formalising partnerships between the NHS and local authorities joining up health and social care) gained momentum, the importance of including carers in the planning and delivery of services was reinforced.

A major development has been the introduction of adult and young carers entitlement to an assessment of their ability to care (carers assessment) independent of any assessment of the person for whom they care. This has been enshrined in legislation as part of the Community Care and Health (Scotland) Act 2002 which was implemented from 1 September 2002.

The Scottish Executive issued full guidance on the legislation in March 2003.

The act also provides for scottish ministers to require NHS Boards to prepare and submit to them a 'NHS Carers Information Strategy'. This will set out how NHS Forth Valley will inform carers who appear to them to be 'substantial and regular' of their potential right to assessment under Section 12AA of the 1968 Act or Section 24 of the 1995 Act.

Scottish ministers may specify the date for submitting the strategy, the form and extent of the strategy, and the consultation that the board must undertake in preparing it. NHS Boards must provide a copy of the carer information strategy to any person who requests it. NHS Forth Valley is planning to approve and implement a draft carers information strategy from April 2006.

The aims of the carers information strategy are to :

- recognise and treat carers as key partners in the provision of care
- work in partnership with carers, local authorities, the voluntary sector and others to provide information to carers as early as possible within the care journey
- provide information in a range of formats or languages enabling carers to access information irrespective of their age, disability, ethnicity, gender religion / faith, sexual orientation or other specific needs
- inform carers of their potential right to a carers assessment under the community care and health (Scotland) act 2002 and to direct carers on to sources of information and practical support
- promote carer awareness amongst all levels of NHS staff whether employed by or contracted to the NHS.

The outcomes of the carers information strategy will be:

- carers are identified early at first point of contact
- carers are informed of their potential right to an assessment of their support needs as carer under Community Care and Health (Scotland) Act 2003
- carers are provided with all appropriate information
- carers are well informed of the process and procedures of hospital admission and discharge and are fully involved in the decisions taken at these key stages
- carers are equipped and supported to carryout effective caring.

Caring for the carer

A carer needs to be as healthy as possible. Caring may be very demanding at times and can increase as time goes by. It is important that carers do not forget their own needs as they may spend each day responding to the needs of others and ignore their own health and wellbeing.

- Carers should tell their GP that they are a carer and ask them to note this in their files. They will be aware that carers are likely to be under pressure at times and may find it easier to diagnose and treat carers in future and offer the advice and support needed.
- Carers should make sure that they attend for regular check-ups and should be encouraged to visit the doctor if they feel unwell. They need to be fit and well if they are to continue caring.
- Carers should be especially careful not to injure their backs and should seek training in the correct way to lift and move the person they are caring for. Health professionals may be able to advise on this.
- Other feelings which carers may experience can range from anger, resentment, hurt, loss, anxiety and depression. Again carers should seek advice from a carers support worker, GP or counsellor.

[Contents page](#)

5.2 – Local Services

Princess Royal Trust for Carers centres

Carer support is available through contacting the local Princess Royal Trust carer centres in Forth Valley as follows;

Stirling

Stirling Carers Centre
65-69 Barnton Street
Stirling FK8 1HH

Telephone - 01786 447003. Email – centre@stirling.carers.net

Falkirk

Falkirk Carers Centre
5 Newmarket Street
Falkirk FK1 1JQ

Telephone – 01324 611510. Email – centre@falkirk.carers.net

Clackmannanshire

Alloa Carers Centre
The Whins Resource Centre
Whins Road
Alloa FK10 3RH

Telephone – 01259 219288. Email – carersoffice@alloa.carers.net

These centres offer free, confidential and impartial services to all carers irrespective of the condition of the person they are caring for. The centres provide advice, support and information to carers to help enable them to make informed choices about their situation and to help them in their caring role.

Carer support is generally offered through the following services :

- Information and advice on a range of subjects including services available to carers
- Practical support
- A listening ear
- Advocacy (helping carers voice their own views)
- Help to set up and support carers groups
- Advice on rights and entitlements (including welfare benefits)
- Contact with other carers
- Young carers group
- Consultation in the planning of local services for carers.

Carers information packs, leaflets and factsheets are also available by contacting the local offices above. There are short information leaflets about these local services in the resource wallet for this section. Further copies are available on request from the centres.

[Contents page](#)

5.3 – Benefits Information

Users are not expected to advise on the following information. However it is vital they are aware of the support that can be available both in terms of practical support and financial advice, so that they can make an appropriate referral to the social work service or encourage the carer to seek support and advice directly themselves.

In particular, a carer should be informed of their right to have their own needs assessed (a duty of social work services) and told how to contact each councils money advice service for support in obtaining benefits they may be entitled too.

Benefits

Caring for someone can be costly, especially if the carer is thinking of giving up their job. Possibly the person being cared for has also had to give up work because of illness or disability. There are hidden costs, such as extra heating and clothing, washing and cleaning, extra bedding or hospital visits and there may be charges for services, such as help at home or a day centre.

Both the carer and the person for whom they care may be entitled to benefits from the Department of Work & Pensions and to other help such as housing benefit or council tax discounts.

The benefits system is complicated. It is a good idea to get expert advice. The Citizens Advice Bureau, a welfare rights adviser from Social Work Services, CarersLine (0345 573 369) Falkirk Carers Centre (01324) 611510, Stirling Carers Centre (01786) 447003 or the Benefit Enquiry Line (0800) 88 22 00 - textphone (0800) 24 33 55 should be able to give both the carer and the person cared for advice on benefits they may be able to claim. They do not hold personal records, but will look at the circumstances and work out which benefit may apply. There are other useful contacts given at the end of this section. It should be noted that the information contained here about benefits is generic and each carer should seek advice about their own personal circumstances and what benefits they can claim.

Attendance Allowance

May be able to claimed if:

- Over 65, and
- Needs help with personal care, or someone to supervise them, because of illness or disability, and
- You have needed help for at least 6 months

If help with personal care is needed, the attendance allowance can still be applied for even if help is not actually received. The type of help needed may include, for example, help with washing, dressing, using the toilet, or to have someone around to make sure the person is safe and to keep an eye on you.

Attendance allowance is not affected by any savings, or any other money being received. It is not treated as income when calculating entitlement to Income Support or Pension Credit.

In fact, when Attendance Allowance is awarded, Pension Credit can often, then be paid, too.

Attendance Allowance can be paid at two different rates:

- **Lower Rate** (£44.50 per week as at April 2005) - for those who need frequent attention or continual supervision during the day **or** during the night.
- **Higher Rate** (£60.60 per week as at April 2005) - for those who need frequent attention or continual supervision during the day **and** during the night.

Special rules apply if someone is terminally ill and is not expected to live longer than 6 months. They may qualify for the higher rate of attendance allowance even if no help is needed. A claim can be made on behalf of the person without their knowledge and can usually be processed within a few days.

Disability Living Allowance

May be able to be claimed if:

- Under 65, and
- With an illness or disability, and
- Needs help with getting around or needs help with personal care or needs help with both of these, and
- Needed help for at least 3 months and likely to need it for at least another 6 months

There are two parts to DLA depending on the needs of the person applying:

DLA Care Component

This may be awarded if help is needed with personal care such as washing, dressing, or using the toilet, or if help needed with preparing a cooked main meal. DLA Care Component can be awarded for help with personal care even if no help is given. DLA Care Component can be paid at three different rates:

- **Lowest Rate** (£16.05 per week as at April 2005)
- **Middle Rate** (£40.55 per week as at April 2005)
- **Highest Rate** (£60.60 per week as at April 2005)

Special rules may apply to those who are terminally ill and not expected to live longer than 6 months. They may qualify for help with personal care at the highest rate automatically.

DLA Mobility Component

This may be awarded if help is needed with getting around, for example, if the person cannot walk at all, has difficulties walking, is both deaf and blind and needs someone with them outside, if the person is severely mentally impaired with severe behavioural problems, or if the person can walk but need someone with you when outdoors.

DLA Mobility Component can be paid at two different rates:

- **Lower Rate** (£16.05 per week as at April 2005) - for those who can walk but need guidance or supervision most of the time in order to walk outdoors
- **Higher Rate** (£42.30 per week as at April 2005) - for those who are unable or virtually unable to walk, have no legs and feet, or are deaf and blind. The higher rate is also payable if the person has severe behavioural problems as a result of severe mental impairment and has been awarded the highest rate of the DLA Care Component.

Carers Allowance

This Benefit is for the carer. May be able to be claimed if:

- Over 16 and
- Caring for someone for at least 35 hours per week, and
- Caring for someone who is receiving (or waiting to hear about) Attendance Allowance, Constant Attendance Allowance at not less than the full day rate, or the Care Component of Disability Living Allowance at the middle or highest rate, and
- Not on a course of full-time education, and
- Not earning more than £82.00 per week after taking off any allowable expenses.

Carers Allowance is payable at the rate of £45.70 per week as at April 2005.

In some cases a carer may fit all the criteria to receive carers allowance but will not receive a payment because of being in receipt of certain other benefits. However, it may still be worth applying even if you do not receive extra money as National Insurance Contributions will normally be credited, and there will be no need to have to 'sign on'.

Also, the amount of Income Support or Pension Credit entitlement may be increased as a Carers Premium is included in the calculation. Housing and Council Tax Rebates can be more generous when a claim for carers allowance is made, even if it is not paid because another Benefit is already in payment.

Please note that, if the person being cared for lives alone and receives Attendance Allowance and Income Support, or the middle or highest rate of the DLA Care Component and Income Support or Pension Credit, they could lose money if the carer claims carers allowance for looking after them. It is therefore advisable to seek advice before claiming carers allowance.

Income Support

Income support is the main benefit for people on a low income. It is means tested but not taxable.

May be able to be claimed if:

- Are aged 16 - 59
- Not working, or are working on average less than 16 hours per week
- No more than £8,000 in savings (£16,000 if living in a residential or nursing home)
- Income falls below an amount the government estimates you need to live on.

Pension Credit

Pension Credit aims to provide people aged 60 and over with a minimum level of income, and to give extra cash to people aged 65 and over with modest incomes, who have made savings for their retirement. There are two components; Guarantee Credit and Saving Credit. May be able to be claimed if:

Are aged 60+ (65 for Savings Credit)

- Income falls below an amount the government estimates you need to live on.
- Savings up to £6,000 are ignored (£10,000 if you live in a care home). There is no upper limit to the amount of savings you can have. £1.00 of benefit will be deducted for every £500 of savings you might have, over £6,000.
- Additional amounts will be paid if you are disabled or a carer
- Pensioners over 65 with modest savings and/or an additional occupational pension, private pension, SERPs, Stakeholder or Second State Pension may qualify for additional benefit, known as Saving Credit. There is no upper capital limit to this benefit.

If you receive Pension Credit, you may also get Council Tax Benefit and Housing Benefit.

To find out if you qualify for Pension Credit contact 0845 606 0265.

Never rely on the benefits advice of friends, neighbours, relatives or anyone else, everyone's circumstances are different. Always seek specialist Welfare Benefits advice.

Housing Benefit and Council Tax Benefit

These are Benefits administered by the Council to help with paying rent and the Council Tax. You can get help with up to 100% of the rent you pay, and up to a maximum 100% of council tax. Water rates and heating charges are not included.

If in receipt of Income Support or Pension Credit, you may receive the maximum amount of these benefits, subject to possible deductions for other people living in the household. Some carers may be eligible for Council Tax discounts, regardless of income and savings (see below).

If not in receipt of Income Support or Pension Credit, and have less than £16,000 savings you may still be eligible for these benefits on low income grounds. (Savings over £3,000 (£6,000 for those over 60) affect how much Council Tax Benefit and Housing Benefit you can receive). In addition to Council Tax Benefit there are also second adult rebates and discounts (see below)

Second Adult Rebate

This is mainly for single people who are liable to pay Council Tax and who live with another person, not their partner, who is on low income.

Discounts (including Carers Discount)

The Council Tax is based on the idea that the average household consists of two people. Single person households pay 25% less. When counting the number of people in a household there are certain people who are 'not counted'.

This includes those who are severely mentally impaired e.g. suffering from Alzheimers.

Carers are not counted if they are:

- living with and caring for someone who is not their, husband, wife, cohabitee or child under 18
- caring for the person for at least 35 hours per week on average
- caring for a disabled person who is in receipt of high rate Attendance Allowance or high care Disability Living Allowance care component.

Both Second Adult Rebates and Discounts are complicated. If you think you may qualify you should contact your local Council, or an advice agency, to check on eligibility.

Council Tax Relief

May be eligible if or a member of the household, has a substantial and permanent disability e.g. if they use a wheelchair in the house. If obtained the bill will be reduced to the Council Tax for the next lower valuation band; e.g. if the house is in Band C you would be charged Band B.

If the house is already in the lowest band, an equivalent reduction will be made. To apply for this, a form from your Local Council Finance office is needed.

The Social Fund

If in receipt of Income Support, Pension Credit, or income-based Jobseeker's Allowance, may be entitled to help from the Social Fund. Payments from the Social Fund include Community Care Grants, cold weather payments, winter fuel payments, funeral expenses, budgeting and crisis loans. You do not have to be on Benefit to receive a crisis loan.

Community Care Grants

If in receipt of Income Support, Pension Credit, or income-based Jobseeker's Allowance, a Community Care Grant may help with extra costs such as furniture, clothing or removals. If you have savings the amount of the grant may be reduced. To apply for a Community Care Grant ask the Department of Work & Pensions for a form.

Budgeting Loans / Interest free loans

The Social Fund may also provide interest free loans for certain items. For information about these, contact the Department of Work & Pensions.

Funeral expenses

Help with funeral expenses may be available if it is reasonable for the carer to be responsible for them and in receipt of certain income-related benefits. Savings over £500, or £1,000 if over the age of 60, will affect how much is paid. If the person leaves an estate the carer will have to pay back some or all of the payment from that estate.

Cold weather payments

This will be paid if in receipt of receive Income Support, Pension Credit, or income-based Jobseeker's Allowance which includes certain premiums, including one of the pensioner or disability premiums, or if in receipt of extra money for a child under 5 with these benefits. The cold weather payment (£8.50) will be made automatically for any week in which the average temperature is, or is forecasted to be, at or below freezing for 7 days in a row.

Winter fuel payments

A winter fuel payment is an annual tax-free payment made to anyone over 60. It is intended to help with winter fuel bills, but, unlike cold weather payments, does not depend on the weather. A payment of £200, or £300 if you are aged 80+ (from April 2003), will be made if living alone or if only one person in the household qualifies for a payment. If there are other people in the household who qualify for a payment, they may each receive a smaller payment.

Bereavement Benefit

If under 60 when widowed, or a partner was not receiving a pension, a lump sum payment of £2,000 (April 2005) can be applied for.

Tax Credits

Working Tax Credit is for people who are employed or self-employed who usually work 16 hours or more a week and who are:

- Aged 16 or over and responsible for at least one child, or
- Aged 16 or over and disabled, or
- Aged 25 or over and usually work at least 30 hours a week.
- Aged 50 or over and working 15 hours or more a week and began work within 3 months and been in receipt of certain benefits immediately before starting work.

The allowance is higher if either partner is disabled.

Child Tax Credit is for people who are responsible for at least one child or qualifying young person. The amount received depends on income. You can see if you qualify or apply online at www.taxcredit.inlandrevenue.gov.uk or call 0845 300 3900.

Claiming benefits

Claim forms for Attendance Allowance, Disability Living Allowance, Income Support and other social security benefits can be obtained from the local Department of Work & Pensions office (see below).

The forms for Attendance Allowance and Disability Living Allowance are very long and it is a good idea to get advice on how to fill them in. Many statutory and voluntary organisations (e.g. Citizens Advice Bureau (see below) will provide help to complete forms.

Staff at the carers centres noted in section 5.2 will also be happy to assist.

Department of Work and Pension Welfare Benefit offices:

<p>Falkirk (01324) 505000 Heron House 10b Wellside Place Falkirk FK1 5SE</p> <p>Postal Districts EH49, 51 , FK1 - 6</p>	<p>Opening hours Monday Tuesday Wednesday Thursday Friday</p>	<p>8.45am - 4.00pm 8.45am - 4.00pm 9.30am - 4.00pm 8.45am - 4.00pm 8.45am - 4.00pm</p>
<p>Stirling (01786) 505000 South Lodge 2 St Ninian's Road Stirling FK8 2HF</p> <p>Postal Districts FK7 - 21, G63</p>	<p>Opening hours Monday Tuesday Wednesday Thursday Friday</p>	<p>8.45am - 4.00pm 8.45am - 4.00pm 9.30am - 4.00pm 8.45am - 4.00pm 8.45am - 4.00pm</p>

Other Useful Contacts for benefits

Local Authority Money advice teams

Stirling Council – 01786 442460
 Falkirk Council – 01324 501404
 Clacks Council – 01259 452512

The Benefit Enquiry Line

Offers advice and information about benefits for people with disabilities and their carers and assistance with claim form completion. Telephone 0800 88 22 00 or Textphone 0800 24 33 55

Welfare Benefits Helpline

The helpline offers confidential and impartial advice. Telephone: 01324 501404

The Disability Information Service

Offers advice on any disability issue, including Benefits. Telephone (01324) 504304

CarersLine

Advice and information line for carers run by Carers UK Tel. (0345) 573 369

The Citizens Advice Bureau

For benefits advice and help with form filling.

47 Drysdale Street ALLOA Tel. (01259) 723880	1 Kerse Road GRANGEMOUTH Tel. (01324) 483467
24 Duke Street DENNY Tel. (01324) 823118	Old Sheriff Court Hope Street, FALKIRK Tel. (01324) 628406
The Norman MacEwan Centre, Cameronian Street STIRLING Tel. (01786) 470239 or 470257	

If a claim is refused

If an application for a benefit such as Disability Living Allowance or Attendance Allowance is refused, there are a number of ways of challenging the decision. A decision may be reconsidered 'on any grounds' within one month of notification of the original decision.

There is no need to show you have any reason for disagreeing with decision. Outside this period, a decision can only be reconsidered in limited circumstances, for example, where there has been an official error.

A claimant can choose to go straight to appeal and bypass the revision process. The claimant will have one month from the date of the decision in which to lodge an appeal. If a claimant has used the revision process s/he will have one month to appeal against the new decision.

A decision may be superseded at any time but only in very specific circumstances, including the following:

- there has been, or it is anticipated that there will be, a relevant change of circumstances
- the decision was made in ignorance of, or was based on a mistake as to a material fact
- a person has become entitled to benefit (or benefit at a different rate) as a result of a decision to award another benefit.

[Contents page](#)

5.4 – Respite break information

Respite care/taking a break

All carers need a break from caring - time to do what they want, time for themselves. This break could be for a few hours, days or a longer period and it could be on a regular or occasional basis. Such a break, also known as 'respite care', can be invaluable to help carers recharge their batteries.

Who to contact

Different services are available in different areas. Some organisations which provide care can be contacted directly while other services are only available following an assessment by a Social Work Services team. Therefore, a good first point of contact, should be the local Social Work Services office.

If you are unsure who to contact in your area, the local Princess Royal Trust for Carers Centres on page 2 are a helpful starting point.

Types of respite care or short breaks

Care may be provided in the person's own home or away from home and can include day centres, care homes, sitter schemes, befriending schemes and play and leisure opportunities for children and young people with special needs and disabilities.

Day care

There are many different types of day care which may be organised by the local council, voluntary organisations or the private sector. Day care may provide companionship for the person being cared for and give the carer a few hours to do some of the things that may be difficult to do normally. The person being cared for may need to be assessed before they can attend these services. The local Social Work Services office will be able to provide more details.

Residential and short breaks

Some local authority or private residential homes or nursing homes will be able to provide care for a few days or weeks. This will depend on whether the home chosen has any vacancies for the time requested. Although this can be used on one-off occasions, for example, if the carer needed to go into hospital, this type of respite can also be arranged on a regular basis and the frequency will depend on the carer's needs. Most people will need help to pay for the fees and will therefore need to be assessed by Social Work Services. This will also help to ensure that the most appropriate type of service is received.

Sitter services

Help for the person being cared for can be provided at home while the carer is not there. Again this can be for a one-off occasion or on a regular basis depending on the situation. Some examples of local sitter services are included in the services section below.

Services

Many different organisations offer care to enable the carer to take a break and a variety of different options are available. The following are some examples of local services:

Home from Home - the Home from Home scheme provides care for people with memory loss and confusion. It provides care in a small group in the home of a day carer. For further details contact Joint Dementia Initiative, Dollar Park, Camelon Road, Falkirk FK1 5RU, Telephone 01324 501730.

Time to Share - the Time to Share scheme is for people with dementia. The person you care for can either stay at home and a care worker will come and live with them, or the person you care for can spend time at the care worker's home. They offer a break of up to eight weeks spread throughout the year and the length of each visit can vary according to the individual needs. Further details are available from Joint Dementia Initiative, Dollar Park, Camelon Road, Falkirk FK1 5RU, Telephone 01324 501730.

Alzheimer Scotland-Action on Dementia Day Care - Day Care services are offered to people with dementia away from their homes in order to provide care and stimulation for the person with dementia and regular short breaks for the carer. Transport is available to and from the Day Care facility. For details contact Alzheimer Scotland-Action on Dementia, 35 Johnston Avenue, Stenhousemuir, Falkirk, FK5 4JZ, Telephone 01324 559480 or 5 New Street, Bridge of Allan, Telephone 01786 831171.

Crossroads Care Attendant Scheme - Crossroads can provide a trained care attendant to relieve the carer for a regular break during the day, evening or overnight. For further information contact the local branch:

- **Falkirk** - Arnotdale, Dollar Park, Camelon Road, Falkirk FK1 5SQ Telephone 01324 612141
- **Clackmannanshire** - 19 Mar Street, Alloa, FK10 1HR Telephone 01259 216760
- **Stirling** – The Old Lodge, Orchard House, 9 Union Street, Stirling FK8 1PA Telephone 01786 464380
- **West Stirlingshire** – 14 Buchanan Street, Balfour G63 0TT

Grangemouth Carers Ltd - Grangemouth Carers provide a range of services including taking over from carers to give them a break. Grangemouth Carers Ltd is a company with charitable status and is non-profit making. For more information about services and charges contact Grangemouth Carers Ltd, Unit 6, Newhouse Business Park, Newhouse Road, Grangemouth FK3 8LL, Telephone 01324 666455.

Independent Living Services (ILS) - ILS is a private care agency which offers advice and support to people who have special care needs and who wish to live as independently as possible. Depending on the level of assistance required and individual financial circumstances, care packages are funded in various ways.

For more details contact Independent Living Services, 2 Cooperage Way, ALLOA FK10 3LP. Telephone 01259 226300 Out of Hours: 07966 199139.

Falkirk Council's Children with Disabilities Team Respite Care Service - This service aims to support families caring for children or young people up to the age of 18 who have special needs arising from a disability. They can arrange to provide care in your own home for a few hours, overnight, or for up to two weeks at a time.

They use volunteer carers who are people with a genuine interest in helping and caring for others. Carers are fully trained and vetted by the Council's Children with Disabilities Team. At present there is no charge for using this service. For information on how to apply to the service contact Children with Disabilities Team, Social Work Service, Oxcgang Road, Grangemouth, Telephone (01324) 504343.

Family Support Service - NCH Action for Children has a Family Support Service based in Brown Street, Camelon which offers children with special needs short breaks, ranging from a few hours to a two week stay. For further information contact Family Support Service, 54 Brown Street, Camelon, Falkirk FK1 4QW Telephone 01324 633772

Family Centres - there are Family Centres in Alloa and Tillicoultry. The Centres provide a wide range of flexible day care services ranging from the traditional day nursery service to a more structured support service to children and families with special needs. For further information contact:

- Alloa Family Centre, East Castle Street, Alloa, Tel. (01259) 218722
- Hillfoots Family Centre, Park Street, Tillicoultry FK13 6AG, Tel. (01259) 751206
- Tullibody Family Project, 101a Newmills. Tullibody, Tel. (01259) 212063.

Similar services are run by the Aberlour Trust in Falkirk - contact:

- Langlees Family Centre, Aberlour Trust, 26 - 32 Dunkeld Place, Langlees, Falkirk FK2 5BZ Tel. (01324) 638080
- Maddiston Family Centre, 68/70 Forgie Crescent, Maddiston, Falkirk FK2 0LZ, Tel. (01324) 711271
- Bo'ness Family Centre, Duchess Nina House. Cadzow Crescent, Bo'ness EH51 9AY, Tel. (01506) 823118.

Further information on residential care, day care services and care at home can be provided by the local Social Work Services office, The Falkirk Carers Centre or the Alloa Carers Office.

Falkirk Short Breaks Bureau - Falkirk Council Short Breaks Bureau organises breaks for adults with physical disabilities, older frail people and people with dementia and people with a learning disability.

The Bureau tries to organise breaks which are flexible and which suit the needs of both the carer and the cared for person. For details contact Kinglass Centre, Bo'ness Social Work Office, Bo'ness, Telephone 01506 778678.

Befriending - Some carers, because of their caring responsibilities, can become isolated and lose touch with friends and family. When breaks are arranged, it can sometimes be difficult to think of things to do and often people are reluctant to go out and do things on their own.

The Carers Befriending Project provides the carer with the opportunity to be linked with a volunteer befriender who will offer companionship and support by visiting on a regular basis or accompanying the carer on outings, perhaps to the shops, the cinema or out for a coffee, or to formal meetings or appointments.

There is a befriending service located in Stirling at Town Break Befriending Service, Order Of Malta Building, 3, Cunningham Rd, Stirling, Stirlingshire FK7 7SW, Tel: 01786 447787.

A befriending service for young carers is also available. For further information on befriending for carers contact The Carers Befriending Project, The Old Burgh Buildings, 12/14 Newmarket Street, Falkirk, FK1 1JQ Telephone 01324 626046 E-mail: befrienders@falkirk.carers.net

Holidays - If the person being cared for is in respite care for a period of time, the carer may wish to stay at home and enjoy a rest, may decide to visit friends or may decide to go on holiday.

However, as mentioned above, being a carer can sometimes mean that you lose contact with your own friends and the thought of going on holiday alone can be daunting. Cost can also be a prohibitive factor.

The Carers Centre and the Short Breaks Bureau have information on carers breaks, group holidays and other holiday alternatives as well as information on grants and funding for breaks and holidays.

Alternatively, the carer and the person being cared for may wish to go on holiday together and in some cases this may mean that special arrangements have to be made such as special transport arrangements, finding accessible accommodation, or finding a holiday where help with nursing or personal care is available. Again the Carers Centre and the Short Breaks Bureau have information on a wide range of holiday alternatives and can put carers in touch with organisations that can help.

Other Useful Contacts

RADAR

A national organisation run by and working for disabled people. The Royal Association for Disability and Rehabilitation, 12 City Forum, 250 City Road, London EC1V 8AF, Tel: 020 7250 3222, Email: radar@radar.org.uk, Website: www.radar.org.uk

Holiday care service

An organisation providing information and advice on such matters as accessible accommodation and general planning of holidays. Holiday Care Service can also provide information about respite care for the person you care for. 2nd Floor, Imperial Buildings, Victoria Road, Horley RH6 7PZ, Tel: 0845 124 9971 (9.00am - 1.00pm)

Accessible holidays in the British Isles

A guide for disabled people - also available on website at: www.radarsearch.org
Published by RADAR & Holiday Care Service in association with The National Tourist Boards.

[Contents page](#)

5.5 – Regional and national organisations

Age Concern Scotland

0845 833 0200 Freephone: 0800 009966 7 days a week 7am-7pm
Website: www.ageconcernscotland.org.uk email: enquiries@acscot.org.uk

Alzheimer Scotland - Action on Dementia

0808 808 3000
Website: www.alzscot.org email: alzheimer@alzscot.org

Breast Cancer Care (Scotland)

Freephone: 0808 800 6000 Mon - Fri 10am-5pm, Sat 10am-2pm Information Line: 0141 221 2244
Website: www.breastcancercare.org.uk email: sco@breastcancercare.org.uk

Breathing Space Scotland

Freephone: 0800 83 85 87 Every evening 6pm – 2am
Website: www.breathingspacescotland.co.uk email: ron@breathingspacescotland.co.uk

Cancer BACUP Scotland

0141 223 7676 0808 800 1234 (Mon - Fri 9am - 8pm)
Website: www.cancerbacup.org.uk

Carers Scotland

Careline: 0808 808 7777 (Wed & Thu 10am-12pm & 2pm-4pm)
Website: www.carerscotland.org.uk email: info@carerscotland.org

Carers UK

020 7490 8818 Careline: 0808 808 7777 (Wed & Thu 10am-12pm & 2pm-4pm)
Website: www.carersuk.org.uk email: info@ukcarers.org

Chest Heart & Stroke Association

Helpline 0845 077 6000 (Mon-Fri 9.30am-12.30pm & 1.30pm-4pm)
Website: www.chss.org.uk email: adviceline@chss.org.uk

The Child Brain Injury Trust

0131 229 1852 Helpline 0845 601 4939 (Mon, Tue, Wed & Fri 10am-1pm)
Website: www.cbituk.org email: helpline@cbituk.org

Cruse Bereavement Care in Scotland

0131 229 6275 or 0870 167 1677
Website: www.crusescotland.org.uk email: info@crusescotland.org.uk

ENABLE

0141 226 4541
Website: www.enable.org.uk email: enable@enable.org.uk

Help the Aged

0131 551 6331 or 0808 800 6565 Mon-Fri 9am-4pm
www.helptheaged.org.uk email: infoscot@helptheaged.org.uk

Huntington's Disease Association

01505 322245
Website: www.hdscotland.org email: sha-admin@hdscotland.org

Macmillan Cancer Relief

0131 346 5346 Freephone 0808 808 2020 (Mon-Fri 9am-6pm)
Website: www.macmillan.org.uk email: cancerline@Macmillan.org.uk

Multiple Sclerosis Society Scotland
0131 335 4050 Helpline: 0800 800 8000
Website: www.mssocietyscotland.org.uk

Muscular Dystrophy Group
020 7720 8055
Website: www.muscular-dystrophy.org email: info@muscular-dystrophy.org

Parkinson Disease Society
Freephone 0808 800 0303 (Mon-Fri 9.30am-5.30pm)
Website: www.parkinsons.org.uk e-mail: enquiries@parkinsons.org.uk

Positive Voice (AIDS & HIV Support)
0131 652 0754
Website: www.positive-voice.org.uk email: manager@positive-voice.org.uk

The Roy Castle Lung Cancer Foundation
Freephone: 0800 358 7200 or 0141 331 0580
Website: www.roycastle.org

Scottish Motor Neurone Disease Association
0141 945 1077
Website: www.scotmnd.org.uk email: info@scotmnd.sol.co.uk

Tak Tent Living With Cancer
Tel. 0141 221 0122
Website: www.taktent.org.uk Email: tak.tent@care4free.net

Terence Higgins Trust
020 7831 0330 or 0845 12 21 200
Website: www.tht.org.uk email: info@tht.org.uk

[Contents page](#)

5.6 – Telephone help lines

Telephone help lines

ACT (Association for Children with Life Threatening/Terminal Conditions) 0117 922 1556 (Mon-Fri, 9am-5pm)

Age Concern Caring Circle Information Line 0800 009966 (7 days, 7am-7pm)

AIDS Helpline 0800 567123 (7 days, 24 hours)

Alzheimer Scotland Dementia Helpline 0808 808 3000 (7 days, 24 hours)

Cancer BACUP 0808 800 1234 (Mon-Fri, 9am-5pm)

Colon Cancer Concern 08708 50 60 50 (Mon-Fri, 10am-4pm)

Macmillan Cancer Relief 0808 808 2020 (Mon-Fri, 9am-6pm)

Prostate Cancer Charity Confidential Helpline 0845 300 8383 (Mon-Fri, 9am-5pm)

Prostate Cancer Support Association (PSA) 0845 601 0766 (Mon-Fri, 9am-5pm)

Chest Heart & Stroke Advice Line 0845 077 6000 (Mon-Fri, 9.30am-12.30pm, 1.30pm-4pm)

The Child Brain Injury Trust 0845 601 4939 (Mon-Fri, 9am-5pm)

Help the Aged 0808 800 6565 (Mon-Fri, 9am-4pm)

Motor Neurone Disease Association 08457 626262 (Mon-Fri, 9am-5pm)

Multiple Sclerosis 0808 800 8000 (Mon-Fri, 9am-5pm)

Muscular Dystrophy Campaign 0207 720 8055 (Mon-Fri, 9am-5pm)

NHS 24 0845 24 24 24 (7days, 24 hours)

NHS Helpline 0800 224488 (7days, 24 hours)

Parkinsons Disease Helpline 0808 800 0303 (Mon-Fri, 9.30am-5.30pm)

Stroke Helpline 0845 303 3100 (Mon-Fri, 9am-5pm)

[Contents page](#)

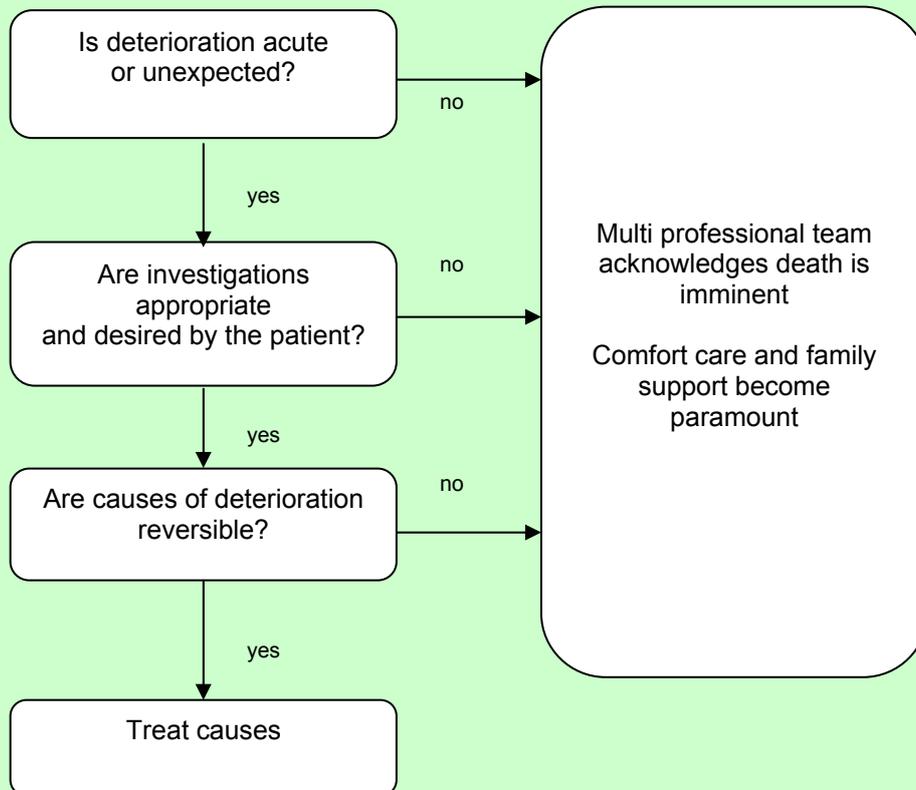
Section 6 – Care of the dying

6.1 - Last days of life

The diagnosis of the terminal phase of an illness is not always easy to make. Pointers are :

- profound weakness and impaired mobility
- drowsiness or reduced cognition
- reduced intake of food/fluids
- difficulty in swallowing oral medications.

However it is important to exclude reversible causes of decline.



When it has been recognised that death is imminent an Integrated Care Pathway should be considered. (See the Information on the Liverpool Care Pathway and the Coping With Dying booklet in the Useful Resources folder for this section).

Plan

Consider care in terms of the 4 domains – psychological, spiritual, social and physical

Psychological

- Explore patient and family awareness of diagnosis and recognition of dying.
- Include children and significant others.
- Encourage open communication and expression of emotions.
- Discuss reconciliation if appropriate.
- Acknowledge and try to meet the needs of carers.

Spiritual

- Consider cultural and spiritual needs
- Obtain appropriate support/advice
- Anticipate bereavement difficulties :
 - patient – young
 - illness – short or protracted, disfiguring, distressing
 - death – sudden, traumatic e.g. haemorrhage
 - relationship – ambivalent, hostile or dependent
 - main carer – young, other dependents, previous mental or physical illness, previous multiple losses or recent losses, little support, low self esteem

Further information on Spiritual care can be found in Section 8.10 of the manual.

Social

- Check that affairs are in order :
 - financial situation including compensation claims
 - will arrangements
 - funeral arrangements
 - particular requests
- Discuss options for terminal care (home, hospital, hospice) but consider that transfer may hasten decline.

Home

- if patient maintained at home ensure adequate support and equipment available (see co-ordinated care section of the manual)
- refer to Palliative care Services as appropriate
- complete verification of death form part 1

Hospital

- if patient maintained in hospital, best practice should be to offer a single room
- ensure relatives are informed re
 - car parking
 - accommodation
 - availability of refreshments etc.
- ensure contact details are unambiguous
 - first contact
 - at any time
 - not at night time etc.

Physical

- continue an analytical approach to symptom control but rely more on clinical findings than investigations
- Negotiate appropriate treatment :
 - discontinue medication, treatment and monitoring not required for symptom control and review regularly
 - choose the most appropriate route of administration of drugs
 - review artificial hydration/nutrition – agitated patients may remove cannulae causing needle-stick injuries
 - be aware that overhydration may increase respiratory secretions
 - ensure frequent mouth care
 - transfer to pressure-relieving bed/mattress
 - record resuscitation status in notes as Allow Natural Death (DNR)
 - inform NHS24/Forth Valley Out-of-hours hub on call staff of patient's situation using pro forma (see section 4 – co-ordinated care)

- consider catheterisation
- Treat symptoms according to tables on page 6.5 and refer to other sections of the manual for information on breathlessness, emergency situations, nausea and vomiting, pain confusion (section 2), syringe driver (section 3)

Symptom Control in the Last Days of Life

Pain

- do not use opiate analgesics to sedate a dying patient
- use appropriate route
- ensure breakthrough available as required
 - if opiate naïve**
 - Oramorph 2.5mg orally
 - Diamorphine 1.25mg SC
 - if on regular opiate**
 - use 1/6 of 24 hour dose
- to convert to SC Diamorphine (from oral Morphine) use 1/3 of total 24 hour oral morphine dose
- Fentanyl patch
 - do NOT discontinue when patient is dying (unless clearly toxic) add Diamorphine via syringe driver if additional analgesia required
 - do NOT start when patient is dying – delay in reaching effective levels
- NSAIDS – continue if previously important e.g. Diclofenac 100 mg PR or SC infusion 150mg/24 hours

Breathlessness

- Reverse the reversible but be aware that options may be limited eg- antibiotics may be neither effective nor easily administered.
- Offer supportive care
 - Relaxation techniques
 - Breathing exercises
 - Fan
 - Positioning
- Oxygen therapy may be helpful. Nasal prongs or sponges may be more comfortable than masks.
- Opioids may be useful orally or parenterally. Initiate at a low dose to avoid toxicity.
- Benzodiazepines may reduce anxiety associated with breathlessness or stridor.
 - Lorazepam 0.5mg sub lingually can give rapid relief
 - Oral Diazepam is longer acting
 - Sub-cutaneous Midazolam may be required if the oral route is unsuitable as a stat. dose or via a syringe driver.
- Carbocisteine 750mg t.i.d. orally may aid expectoration of thick, sticky secretions.
- Nebulised Saline 0.9% 2.5ml PRN may ease a dry cough
- Nebulised Salbutamol 2.5mg PRN may help bronchospasm
- Increased respiratory secretions may be reduced by sub-cutaneous Hyoscine Hydrobromide 400mg as a bolus or via a syringe driver.

Nausea and Vomiting

- Nausea and vomiting may rarely occur as new symptoms in the last days of life. If possible, identify and, if practical, treat the cause.
- Choose an appropriate anti-emetic based on the site of effect eg – Metoclopramide to increase gastric emptying.
- If the cause is unclear, consider a broad spectrum or centrally acting anti-emetic.
- If there are several causes more than one anti-emetic may be required. The sub-cutaneous route is likely to be required.
- If anti-emetics have been required regularly prior to the terminal stage they should be continued.

Restlessness and confusion

- Causes – Drugs (particularly opiates), metabolic upset, anxiety and distress, cerebral irritation, infection, pain.
- Treatment
 - General measures – calm surroundings, safe environment and familiar faces
 - Drug treatment – if opioid toxicity present, reduce opiate dose, hydrate and add Haloperidol, Midazolam or Levomepromazine while the opiate dose is reviewed
 - If no toxicity present, identify other possible causes. Twitching or jerking may suggest metabolic or cerebral problems.
 - Useful drugs to treat restlessness and confusion are Midazolam, Haloperidol & Levomepromazine. Midazolam also has anti convulsant activity but rectal Carbamazepine suppositories may be necessary in addition to Midazolam if oral anticonvulsants have been taken previously.
 - Be aware that spiritual distress will not be relieved by drugs.
- Educate, support and inform relatives and carers on a regular basis.

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[Contents page](#)

Summary tables – symptom control in the last days of life

Pain

Drug Class	Drug	Route	Dose	Comment	Miscible with Morphine
Opiate	Diamorphine	s/c bolus or as s/c infusion via SD over 24 hours	Use 3:1 conversion from oral morphine : s/c diamorphine	1 - Titrate dose individually. 2 - If opiate naïve use 1.25mg as stat dose. 3 - Ensure breakthrough analgesia (1/6th of 24 hour dose) available.	N/A
Opiate	Oxycodone	As above	Use 1:1 conversion for oral oxycodone : s/c oxycodone		
Opiate	Fentanyl	Transdermal	Continue current patch strength	Do not initiate in terminal stages. Add in diamorphine via SD if necessary	N/A
NSAID	Diclofenac	s/c infusion via SD	150mg over 24 hours	Bone or soft tissue pain	Yes – saline 0.9% as diluent
NSAID	Diclofenac	per rectum	100mg once daily	Bone or soft tissue pain	N/A

Nausea and vomiting

Drug Class	Drug	Route	Dose	Comment	Miscible with Morphine
Phenothiazine	Levomopromazine	s/c bolus or as s/c infusion via SD over 24 hours	6.25mg bolus, titrate up to 100mg via SD over 24 hours	Sedative, broad spectrum anti-emetic	Yes
Butyrophenone	Haloperidol	s/c bolus or as s/c infusion via SD over 24 hours	1.5-5mg bolus, 5-20mg over 24 hours	Lower doses for hiccups and vomiting. Higher doses for confusion	Yes
Antihistamine	Cyclizine	s/c infusion via SD over 24 hours	150mg over 24 hours	May need to dilute further - 20 ml syringe	Yes – but may cause site irritation
Dopaminergic. Direct effect on GI tract	Metoclopramide	s/c infusion via SD over 24 hours	40mg over 24 hours	Increases gastric emptying	Yes
Anti-muscarinic	Hyoscine Hydrobromide	Transdermal	1mg over 24 hours	Apply to hairless skin behind ear	N/A
Anti-spasmodic and anti-secretory	Hyoscine Butylbromide	s/c infusion via SD over 24 hours	20mg bolus, 20-80 mg over 24 hours	Useful for colic in bowel obstruction	Yes
Somatostatin analogue	Octreotide	s/c infusion via SD over 24 hours	300-600mcg over 34 hours	Large volume vomit associated with bowel obstruction	Yes – saline 0.9% as diluent

Restless, agitation and confusion

Drug Class	Drug	Route	Dose	Comment	Miscible with Morphine
Butyrophenone	Haloperidol	Oral	1.5mg – 3mg	Repeat after 1 hour if necessary	N/A
Butyrophenone	Haloperidol	s/c bolus or as s/c infusion via SD over 24 hours	2.5mg – 5mg bolus, 5-30mg infusion over 24 hours	1 - Use for drug toxicity, metabolic upset or altered sensorium 2 - May be combined with Midazolam if anxiety present	Yes
Benzodiazepine	Midazolam	s/c bolus or as s/c infusion via SD over 24 hours	2.5mg – 10mg bolus, 5-80mg infusion over 24 hours	Anxiolytic, Higher dosages may be required if risk of seizures	Yes
Phenothiazine	Levomopromazine	s/c bolus or as s/c infusion via SD over 24 hours	6.25mg-12.5mg bolus, 25-100mg infusion over 24 hours	Sedative, Can lower seizure threshold	Yes

Breathlessness

Drug Class	Drug	Route	Dose	Comment	Miscible with Morphine
Opiate	IR Morphine	Oral	2.5mg 4 hourly if opiate naïve	If on regular analgesia may need higher breakthrough dose than for pain	N/A
Opiate	Diamorphine	s/c bolus or s/c infusion			N/A
Benzodiazepine	Lorazepam	S/I	0.5mg up to 6 hourly	Works quickly, lasts a short time	N/A
Benzodiazepine	Midazolam	s/c bolus or as s/c infusion via SD over 24 hours	2.5-10mg bolus, 5-60mg infusion over 24 hours	Anxiolytic at smaller doses, anticonvulsant at higher doses	Yes
Anti-muscarinic	Hyoscine Hydrobromide	s/c bolus or as s/c infusion via SD over 24 hours	0.4-0.6mg bolus up to 24 hours via SD	Dries respiratory secretions	Yes

6.2 - What to do after a death

Verification of death

It is essential that all professionals involved in caring for a patient after death, do so in a compassionate and respectful manner as this is often the last service which can be provided for an individual and at may ease the distress of those who are bereaved.

The time should be noted and the following physical signs should be checked to ascertain that death has occurred.

- Pupils will be fixed and dilated and unreactive to light
- No pulsation in retinal vessals
- Absent breath sounds for 1-2mins
- Absent heart sounds for 1-2mins
- No peripheral pulsation

Guidance on Verification of Expected Death by Nursing Staff is at an advanced stage of development in Forth Valley and will be adopted pending Clinical Governance ratification.

A training programme has been developed jointly by The University of Stirling, Strathcarron Hospice and NHS Forth Valley Practice Development Unit and training will be delivered by each of these units.

Following approval by Clinical Governance Sub-committees, the guidance will be incorporated into the manual.

Care of relatives

- Introduce yourself
- Ascertain circumstances of death
 - expected vs. unexpected
 - relatives present
- Be Practical – Tea, Tissues, Transport
- Advise against tranquillisers and warn about excessive alcohol. Explain that they are unhelpful and may postpone the grieving process until a time when less support is available.
- Encourage company and encourage good memories (photographs etc), to counteract any bad memories.
- Encourage grief to be expressed but be prepared for variable grief reactions – denial, anger, guilt, bargaining, depression, acceptance.
- Discourage hasty decisions.
- Avoid black bag syndrome – when belongings have to be collected encourage use of a suitcase .

- Explain the grieving process (See page Appendix A on pages 6.13 & 6.14 – The Grieving Process) but be discerning as how much is appropriate when. Consider :
 - Initial numbness.
 - Up and down Days
 - Hallucinations are not abnormal – relative may see dead person, sense presence of deceased, forget patient is dead.
 - Times of particular difficulty.
 - After - 6 weeks, 6months
 - Special anniversaries e.g. birthdays
 - Particular times of family ritual e.g. Christmas, Diwali, Bar mitzvah

Remember that attitudes of respect, acceptance and empathy will be appreciated more by distressed relatives more than the words you say. Allow the bereaved to express their feelings, talk about the deceased and other family members and to explore their current, past and future life experiences and ambitions.

- Arrange for the relatives to be seen subsequently at home, and then in Surgery.
- Consider tagging relatives' case notes with date of death of the patient (in general practice.)
- Consider Pet problems
- Be aware of the particular problems of children.

Administrative and Legal requirements

Death certificate

- A certificate should be completed accurately with particular emphasis on the fatal sequence.
- Ensure histology and primary site of tumour are recorded and the interval between onset and death.
- Do not abbreviate or symbolise causes of death.
- Issue the certificate as soon as practicable. If this is not possible due to Fiscal notification or other reasons the relative should be informed and an explanation given as sensitively as possible. The certificate should be explained to the relative(s) in simple language remembering that the relative may be very distressed and have poor concentration.

Cremation certificate

If cremation is required, part B of the certification should be completed by a doctor who has seen the deceased before and after death. Arrangements should be made for part C to be completed by a practitioner who has been fully UK registered for five years. Pacemakers should be removed with consent from the next-of-kin.

What to do after a Death booklets (see useful resources folder)

- Go through the booklet, highlighting appropriate parts. Ensure the relatives are aware that the certificate should be presented to the registrar within eight days, by any person possessing all the information needed for registration.
- They may go either to the registrar's office in the district where the death occurred or the district where the deceased resided.
- Explain that copies of the certificate can be obtained from the registrar for pensions, insurance etc. and it is more practical and cheaper to obtain these at registration than at a later date.
- Mark the "What else has to be done?" section.
- Explain that you will arrange for a team member to contact GP/Hospital and cancel OP appointments and ambulances.
- Ensure that relatives are aware that all unused medications must be returned to the local pharmacy, as drugs may only be used for the person for whom they have been prescribed.
- Arrangements should be made for the return/uplift of loaned equipment.

Religious, faith and cultural issues

- Ensure knowledge of and observe the demands of the deceased person's faith and culture. The booklet "Religions and Cultures" provides helpful information and is available at www.religionsandcultures.co.uk
- Ensure the family has access to (or is able to contact) the relevant faith/cultural leader if spiritual support is requested. (Section 8.10 of the manual provides a variety of spiritual care contact telephone numbers).

You may also find the cultural and religions considerations information board in the care of the dying resource wallet helpful.

Procurator Fiscal Notification

- The Procurator Fiscal mainly deals with unnatural causes of death. In palliative situations the main reasons to refer to the PF are deaths from Industrial diseases (Mesothelioma) or accidents and deaths where a complaint of medical negligence has been lodged prior to death.
- Initial contact is made by telephone using an F5 form
- The police then visit to take statements from relatives and doctors.
- A Post Mortem may or may not be required.
- Locally the use of the Mesothelioma pro forma may reduce distress. See Appendix D at pages 6.19 to 6.24

Donation of body to medical science

According to the 1984 Anatomy Act, the patient must have made arrangements in advance with a medical school and a written statement of the intention to benefit medical science should be among the dead person's papers. Bodies will be refused if :

- Very obese or emaciated.
- Distorted anatomy
- Pressure sores or open wounds present
- Infectious disease
 - Tumour
 - Treatment

A consented PM may be an acceptable alternative to relatives in which case a triplicate consent form will be required.

Transplants

The deceased may have a donor card. Permission of relatives is required.

For eye donation contact the duty ophthalmologist. The eyes must be removed within 24 hours. Blood will be required for Hep/HIV status. There are many contra-indications to transplant. Consent in triplicate will be required.

Other transplants e.g. kidneys are unlikely to be feasible.

No next-of-kin

a) If the deceased had no finances

The responsibility for making funeral arrangements may fall on the local council if:

- There is no next of kin or the next of kin cannot be found
- The next of kin is unable to make arrangements due to age or infirmity
- There is no executor or other person able to accept responsibility.

When the council makes funeral arrangements, a simple dignified ceremony is held. Unless a family lair is available or the deceased expressed a wish to be cremated, normally burial is in a common grave at one of the council's cemeteries. Receipts of reimbursement must be obtained from the local authority using an approved form (please see Section 4 for local authority contact information).

b) If the deceased had finances but died intestate (without a will)

In this situation the estate falls to the crown. (Ultimus Haeres).

In Scotland the Office of the Queen's and Lord Treasurer's Remembrancer (Q<R) ingathers and administers such property on behalf of the crown through the crown agent.

Complicated grief reactions and bereavement

The majority of people who are well supported by family and friends do not need extra help with their bereavement.

Some people appear to be more at risk of increased disability following bereavement and it is useful if health professionals can recognise them and offer further support. Indicators of concern include excessive expressions of self harm, blocked or excessive emotions, idealisation of the individual who has died and clinical depression.

Atypical grief is more likely if:

- Death is sudden or unexpected.
- The bereaved person
 - is unable to view the body of the deceased or to express appropriate grief at an early stage.
 - experienced loss of his/her own parent as a child.
 - has low self esteem or previous mental health problems.
 - had poor general health before bereavement
- There was an ambivalent or hostile relationship with the deceased.
- The loss was of a small of fully-grown child.
- The loss was as a result of trauma
- There are few relatives or other social supports.
- There are reduced material resources

Complicated grief reactions are more common in women than men and can be prolonged and severe. If there are initial indications that the reaction to grief may take a pathological course, the G.P. should be informed and the bereaved relatives may be referred for psychiatric help. There is general agreement that mental illness in bereaved relatives carries a better prognosis than most other forms of mental illness.

Relatives with psychiatric problems or alcohol dependence before the death of a loved one should be closely observed when bereaved.

If the intensity and pain of emotions relating to the death event, or absence of the deceased, increase with time rather than gradually subside, then the bereaved person may need professional help from a trained grief counsellor or psychologist.

A bereavement risk assessment tool (see Appendix B for a sample on pages 6.15 to 6.16 and genogram (see Appendix C on page 6.17) may be useful to identify those who require support.

N.B. Various booklets, pamphlets and work sheets are available for children, adolescents and adults and can be obtained readily by hospital, hospice or community staff. Early appropriate information and pre-bereavement counselling may prevent abnormal reactions or prolonged grieving.

The following websites may also be useful :

www.strathcarronhospice.org

www.info@crusescotland.org.uk

www.samaritans.org.uk

www.caringinfo.org

www.childbereavement.org.uk

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[Contents page](#)

Appendix A – The grieving process

Professionals need to be familiar with the process of grief so that they can recognise if and when extra support is needed.

Physical and psychological processes of loss and bereavement

These may include;

Emotional:

Sadness, depression, anxiety, fearfulness, anger, guilt, hyper vigilance, loneliness, feeling/seeing the person who is deceased.

Cognitive:

Lack of concentration, preoccupation with repetitive thoughts especially of the deceased, helplessness/hopelessness, feeling detached and distant.

Behavioural:

Irritability, hostility, restlessness, searching, pacing, crying, social withdrawal.

Physical:

Fatigue, change in sleep usually insomnia, aches and pains, appetite changes, gastrointestinal changes including nausea, constipation, minor infections

Tasks of Mourning

One framework to look at this over time is provided by Worden (1991) and the table below provides a summary. It is important to remember that people move back and forward between the different Tasks of Mourning and that the process of grief is unique to everyone over a period of months and years. The intensity of the early stages of grief often returns when reminders such as anniversaries, birthdays, special places and events occur.

The four tasks of mourning (Worden 1991 p10-18)

Accept the reality of the loss	To accept the death at emotional and intellectual levels.
Work through the pain of grief	To experience the painful feelings of grief and release them
Adjust to an environment without the deceased	To adapt to changes of circumstances and role identity
Emotionally relocate and move on with life.	To adjust the emotional attachments and find a new place for the deceased within themselves

Many relatives cope well without external assistance but it may help them to know how support may be accessed promptly if required. Useful information can be found at the following websites.

www.strathcarronhospice.org

www.info@crusescotland.org.uk

www.samaritans.org.uk

www.caringinfo.org

www.childbereavement.org.uk

[Contents page](#)

Appendix B – Bereavement Support Assessment Tool

Patients Name	Date of Birth
Address	Date of Death
.....	Place of Death
Next of kin	Relationship (to patient)
Address	
.....	Tel. No.

Please circle your response to the following questions, on the basis of your observations.

1 Did the bereaved person appear unusually

(a) Dependent?	NO	YES	DON'T KNOW
(b) Self-reproachful?	NO	YES	DON'T KNOW
(c) Bitter or angry?	NO	YES	DON'T KNOW

2 Is the bereaved person facing other life crises?

(a) House move	NO	YES	DON'T KNOW
(b) Financial difficulties	NO	YES	DON'T KNOW
(c) Unemployment	NO	YES	DON'T KNOW
(d) Other	NO	YES	DON'T KNOW

3 Are there signs of alcohol or drug dependency?

NO	MODERATE	HEAVY	ADDICTION	DON'T KNOW
----	----------	-------	-----------	------------

4 How did the relationship with the deceased seem?

STRONG	INTENSE	EXCLUSIVE
AMBIVALENT	DISTANT	DON'T KNOW

5 Was the bereaved reluctant to face the patient's illness?

NO	A LITTLE	YES	DON'T KNOW
----	----------	-----	------------

6 Does the bereaved person have a caring family, friends or support networks?

NO	A FEW	YES	DON'T KNOW
----	-------	-----	------------

PTO

7 Have you informed the relevant professionals involved about the death?

NO

YES

Please record the names and dates of contact

8 Comments: please include anything that concerned or encouraged you in terms of the bereaved person's ability to cope with loss (particularly if the patient is not well known to you).

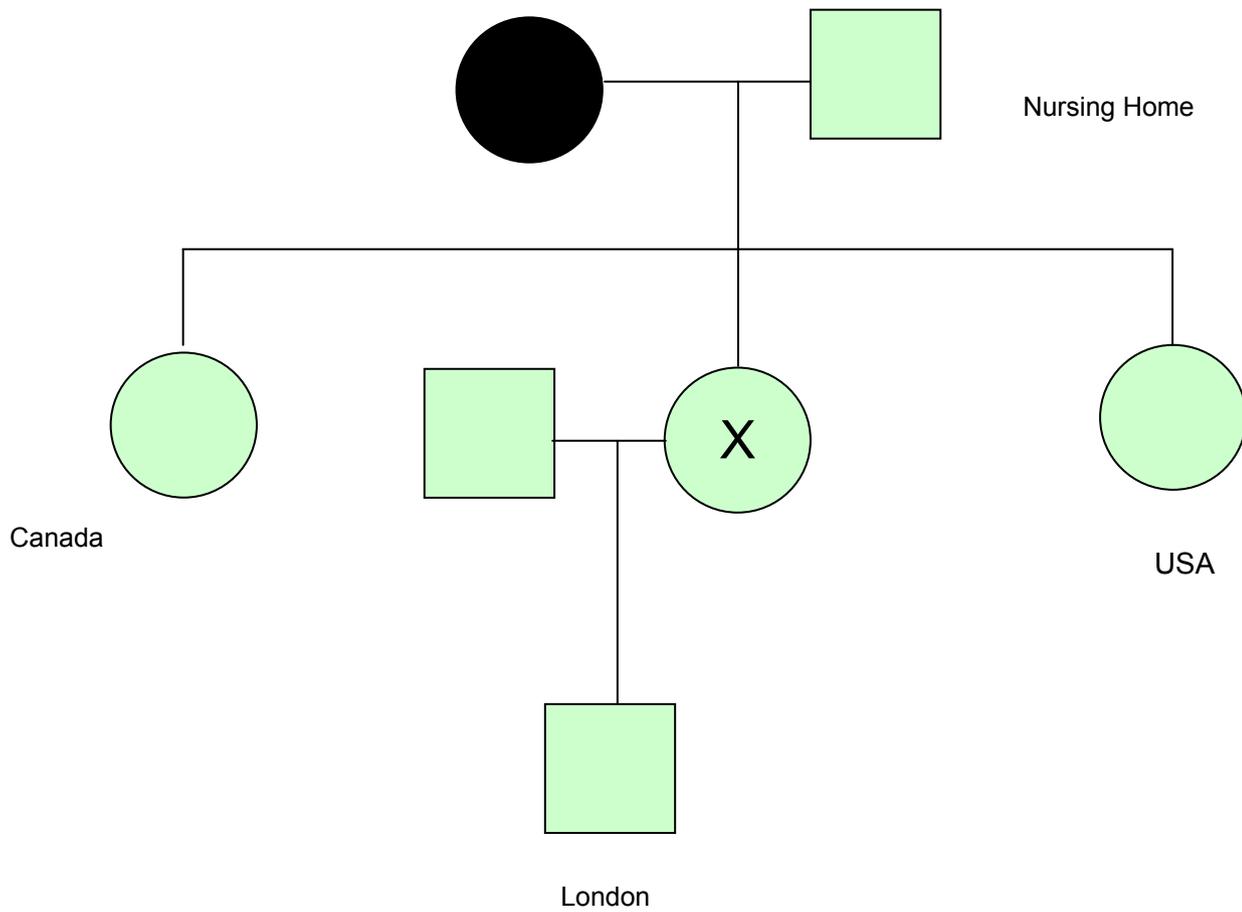
9 Please record names and addresses of significant individuals who are to receive support information.

10 Detail support to be offered.

Form completed by

Date form completed

Appendix C – Sample of a simple genogram



Code

- female
- male
- X index case
- deceased

A genogram is a useful method of recording family information in a concise way. Information can be added as it becomes available.

[Contents page](#)

Appendix D – Mesothelioma proforma

PRO FORMA FOR PROCURATOR FISCAL
NOTIFICATION OF DEATH FROM MESOTHELIOMA

Demographic particulars of deceased

Name DOB Age Hospital No

Address.....

..... Post code Phone No

Marital Status..... Occupation

When retired

Date of death Time of death

Location at time of death

General Practitioner GP address

GP Tel No

Consultant in charge at time of death

Consultant in charge at time of diagnosis

Next of kin Relationship to deceased

Address.....

..... Post code Phone No

Employer information (specify nature and content of asbestos exposure)

.....

..... Dates of employment

.....

..... Dates of employment

Details of admission / final phase of illness

Referral details

.....

Treatment / management immediately prior to admission

.....

.....

.....

Treatment / management during admission

.....

.....

.....

Medication on admission with any changes made

.....

.....

.....

.....

Other relevant treatment / management in the last few days

.....

.....

Last few days (specify any sudden event – e.g. collapse)

.....

.....

Any food taken in the last few days Yes No

Verification of death

Doctor with responsibility for verification of death

Name

Designation

Qualification

Date of Birth

Suggested cause of death

(i) a

b

c

d

(ii)

Willingness to certify

Yes

No

Date

Any other relevant information

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Completed for Strathcarron/ SRI/ FDRI/ GP practice

Name Signature
Date Tel No

Certification of death

Date of certification Time
Certifying doctor Location

Completed by procurator fiscal

Signed Date

Dr Fiona Downs
Strathcarron Hospice
© February 2002

[Contents page](#)

Section 7 – Continued Learning

7.1 Cancer and palliative care education opportunities.

Multiprofessional Courses

- CREATE
(Community Resource for Education Audit & Teamwork)
www.show.scot.nhs.uk/nhsfv/clineff/CREATE/CREATE.htm
- COSCA – Certificate or Diploma in Counselling
 - Certificate in Counselling has been adapted for Cancer / Palliative Care at Strathcarron Hospice. www.cosca.org.uk (Homepage)
- Dundee University (Follow links under the heading 'For Students')
www.dundee.ac.uk/nursingmidwifery
Centre for Medical Education
 - Undergraduate to MSc –
Distance learning in Palliative Care
Multidisciplinary & International
www.dundee.ac.uk/facmedden/dlc/m13.htm
- **Glasgow Caledonian University**
 - Undergraduate Palliative Care at Level 2 / 3
www.gcal.co.uk/undergrad/index.htm
 - Postgraduate Certificates / Diploma in Cancer Care
 - Master programme - generic and community health
www.gcal.co.uk/postgrad/index.htm
- **Glasgow Palliative Care Information Network**
www.palliativecareglasgow.info - Follow links for Professionals
- Lymphoedema & other Chronic Oedemas
www.gla.ac.uk/schools/nursing/oedema/intro.html
- NHS Education for Scotland
<http://www.nes.scot.nhs.uk/> (Homepage)
- St. Columba's Hospice and Queen Margaret University College –
 - BSc Hons Palliative Care
 - Interprofessional MSc in Palliative Care (in development stage)
www.stcolumbushospice.org.uk/education
- Scottish Partnership for Palliative Care
<http://www.palliativecarescotland.org.uk/coursesandconfs/index.htm>
- Strathcarron Hospice
 - Certificate in Counselling Skills (COSCA Accredited)
 - Short courses and study days in Palliative Care
 - Communication Courses (multi and uni professional)
 - GP Structured Clinical Placement (four weeks) NOF funded
 - www.strathcarronhospice.org (Homepage)
 - MSc in Enhanced Cancer Care Practice
 - MSc in Enhanced Palliative Care Practice
 - MSC in Enhanced Care Practice of Progressive Conditions
 - Postgraduate Certificate/Diploma or stand alone module in the above
 - www.nm.stir.ac.uk

Medical Staff

- Royal College of Physicians
Specialist Registrar Programme in Cancer & Palliative Care
www.rcpsglasg.ac.uk (Homepage Glasgow)
www.rcpe.ac.uk (Homepage Edinburgh)
www.rcplondon.ac.uk (Homepage London)

- University of Wales College of Medicine (Cardiff University)
 - Diploma in Palliative Medicine
 - MSc in Palliative Medicine
 - Certificate in Palliative Carewww.palliumwales.co.uk
www.cardiff.ac.uk (Homepage)
Courses in collaboration with Marie Curie
www.mariecurie.org.uk/healthcare/education:-wales.html

Nursing Staff

- Bell College (Strathclyde University)
 - MSc – Chronic Disease (including palliative care)
www.bell.ac.uk (Homepage)

- Edinburgh University – generic courses only
 - MSc (can share modules with the University of Glasgow)
www.ed.ac.uk/nursing (Nursing Studies Homepage)
www.cpa.ed.ac.uk/calendar/pgradh/courses/CHSS/087.html
www.cpa.ed.ac.uk/prosp/postgrad/249_NursingStudies.html

- Marie Curie – Undergraduate – Modules in Cancer and Palliative Care
 - BSc Cancer & Palliative Care – Napier University
 - MSc Palliative Care & MSc Palliative Care & Applied Education – Napier
www.mariecurie.org.uk/healthcare/napier-university.html
www.mariecurie.org.uk/healthcare/education.html

- Napier University
 - Cancer Modules in BA degree programme
www.napier.ac.uk (follow links through Postgraduate Courses and then Health & Life Science Programme. Also, see Marie Curie)

- Paisley University
 - Undergraduate – Palliative Care /Breast Care & other Cancer Modules
www.paisley.ac.uk/hnm/post-reg.asp

- Queen Margaret University College
 - Courses in Cancer Care e.g. Breast Care
 - Palliative Care – St. Columba's Course
 - Teacher TrainingSee also St. Columba's Hospice for proposed inter-professional MSc
www.qmuc.ac.uk/prospective (follow links through Postgraduate Courses)

- Robert Gordon University
 - Cancer and Palliative Care Modules – Undergraduate leading to BA
www.rgu.ac.uk/nursing/home
- St. Andrews Hospice / Glasgow Caledonian University –
 - Educational programme
 - Postgraduate Certificate/Diploma in Cancer Care (Level 3)
 - Postgraduate Certificate/Diploma in Palliative Care
http://www.st-andrews-hospice.com/html/training_courses.php
- St Margaret's Hospice Clydebank / Glasgow Caledonian University
 - Level 2 Module in Palliative Care
 - Level 3 Module in Palliative Care (Work based learning)
 - Certificate in Counselling Skills (COSCA accredited)
 - Bereavement Module
 - www.smh.org.uk/educationcentre.html
- Stirling University
 - Undergraduate modules – mainly generic modules
 - MPhil by Research
 - Masters Research
 - Clinical Doctorate
 - MSc in Cancer Care, Palliative Care and progressive conditions
 - www.nm.stir.ac.uk & see Strathcarron Hospice for more details
- Thames Valley University & Marie Curie
 - Diploma (HE) Cancer and Palliative Care
www.tvu.ac.uk/courses/Course_details.jsp?course=2407
 - BSc (Hons) Cancer & Palliative Care
www.tvu.ac.uk/courses/Course_details.jsp?course=2408
www.mariecurie.org.uk/healthcare/education:-wales.html
www.mariecurie.org.uk/healthcare/thames-valley-university.html

[Contents page](#)

Section 8 – Other useful information

8.1 – Adults with incapacity

The Adults with Incapacity (Scotland) Act 2000 is a legal framework to allow financial, welfare and medical decisions to be taken for adults who have lost mental capacity and came into force in 2002. It is intended as enabling legislation to support the human rights of a vulnerable section of society. Although a statutory document, it does not impose a legal duty to complete a Certificate of Incapacity but, without completion, treatment would lack justification. It would be difficult to defend an action of assault or negligence if the principles of the Act were disregarded.

The definition of incapacity

A person may be incapable of :

- acting or
- making decisions or
- communicating decisions or
- understanding decisions or
- retaining memory of decisions

by reason of mental disorder OR

- incapable of communicating because of physical disability not alleviated by human or mechanical aid.

Assessment of capacity

There are no algorithms or tools for assessment but there are guidelines within the code of practice. At present only medical practitioners can assess capacity but this may change when the Act is revised.

It is essential to determine whether the adult :

- Is capable of making and communicating choice
- Understands what is being asked and why
- Has memory to allow retention of information
- Is aware of alternatives
- Has knowledge of risks and benefits
- Is aware of personal relevance of information
- Is aware of the right to refuse and consequences
- Has ever expressed his wishes when greater capacity existed (consult others)
- Is expressing views consistent with his previous moral, cultural, family and experiential background.

Capacity is task specific. Where the treatment or investigation is complex, or associated risks and side effects are likely to be severe, greater capacity is required in order to give valid consent and assessment should be more stringent.

Certificate of incapacity

Medical treatment is defined as any treatment or procedure designed to safeguard or promote the physical or mental health of the adult. The doctor primarily responsible for medical treatment certifies incapacity. The certificate is therefore 'setting specific'.

A leaflet entitled Adults with Incapacity can be found in the Other Useful Information resource wallet with this manual including the medical treatment flow chart which should be followed in all settings :

- A certificate must be completed and any proxy must be consulted
- The maximum duration is 1 year at present but the certificate is renewable
- It would be good practice to record completion in the patient's notes
- The medical practitioner must have in contemplation acute or continuing treatment
- The certificate is treatment specific but the use of treatment plans can allow 1 certificate to cover several treatments.
- The certificate does not permit force or detention or detention under the Mental Health (Scotland) Act or action inconsistent with a court or tribunal decision.
- The Act does not cover advance directives or withholding or withdrawing of treatment.
- Under Scots law, euthanasia is a criminal act but the law does not "impose a duty to provide futile treatment where the burden to the patient outweighs the clinical benefit".
- Emergency treatment is not included in the Act and research may occur only if stringent guidelines are followed.

Application to palliative care

Palliative care is perhaps unique as a specialty in terms of the attention to details of assessment, symptom control and communication with patients and relatives. Our intuitive assessment of our patients' capacity to make decisions about medical treatment is now required as explicit practice.

A clear plan is therefore required with regard to the application of the Act.

- If the patient is deemed incapable, after assessment, a certificate of incapacity should be issued and a treatment plan completed after a multi-disciplinary discussion and wide consultation with relatives and proxy. Please refer to the leaflet on Adults with Incapacity in the resource wallet for further information and sample forms.
- The treatment plan is likely to include fundamental healthcare procedures and palliative treatment for the relevant condition. Exceptions can be included after discussion e.g. drugs to which the patient has an allergy, insertion of a catheter or use of antibiotics. Discussion regarding resuscitation status may be facilitated.
- Patients likely to have "incapacity " are those with dementia, learning difficulties, Korsakoff's psychosis, cerebral metastases, acute confusional states related to drugs or biochemical upset or those with advanced neurological conditions where communication even by mechanical means is no longer feasible.

- If treatment reverses the incapacity the Certificate of Incapacity should be revoked and the wishes of the patient regarding future interventions ascertained. If further treatment is declined or regret expressed regarding previous intervention, this should be taken as advance refusal of treatment and be respected.
- No certificate need be issued for those patients who have had capacity but who become unconscious during their few days of life. This will prevent unnecessary distress to relatives who would find it difficult to reconcile a peaceful expected death with incapacity.
- Patients requiring palliative care seldom remain static. In view of the dynamic nature of their diseases, regular review of their status regarding capacity should take place, preferably with multi-disciplinary discussion.
- The status of a patient with regard to capacity should be conveyed to the hospital or hospice on admission and to the PHCT on discharge.

Copies of the forms can be obtained via the order form with the leaflet in the useful resources wallet or further information can be found at

www.scotland.gov.uk/Topics/Justice/Civil/16360/4927 or
www.opsi.gov.uk/legislation/scotland/acts2000/20000004.htm

Bibliography

- General Medical Council** (1999) *Seeking Patients' consent: The Ethical Considerations*; GMC London
- Scottish Office** (2002) *Adults with Incapacity (Scotland) Act 2000*, HMSO Edinburgh

[Contents page](#)

8.2 – Blood tests in palliative care

Blood tests should not be taken routinely in palliative care. However, they may help to confirm or exclude treatable causes of decline and allow a management plan to be instituted. They may also help with prognostication.

Decisions regarding the active treatment/non-treatment of various metabolic or haematological abnormalities in patients with advanced cancer may be difficult. Management protocols should be tailored to reflect individual patient needs, circumstances and wishes and the benefits of aggressive treatment should be weighed against toxicity or inconvenience for the patient. A list of common symptoms, possible causes and useful blood tests are noted below. The list is by no means exhaustive and individual assessment is required to determine the appropriateness of any investigation or treatment.

Symptoms	Possible underlying cause(s)	Suggested bloods
Breathlessness	Chest Infection Anaemia	Full Blood Count (FBC)
Fatigue	Anaemia Liver Metastases	FBC, Magnesium (Mg) Liver Function Tests (LFTs) NB – Normal LFTs do not always exclude Metastases
Confusion	Dehydration Hyponatraemia/SIADH Hypercalcaemia Opiate Toxicity, Uraemia, acute/chronic renal failure Infection/Neutropenic Sepsis Liver Failure, Liver metastases Diabetes Mellitus (may be steroid-induced)	Urea & Electrolytes (U&Es) specifically Sodium, Urea & Creatinine Corrected Calcium, U&Es U&Es, specifically Urea & Creatinine FBC specifically WBC, Neutrophils & Platelets, ESR LFTs including Bilirubin Glucose
Jaundice	Obstructed common bile duct Liver metastases	LFTs including Bilirubin
Nausea & vomiting	Hypercalcaemia Dehydration, Hyponatraemia	Corrected Calcium U&Es Particularly Sodium
Oedema/ascites	Hypoalbuminaemia, Liver disease	LFTs particularly albumin
Bleeding tendency	Abnormal clotting secondary to liver disease Myelosuppression	INR PTT Coagulation Screen
Unexplained decline in condition	Many causes	FBC U&Es LFTs Corrected Calcium

[Contents page](#)

8.3 – Cancer BACUP

Cancer BACUP is a national charity providing a helpline for cancer patients, their families and friends. Their specialist cancer nurses can give information on any type of cancer or treatment. They can provide emotional support, practical advice, and details of local support groups and other services for people with cancer.

They also provide 9 local walk-in centres across the country and the UK's most comprehensive cancer information website at www.cancerbacup.org.uk. They produce 68 patient-friendly booklets and over 260 factsheets that are free to patients.

A sample of the leaflets available can be found in the resource wallet for this section of the manual and copies can be ordered through the cancer bacup website www.cancerbacup.org.uk.

[Contents page](#)

8.4 – Complementary therapies in palliative care

Complementary therapies are used alongside orthodox treatments with the aim of providing psychological and emotional support through relief of symptoms.

Alternative therapies purport to offer a distinct alternative to orthodox medical treatments.

What are complementary therapies?

Complementary therapies encompass a diverse range of interventions including physical, psychological and pharmacological therapies. Therapies may be considered as self-care (e.g. medication), as techniques (e.g. massage) or as interventions with a wide range of clinical applications (e.g. homeopathy). The most widely used are touch therapies (aromatherapy, reflexology and massage) and psychological interventions (relaxation, meditation and visualisation).

Why do patients use complementary therapies?

Patients use complementary therapies because they feel the remedies are non-toxic and holistic, allow them more participation in their treatment and involve supportive relationships with practitioners. They also see complementary therapy as a means of improving their quality of life and controlling symptoms of their disease or side effects from the orthodox treatments they are receiving.

Reasons for referral

- For relaxation
- To improve the quality of life through comfort, well being, support
- Tension, stress
- Anxiety, fear, panic attacks
- Low mood, depression
- Pain
- Musco-skeletal problems
- Breathlessness
- Nausea & vomiting
- Constipation
- Hot flushes
- Sleeplessness
- Fatigue
- Body image changes

Regulation & training

For any patients planning to undertake any form of complementary therapy it is vital that the therapist they are being treated by are trained to the standard required for registration with professional complementary therapy bodies and adhere to precautions for the safe practice of the therapy they practice. Patients should seek medical or nursing advice prior to undertaking any complementary therapy. Presently, there are limited complementary therapies offered by NHS Forth Valley.

Patients seeking to utilise any form of complementary therapy should ensure that the therapist :

- is registered with a relevant professional association
- has indemnity insurance to practice the chosen therapy
- has knowledge of the National Guidelines for the use of complementary therapies in supportive and palliative care
- advises the number of treatments required and the total cost of the course of treatments before beginning the course.

A list of appropriate professional associations and relevant reference books is included at the rear of this section. This will help the patient identify complementary therapists who are licensed to practice within Forth Valley and the surrounding locality.

Types of complementary therapies used in palliative care

Acupuncture

Acupuncture is a form of traditional Chinese medicine that is based upon Taoist philosophy stemming from the principle that health is a balance between yin and yang energy. The energies form an interdependent and continuous rhythmic movement that attempts to achieve balance and harmony. In palliative care, acupuncture is used alongside conventional medical treatment and has an increasing supportive role for pain and symptom management.

Contra-indications & precautions

- Avoid any area of actual or potential spinal instability due to cancer.
- Avoid inserting needles directly over the tumour itself or nodes or related sites such as ascites.
- Avoid indwelling needles on patients with neutropenia.
- Do not use acupuncture on patients with severely disordered clotting function.
- Avoid any lymphoedematous limbs.
- Avoid needling into prosthesis.
- Only use sterile, single use disposable needles.
- Avoid the arm on the side of patients who have had mastectomy.
- Be aware if patients are undergoing chemotherapy, radiotherapy or hormonal treatments.
- Be aware patients may be fatigued and are living with life limiting diseases.

Aromatherapy

Aromatherapy can be defined as the art and science of utilising naturally extracted aromatic essence from plants to balance, harmonise and promote the health of body, mind, and spirit. The essential oils are added to the bath or massaged into the skin, inhaled directly or diffused to scent the whole room. The therapeutic effect of aromatherapy results from a combination of the physiological effects of the oils and the relaxation of massage.

Contra-indications & precautions

- Deep massage to any part of the body is not advisable for those with active cancer, in order to avoid trauma and activation of the immune system.
- Patients with low platelet count, petechiae, or on anti-coagulation medication.
- Patients with pyrexia/infection.
- Avoid limbs or foot with suspected or recently diagnosed deep vein thrombosis.
- Avoid lymphoedematous limbs.
- Avoid massaging over ascites.
- There are differences in opinions on whether it is safe to use certain essential oils on patients who have oestrogen sensitive cancers and patients with reduced kidney function and hypertension.

Homeopathy

Homeopathy is a medical therapy using natural substances to stimulate the body's natural defences that are thrown out of balance when stressed. The word homeopathy comes from the Greek and means similar suffering. Practitioners of homeopathy view both mental and physical symptoms as attempts by the body to defend itself. It is the treatment of illness by using remedies prescribed according to the principle that "like cures like"

Contra-indications & precautions

- The reviews of the safety of homeopathy conclude that the main risks are indirect rather than direct, that is they relate to practitioners, not the medicines.

Hypnosis and hypnotherapy

Hypnosis is a valuable tool which involves interaction between body and mind, using the mind to affect therapeutic change, and can be instrumental in encouraging coping strategies, helping people to connect with their inner being and activate innate healing forces.

Contra-indications & precautions

- Psychiatric status-where any psychiatric condition exists which may lead to unpredictable behaviour and responses, hypnosis is contra-indicated.
- Emotional status-depression is often present in patients with life limiting disease.
- Be aware of inexperienced use.

Massage

Massage is the generic term for a variety of techniques that involve touching, pressing, kneading, and manipulation. Massage therapy in palliative care refers to therapeutic massage, in which touch is considered to be an independent channel of communication.

Evidence suggests that massage therapy has the potential to produce physiological and psychological benefits for patients with palliative care needs. There is concern that massage may spread cancer and this causes some confusion. Gentle massage can be given to areas of the body not affected by cancer.

Contra-indications & precautions

- As for aromatherapy

Mind/body techniques

Mind/Body treatment approaches concern the mind's ability to elicit responses from the body and its ability to be trained to reduce pain and disease. This can include superficial and deep states of relaxation.

Mind/body techniques largely train the mind to focus without distraction in order to make conscious suggestions to the subconscious and to decrease anxiety. Relaxation techniques include breathing exercises, progressive muscle relaxation, and meditation and guided imagery.

Imagery is defined as the thought process that invokes all the senses-vision, hearing, smell, taste, movement and touch. In combination with other relaxation techniques, guided imagery can influence a wide range of physiological functions, including heart rate, blood pressure, breathing patterns, immunological changes, and the release of various hormones and neurotransmitters.

Scientific data show that medication and related relaxation techniques are highly beneficial to health. Meditation decreases heart rate, respiratory rate, oxygen consumptions, and blood pressure. Patients who engage in regular meditative practices report an overall sense of well being and improved feelings of calm and peace.

Contra-indications & precautions

There are no specific contra-indications but there are some precautions:

- Give treatment only in response to a request from patient or carer.
- Patient may misunderstand the word healing to mean cure.
- Ensure sessions are not overlong.

Music therapy

Music therapy is particularly effective in the palliative care setting where music therapy produces emotional and physiological benefits and reduces anxiety, stress, depression and pain. Music therapy is often used in combination with other mind/body modalities to enhance health and balance the body. Music therapy encourages patient participation and helps patients create original music where appropriate.

Contra-indications & precautions - nil

Reflexology

Reflexology involves a method of treatment using a non-invasive ancient art of foot or hand massage. More commonly, the feet are the areas mostly treated. In the feet there are reflex areas corresponding to all parts of the body and these areas are arranged in such a way as to form a map of the body in the feet. By having the whole body represented in the feet, the method offers a means of treating the whole body. It improves circulation, cleanses the body of toxins and impurities, balances the whole system and revitalises energy.

Contra-indications & precautions

- Avoid a limb or foot with suspected deep vein thrombosis and avoid varicose veins.
- Only treat lymphoedematous limbs after consultation with lymphoedema nurse specialist.
- Adjust pressure for patients with low platelet count.
- Be aware that peripheral neuropathy may be a symptom of disease such as multiple sclerosis.
- Avoid areas corresponding to colonic stimulation if there are any symptoms or risk of intestinal obstruction.
- Palpate gently and sensitively over the reflexes relating to tumour sites.

Reiki

Reiki is an oriental healing art that promotes healing on all levels, physical, mental and spiritual. Reiki is the Japanese word that means universal life force energy, and is in all living things. Reiki is a way of channelling the life force energy into the body through the therapist's hands.

This balances and harmonises the mind and emotions and accelerates the healing process in the body. As the energy comes into balance, stress and tensions are released and there is a deep sense of relaxation. It is not a massage as the hands remain still and Reiki can be given through clothes.

Contra-indications & precautions

- As for mind/body techniques

Spiritual healing

Spiritual healing, often referred to as healing, is the process that promotes better health, through the channelling of healing energies through the healer to the patient. Healers view human life as four-dimensional comprising body, emotions, mind and spirit. Healers draw upon the finer energies of the universe, and they may or may not follow a particular religion.

Contra-indications & precautions

- As for Reiki

Therapeutic touch

Therapeutic touch is not regarded as involving channelling of energy or an energy exchange but a mutual process, a healing meditation. During a treatment, the practitioner's hands are moved in a rhythmic, downward movement, a short distance away from the body of the client, starting at the head and working towards the feet.

Contra-indications & precautions

- As for Reiki

Forth valley resource

- Complementary Therapy Co-ordinator, Strathcarron Hospice, 01324 826222

Other useful resources

Acupuncture Association of Chartered Physiotherapists
Mere Complementary Practice, Castle Street, Mere, Wiltshire, BA12 6JE Tel: 01747 861151,
Fax: 01747 861717 Email: sec@aacp.uk.com Website: www.aacp.uk.com

Aromatherapy Regulatory Working Party
Geoffrey Lawler, Independent Chair, The Public Affairs co, 21 Otley Road, Leeds, LS6 3AA

Association of Chartered Physiotherapists in Reflex Therapy
Alison Stain, 3 Whichcote Avenue, Meriden, Coventry, West Midlands, CV7 7LR

British Acupuncture Council
63 Jeddo Road, London, W12 9HQ
Tel: 020 8735 0400 Email: info@acupuncture.org.uk, Website: www.acupuncture.org.uk

British Association of Therapeutic Touch
C/o David Lewis, 3 Union Street, Carmathen, Carms, SE31 3DE
Tel: 01267 232715 Email: dlewis@clara.co.uk, Website: www.touch.org.uk

Other useful resources continued

British medical Acupuncture Society
12 Marbury House, Higher Whitley, Warrington, Cheshire, WA4 4QW, Tel: 01925 730727,
Fax: 01925 730492 Website: www.medical-acupuncture.co.uk

Bristol Homeopathic Hospital
Dr E. A. Thompson, Cotham Hill, Bristol BS6 6JU
Tel: 0117 9731231, Fax: 0117 9238759 Email: Elizabeth.thompson@ubht.swest.nhs.uk

General Council for Massage Therapy
46 Millmead Way, Hertford SG14 3YH
Tel: 01992 537637 Email: admin@gcmt-uk.org, Website: www.gcmt-uk.org

Help the Hospices
Hospice House, 34-44 Britannia Street, London WC1X 9JG Tel: 02075208200, Fax: 020
72781021 Email: info@helpthehospices.org.uk, Website: www.helpthehospices.org.uk

Macmillan Cancer Relief
89 Albert Embankment, London, SE1 7UQ Tel: 020 78407840, Fax: 020 78407841
Email: cancerline@macmillan.org.uk, Website: www.macmillan.org.uk

Marie Curie Cancer Care Scotland
29 Albany Street, Edinburgh EH1 3QN Tel: 0131 456 3700
Email: info@mariecurie.org.uk, Website: www.mariecurie.org.uk

National Association of Complementary Therapist in Hospice and Palliative Care
Chair, Marianne Tavares, c/o 329 Harrogate Road, Leeds, LS17 6QD
Tel: 0113 3689466

Reflexology Forum
PO Box 2367, South Croydon, Surrey, CR2 7ZE Email: reflexologyforum@aol.com

Royal College of Nursing, Complementary Therapies Forum
Chair, Julia Fearon, 20 Cavendish Square, London, W1G 0RN Tel: 0207 6473756

UK Confederation of Hypnotherapy Organisations
Suite 401, 302 Regent Street, London W1R 6HTel/Fax: 0800 9520560
Email: UKCHO@hypnother.apy.demon.co.uk , Website: www.ukcho.org.uk

UK Healers
Chris Denton, Secretary, PO Box 4137, London W1A 5FE
Tel: 01943 468276 Email: healing@cpdenton.freeserve.co.uk, Website: www.ukhealers.info

UK Reiki Federation
PO Box 1785, Andover, SP11 0WB
Tel: 01264 773774 Email: enquiry@reikifed.co.uk, Website: www.reikifed.co.uk

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[Contents page](#)

8.5 – Driving and opioids

Doctors and nurse prescribers have a duty to inform patients of the side effects of prescribed medications. The General Medical Council states that doctors should convey information in an understandable way, permitting a partnership between doctors and patients in the healthcare process.

Opioid analgesics can all cause drowsiness, which may impair driving ability. Therefore when strong opioids are prescribed, it is important that patients are given sufficient information to decide whether or not it is safe to drive.

Neither the BNF label nor the manufacturers' patient information sheets contain information on when driving is safe with opioids. The DVLA website provides no specific advice on driving whilst taking opioids prescribed as analgesics. In a review of 48 studies, Fishbain et al concluded "the majority of the reviewed studies indicated that opioids appear not to impair driving-related skills in opioid-dependent patients."

Pease and Taylor, with assistance from the Senior Medical Advisor to the DVLA, developed an advice sheet for patients. The content of their advice sheet is summarised below and a patient information sheet can be found in the resource wallet for this section. This can be copied and given to patients and carers.

How painkillers affect people

Opiates affect each person in a different way. They can cause drowsiness and reactions can be slower than usual. This may be worsened if alcohol or sedatives are taken concomitantly.

Commonly prescribed opiates include: Oramorph, MST, Oxynorm, Fentanyl, Oxycontin.

Advice for patients on driving whilst taking strong painkillers :

- Patients should not drive for five days after starting or changing the dose of opiate. Sometimes longer is needed.
- Patients must not drive if they feel sleepy.
- Patients must not drive after drinking alcohol or taking strong drugs which have not been prescribed or recommended e.g., cannabis.
- Patients must not drive if they start taking other drugs which cause sleepiness, either prescribed or bought from the chemist e.g., hay fever medicine.
- Patients must not drive on days when they have had to take extra (breakthrough or rescue) doses of a strong painkiller e.g., Oramorph.

Restarting driving

If after 5 days, patients are not sleepy, they may re-start driving. It is recommended that the trip is :

- short
- on familiar roads
- when the traffic is not too busy
- accompanied by an experienced driver

Drivers Vehicle Licensing Agency (DVLA)

Patients do not need to inform the DVLA that they are starting a strong painkiller.

However, there may be other information about the illness that the DVLA needs to know.

Telephone number for licensing enquiries – 0870 600 0301 (Please have the driving licence number available)

Website – www.dvla.gov.uk

Address – DVLA, Longview Road, Morrision, Swansea, SA99 8QD

Car insurance

- Patients may need to inform their motor insurance company about their state of health and what medication they are taking.
- Each insurance company is different.
- It is best for patients to discuss their circumstances with their insurance company to ensure that they are covered.

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[Contents page](#)

8.6 - Infection

Patients with advanced malignancy are susceptible to infections for various reasons including :

- bacterial colonisation
- impairment of normal anatomical barriers
- impairment of humoral or cellular immunity
- neutropenia or qualitative defects in neutrophil function
- concomitant drug therapy

Common sites of infection are :

- respiratory tract
- gastrointestinal tract
- urinary tract
- skin
- CNS

Clinical signs and symptoms of infection may be atypical in patients with advanced cancer and concomitant drugs may mask pain and pyrexia. Non specific signs may be the only evidence of infection e.g. confusion, falls, anorexia. In addition, fever may not be related to infection but due to neoplasia and the white cell count may be elevated as part of the neoplastic response or steroid therapy.

Investigations

The diagnostic work-up for palliative care patients must be tailored to the individual. In general laboratory and radiological investigations should only be performed if the result will influence treatment and the patient should not be subjected to unnecessary or painful examinations.

Treatment

There are ethical considerations related to treating infection. Overwhelming infection may be a painless and rapid mode of death and pneumonia can still be the "old man's friend". In end of life situations where oral antibiotics cannot be taken and IV access is denied, symptoms can be palliated in other ways e.g. rectal Paracetamol / cooling for fever, Hyoscine Hydrobromide for noisy secretions, aromatherapy oils and charcoal dressings to mask malodorous lesions. However, distressing infections require appropriate investigation and treatment.

Three issues merit particular mention :

Neutropenia – FV guidelines should be followed

Clostridium difficile infection – FV guidelines should be adhered to, subject to bacteriological advice.

MRSA infection

Guidance is changing and no single document covers MRSA in hospital, hospice, nursing homes, community hospitals and homes.

The Scottish Executive is planning to produce a guidance template. Following risk assessment, an individual area may tailor its own protocol to local requirements. Standard precautions should be taken in all situations and the documented procedures should be followed. Patient information leaflets should be provided.

Identification of affected individuals should be unobtrusive e.g. sunflower sticker.

The main potential problems are :

- cross infection
- psychological problems due to isolation of an individual
- extending infection in an individual
- environmental contamination.

Staff protection

- In all settings Infection Control procedures should be observed as per FV guidelines.
- Appropriate equipment – gloves, aprons and disposal bags should be available.
- If with an agitated patient there is a risk to staff of blood-borne infection from the needle of a CSCI , then a plastic cannula should be substituted.

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[Contents page](#)

8.7 - Nutrition in palliative care

The principle objectives of nutrition in palliative care are to maximise food enjoyment and to minimise food related discomfort. It is also important to prevent or treat any avoidable and unnecessary malnutrition since this can affect both physical and psychological well-being. It is however, equally important to ensure that nutritional support measures are not so invasive or unacceptable to the patient that they impair quality of life.

Terminal illness can affect nutritional status in a number of ways :

- The psychological effect of the diagnosis and progressive illness, anxiety and /or depression can markedly impair food intake.
- Worsening physical symptoms of the disease, especially if they are related to swallowing or gastrointestinal problems e.g. diarrhoea, abdominal discomfort.
- Medications and treatments may cause side effects such as nausea, vomiting, constipation and a consequent reduction in food/fluid intake.
- Nutritional requirements may be increased by the physiological effects of the illness e.g. pyrexia, increasing tumour size or by nutrient losses e.g. through malabsorption or diarrhoea.
- Poor appetite due to the effects of pain, discomfort, drug or treatment related side-effects.

Patients should be encouraged to maintain an interest in food and regard good nutrition as a positive step to help maintain strength and wellbeing. If nutritional requirements are not being met, strategies to improve this should be adopted which are acceptable to the patient.

- Eating little and often to spread the volume of food consumed over the day
- Choosing foods of greater nutritional value
- Food fortification measures
- If required, oral nutritional supplements may be used. (Not used as first line treatment for nutritional support.)

Good hydration is important but over use of high volume, low energy fluids e.g. water, thin soups, jelly, black tea and coffee, will result in a feeling of fullness and may impair appetite and minimize nutrient intake from foods. Where food intake is poor, fluids should be encouraged after foods and some nutrient rich fluids should be offered e.g. milk, fruit juices, glucose drinks, thick soups.

The role of the dietician is to identify and alleviate where possible any nutritional problems which may be impairing well being and quality of life. Evidence suggests that dietetic interventions; dietary modification, nutritional supplementation and artificial nutritional support are vital in the management of people with palliative care needs.

Recognising nutritional risk.

It is considered best practice to screen patients on a regular basis to identify their nutritional risk. Early identification and treatment of the nutritional problems affecting patients with palliative care needs may help the patient either gain weight, maintain weight or minimise weight loss and can have a positive impact on quality of life.

Regular nutrition screening using a validated screening tool (e.g. Malnutrition Universal Screening Tool - MUST) is recommended for patients who are in the early stages of palliative care.

Nutritional screening is not recommended when the patient's condition deteriorates and there is a general increase in other symptoms. The goal of nutrition therapy in late palliative care is comfort, symptom relief and enjoyment of food.

How to tackle problems affecting food intake

Poor appetite

- Eat small, frequent, attractively presented foods
- Eat favourite foods or those which are fancied
- Take fluids after, rather than with meals to maximise food intake
- Ensure that the posture helps rather than hinders eating
- Eat in surroundings which are as pleasant as possible
- Eat where there is plenty fresh air and avoid strong cooking smells
- Eat in the company of others to increase the social aspect of meals
- Try a small amount of alcohol before meals if permitted by the doctor

Oral problems

Dry mouth

- Soft, moist or liquidised foods may be easier to take
- Take plenty of fluids by taking frequent sips of fluid, and sucking ice cubes, ice lollies
- Try sharp tasting foods e.g. lemon flavours, boiled sweets, fruit pastilles or chewing gum to stimulate saliva production.
- Use a water spray to freshen the mouth or artificial saliva sprays, pastilles, gels and lip balms.

Sore mouth

- Avoid any foods which may irritate the mouth e.g. very hot or very cold foods, salty, spicy or acidic foods e.g. pickles, curries, vinegar, lemon, orange.
- Avoid coarse or dry foods e.g. crisps, muesli, crispbreads.
- Try soft, moist foods.
- Cold foods and drinks may be soothing.
- Keep the mouth fresh and clean.
- Take pain relief as recommended by medical or nursing staff.

Taste changes

- Problem foods should be substituted with nutritionally similar alternatives e.g. chicken or fish instead of red meat.
- Soft drinks, milk, peppermint or fruit teas instead of tea or coffee.
- Boiled sweets or pastilles instead of chocolate.
- Add herbs or spices to improve or enhance the taste e.g. rosemary, garlic, basil, chilli
- Concentrate on foods and drinks that are enjoyed and ignore those that have lost their appeal
- Experiment with different flavours, textures and temperatures of foods
- Tart/sharp foods and drinks may refresh the mouth

Dysphagia

- Dysphagia is the term to describe a difficulty with swallowing or inability to swallow. In this situation the consistency of the diet may need altered, but it is still essential to meet nutritional requirements. The management of this problem should be by a combined speech and language therapy/ dietetic approach.

Nausea and vomiting

Feeling sick and being sick is now less of a problem than it used to be due to the use of anti-sickness medications. Some helpful hints are listed below:

- Drink plenty of fluids
- Avoid fried or fatty foods, very spicy foods or very sweet foods.
- Try to eat little and often and take your time when eating
- Eat foods at room temperature as the smell from hot foods may make nausea worse
- Do not try to eat your favourite foods when nauseated as you may come to associate this with nausea
- Keep your mouth clean and brush your teeth well
- Taking ginger can be helpful – e.g. ginger ale, stem ginger
- Make sure the house is well ventilated – open windows to let fresh air in

Food Fortification

Eating little and often is the best way to increase the calorie and protein content of the diet. Aim for 3 small meals and 3 small snacks per day. It is also useful to use higher calorie food and drink options wherever possible e.g. full fat milk instead of semi skimmed milk, full sugar drinks instead of diet drinks. Some simple ways to increase the calorie and protein content of foods are listed below.

- Add margarine or butter to mashed potatoes and vegetables
- Spread margarine or butter thickly on bread/rolls/biscuits/scones/pancakes etc
- Do the same with jams/marmalade/cheese spread/ meat spreads
- Add grated cheese to vegetables/sauces/ soups/egg dishes/mashed potato
- Add cream to porridge/soups/puddings and fruit
- Add chopped meat into soups
- Try frying some foods as this will increase the calorie content of foods
- Include nourishing drinks every day e.g. milky drinks (cocoa, malted milk drinks, milk shakes, milky coffee), fruit juices or sugar/glucose containing soft drinks.

Nutritional supplements

Many types of nutritional supplements are available either over the counter or on prescription. These may be in the form of drinks (milk based or juice based), desserts or powders. These products should not be used as a first line method of dealing with a poor intake. Supplements should only be considered when dietary measures, as described above, have been or clearly will be insufficient to meet the patient's needs. Dieticians are best placed to advise on the suitability of nutritional supplements for individuals.

Compliance with nutritional supplements will depend on factors such as appetite and taste. Patients should be allowed to sample different products to ensure the product is acceptable to them before a product is prescribed. Once started on supplements patients should be monitored to ensure their needs are continuing to be met and to deal with any problems of taste fatigue or poor compliance with the supplement.

Tube feeding

Tube feeding may be considered in a small number of patients who are unable to meet their nutritional requirements by eating and drinking. The patient's circumstances will determine how appropriate this is. This must be done in consultation with the patient's wishes and only if other methods of nutritional support have proved to be insufficient. A dietician should be involved to ensure the appropriate feeding and equipment is provided.

Alternative diets

There are a number of alternative diets available in media sources. Many of these diets are not based on scientific evidence. Most are very restrictive and some may be harmful. It is advisable to contact a dietician for advice before embarking on any alternative diet.

Access to a dietician or speech and language therapist.

Dieticians and Speech & Language Therapists are based within both the Acute and Primary Care Operating Divisions of Forth Valley Health Board. There is no dedicated service to palliative care and referrals / enquires are prioritised according to perceived need.

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[Contents page](#)

8.8 - Paediatric palliative care

Paediatric palliative care in Forth Valley is offered in both acute and community settings and is currently centralised from Stirling Royal Infirmary.

Children who require palliative care often have rare chromosomal or metabolic disorders or severe congenital disorders as well as children who develop malignant disease.

Paediatric palliative care needs are met within the general paediatric service, which includes Paediatric Consultants, Paediatric Departments at Stirling Royal Infirmary, Community Children's Nursing and the Paediatric Complex Care Service. The children's hospice (Rachel house) also provides invaluable support and care to families in Forth Valley. Primary care services liaise with paediatric services in Forth Valley and also with Rachel house. There is often involvement of tertiary paediatric services (Schiehallion unit Glasgow, Edinburgh Children's cancer services).

The Community Children's Nursing service is provided Monday to Friday, 9am – 5pm, and out with these times home nursing support is provided by the district nursing service where appropriate.

The aims of paediatric palliative care are to:

- provide family-centred care in both community and hospital settings for children with life-limiting/life-threatening illness
- offer support and advice for the child, family and staff
- provide education for the child, parents/carers, family, schools and professionals in the community, hospital and voluntary sectors
- co-ordinate care between home, clinic, hospital and respite/residential services, liaising with fellow professionals as appropriate
- provide specific advice on pain and symptom control in conjunction with consultants and specialist nurses at tertiary centres and children's hospices.
- assist with care of the child at home in the terminal stages of their illness in collaboration with the family and primary care team
- provide bereavement support for family members and fellow professionals
- provide an evidence-based resource centre for paediatric palliative care
- make referrals and work jointly with social work colleagues to access equipment and arrange joint packages of care.

Symptom management

The majority of drugs listed in the adult section are applicable for use in paediatrics. However, paediatric doses are much smaller than those of adults and are calculated according to the weight of each individual child.

Specialist advice from the paediatric pharmacist at Stirling Royal Infirmary/tertiary centres/GP at Rachel House should always be sought before prescribing medication for children.

N.B. Metoclopramide is not recommended for use in paediatrics

It is also important to remember that children are less tolerant of injections than adults. Always consider alternative methods of drug administration first (for example, melts used in children's ward for post-operative nausea).

In assessing paediatric pain, there are a variety of specialist tools available depending on the age and cognitive ability of the child. For further advice on pain assessment tools contact the Community Children's Nurses or Ward 17 at Stirling Royal Infirmary

Working with children and young people facing loss

Most of the information in this section applies to children/young people who are dying and to children who are facing bereavement.

Fortunately, death in childhood is uncommon, but for those families who have to confront the problems of caring for a terminally ill child, the burden is great. For the health care workers too, dealing with the particular problems of the dying child and their family, as well as acknowledging and coming to terms with their own sadness, can provide considerable stress and anxiety (Goldman 1994).

An important part of a child's life occurs during the years they spend at school. To provide comprehensive, child and family-centred care, normality must be maintained as far as possible. This will include continuing to facilitate the child's education, in addition to providing support and advice for colleagues in education and peers in school.

The importance of clear, concise communication cannot be overestimated. Recognise and respect the existing systems of communication within a family.

Children will process information in different ways according to their age and conceptual cognitive ability. The following statements offer some broad principles to consider :

- Children do not need protecting from their feelings, but support in them.
- Children will not grieve in the same way as adults.
- Children often express themselves through play, drawing or with friends.
- Children require clear, simple, truthful and often repeated, but brief, explanations about what has happened, and what will happen to them.
- Children will use their imaginations to 'make up' stories about facts/situations which they do not understand.
- Children read body language, overhear conversations and notice subtle changes in routine. They may then misinterpret them if concise explanations are not given.

Children's reactions and understanding are also different:

- They have a shorter concentration span and do not tolerate intense emotions for long.
- They may switch abruptly from crying to playing (which can be very distressing for the parents).
- They can appear casual and 'not caring' in their attempt to deal with the situation.
- Feelings may be manifested through behaviour e.g. clinging, bed-wetting, temper tantrums, sleep disturbances.

Concepts of death and dying

Children's concepts of death and dying are specifically related to their age and stage of cognitive development in addition to previous life experience. The following section will deal with specific issues surrounding concepts of death and communication in 3 separate age-related sections:

- the pre-school age child (under five years)
- the primary school child (five-12 years)
- teenagers and young adults (13 years and above).

Working with children under five

As with children of all ages, the child under five still requires open and honest communication about their illness or that of a sibling or parent. Their understanding of death parallels their cognitive and psychosocial development.

Concepts of death

Birth to 12 months

- Babies have no intellectual capacity to comprehend death.
- They view any separation as permanent.

13 months to three years

- The infant is able to recognise when something is dead but cannot comprehend the finality of death.

Three to five years

- The child is unable to separate death from fantasy and will require sensitive reinforcement of the truth.
- They see death as a temporary state and reversible.
- They may also think they have caused this situation and require reassurance that they are not responsible.

Communication

Birth to 12 months

- Children in this age group require physical reassurance that someone is caring for them in the form of cuddles and affection.
- They need to maintain normality in their environment and routine as much as possible.
- If it is the parent who has died the presence of a consistent caregiver for the child is of paramount importance for their sense of security.

13 months to three years

- Children need to be involved in the situation, and be given open and honest communication.
- The child who is dying in this age group will not question 'why' but may vocalise pain or distress at the situation.

Three to five years

- Children in this age group need direct answers. It is better to use the term 'death' rather than 'special sleep' or other similar phrases.
- Parents of these children require support in understanding the child's behavioural reactions which again will be related to their age and stage of conceptual development.

Working with the school age child of five to 12 years

It is easy to assume that children do not experience the same depths of feelings as adults when faced with grief and loss. Nevertheless, though their ways of expressing themselves and their interpretations of what is happening may be different, the intensity and impact of their experiences should not be underestimated. Although their understanding of cause and effect and sense of time are different from adults, the pain, guilt and anger through loss and grief may be very great.

School age children wish to discuss death and tend to have no "unspoken barriers". The best explanations are those that are "simple", direct and draw as much as possible from the child's own experience.

Usual reactions include:

- Anxiety and fear
 - It may happen to another "loved one"
 - It may happen to them
- Younger school age children may become clinging and demanding
- Sleep difficulties and nightmares
- Anger and acting out
- Guilt, self-reproach and shame
- School problems

A child of school age follows the concept of concrete thinking. Children can perform functional tasks, and logical reasoning replaces intuitive thought as long as reasoning can be applied to specific or concrete examples such as appropriate pictures and stories. The school age child has the understanding that once people die they cannot come back to life again. Children are pre-occupied with topics related to death and play games about dying, but then leap to life the next minute. Pretend and real death needs to be made clear, so that the child realises that 'real' death means never living again.

The school age child will understand there is always a physical cause of death, but the younger child may have magical ideas about what causes death. It is vital that the child is told the truth in order that fact and fictional ideas are clarified. Explanations about death to this group of children should include the cessation of bodily functions such as: the body stops breathing; growing, seeing, hearing, thinking, feeling, and the heart stops beating.

It is vital that the school age child is included in all conversations, and that the information is provided in an age appropriate way. They normally require support from a familiar family member for comfort and reassurance, but questions should also be directed to them to enable them to feel valued and included.

When communicating with the school age child, feelings should be shared. They want and need to receive information and participate in the grief process. Often parents wish to protect their children from reality seeing it as a time of innocence, but this can lead to misconceptions, insecurity and loss of trust later on in life.

“A child can live through anything so long as he or she is told the truth and is allowed to share with loved ones the natural feelings people have when they are suffering.” (Eda le Shan)

Working with teenagers and young adults of 13 years and older

This group of young people have special needs, which are not only unique to their age group but also broader in scope and more intense than at any other time in life.

Teenagers and young people think very similarly to adults and have an adult understanding of death, but their behaviour and the way they deal with death varies. At any given time they may exhibit both dependent childlike behaviour and independent adult behaviour and thinking. Therefore, it is vital that the young person is spoken with and that questions are directed to them and not their parents or carers.

This enables them to:

- make their own decisions
- keep control
- maintain independence

The teenager or young person may appear to be in denial, as they have a strong sense of invincibility and may minimise physical symptoms. Professionals have to deal with a young person on the edge of autonomy, and when teenagers face their own death or that of people close to them, events may spiral out of control and make them behave in the following ways:

- non-compliant
- aggressive
- non-communicative
- emotional

For teenagers and young adults in a relationship, the union will be tested by the strain of the palliative diagnosis and the patient may wonder whether the partner stays in the relationship out of guilt or sympathy. They are not yet mature enough to fully understand a complex, committed relationship so they may push the friend away. The friend may have as much, or even more impact on the teenager's or young adult's decision-making than the parents.

Treating the teenager with respect and ensuring they are involved in decision-making helps to foster a positive working relationship at a very important and emotional time in their life.

This group of people tend to rely on peer support to help them through difficult situations, therefore confidentiality and respect should be uppermost in discussions surrounding their care. It is also important to remember that consent must be obtained from the teenager or young person before any discussion or information is disclosed to, or shared with, parents or guardians.

Specialist Clinical Services

Local Healthcare professionals link with Specialist Nurses and Consultants as required.

General Information – Local/National Support Services

Hospital Chaplains, Stirling Royal Infirmary

Contact: 01786 434038 (part-time base) but hospital staff can contact at any time.

Children's Ward, Stirling Royal Infirmary Tel: 017896 434417

Community Children's Nurses Tel: 01786 434000 ext. 4328

Paediatric Complex Care Service Tel: 01786 434000 ext. 4615

Stirling Council Social Work Services Tel. 01786 471177

Falkirk Council Social Work Services Tel: 01324 506400

Clackmannan Council Social Work Services Tel: 01259 450000

Robin House Children's Hospice, Boturich, Balloch, Alexandria, West Dumbartonshire, G83 8LX Contact: 01389 722055

Rachel House Children's Hospice, Avenue Road, Kinross

Contact: 01577 865777 (fax: 01577 865888)

The Children's Hospices offer support, which ensures the best care for the child and family. They offer the family the opportunity to relax, have a break and spend quality time together. The hospices welcome any child/young person up to the age of 18 years who has a progressive or life-limiting/life-threatening disorder and their families.

Children with Cancer and Leukaemia Advice and Support for parents

Suite 5 Leith Walk Business Centre, Leith Walk, Edinburgh

Contact: 0131 467 7420/7241

Voluntary support group run by parents whose children have been affected by cancer. The group is tailored to meet the needs of both the parents and the affected child.

Paediatric Oncology Outreach Nurses (CLIC)

This team, based at Yorkhill in Glasgow, offers support and care to children with cancer/leukaemia. Contact: 0141 201 9314

Special Needs Information Point (SNIP)

Contact: 0131 536 0583, 0131 536 0360

Run by families of children with special needs. A comprehensive information service on resources for children with disability and rare conditions.

Children 1st, Polwarth Road, Edinburgh

Contact: 0131 313 0322

Provides counselling and support for families who have children of primary school age.

SANDS (Stillbirth and Neonatal Death Society)

Contact: 0131 447 2207

Offers help, counselling and support to families affected by the death of a newborn baby.

React (Rapid Effective Assistance for Children with a potentially Terminal illness)

107 Sandycombe Road, St Luke's House, Kew Gardens, Surrey

Contact: 020 8940 2575

Charity which offers financial assistance to families of children with a life-limiting illness.

Winstons' Wish Contact: 01452 394377

Charity providing support and residential breaks for children and families following a bereavement.

Child Death Helpline

Freephone 0800 282 986

National Association of Bereavement Services

Contact: 020 72471080

Telephone and counselling service providing information on similar affiliated groups.

Child Bereavement Trust

Contact: 01494 678088

Produces books and literature on death of a baby/child.

Compassionate Friends

Contact: 01179 539639

Library service and support and counselling for bereaved families and families who have a child with a terminal illness. Support and counselling is also available to staff.

Scottish Cot Death Trust

Contact: 0141 357 3946

Provides support for families following a cot death. Also funds research.

Hawthorne House

Contact: 0141 201 9257

Provides support for any parent whose child has died.

Family Fund Trust, Unit 4, Alpha Court, Monks Cross Drive, Huntington, York. Y032 9WN

Contact: 0845 130 4542

Can provide financial assistance with e.g. washing machines, microwaves, other equipment.

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[Contents page](#)

8.9 - Sexuality In palliative care

Sexuality and intimate relationships are an important aspect of life and this is no less true for patients in palliative care. Sexual activity can add to the quality of a patient's life and add a positive focus to it. It adds to the closeness that couples may need to feel at this difficult time. Most patients with terminal conditions will have experienced changes to their sexuality as a result of the disease or its treatment.

However, sexuality in palliative care is often a taboo subject; it is an area that staff, patients and families often find difficult to address. It is therefore important that the assessment of sexuality is incorporated into the holistic care given by the health and social care team

What is sexuality?

Sexuality is a broad concept. All health and social care staff should include issues related to sexuality as part of general and on-going assessment. These include :

- Body image
- Gender identity
- Acceptance of one's body appearance
- Ability to develop and maintain intimate relationships
- The need to touch and be touched
- The ability to communicate intimate feelings and thoughts
- The ability to engage in satisfying sexual activities with or without a partner (Wilmoth, 1998)

If problems are identified from initial discussions, detailed problem-focussed assessment should then be undertaken by specialist staff. At this level it is important to consider sexual functioning in terms of distinct phases rather than using global terms such as 'impotence' and 'frigidity'. This enables a practical problem solving approach to be used. The phases are commonly identified as :

- Desire or libido
- Excitement or arousal
- Orgasm
- Resolution (Gallo-Silver, 2000)

Cancer may impact on sexuality in a variety of ways (Hughes, 2000)

Consider the following areas during assessment.

Changes in body image due to :

- Weight loss/gain
- Skin problems
- Stoma/catheter
- Hair loss/gain
- Loss of a breast
- Loss of sexual organs

Drug effects, for example :

- Metoclopramide has been proven to cause loss of function even though it is used frequently.
- Zoladex is a hormone replacement used in prostate cancer which may cause loss of function. However, Casodex does not.
- Commonly used anti-depressants such as SSRIs may be associated with sexual dysfunction.

Incontinence :

- Tumour related
- Post treatment.

Fatigue

Depression

Pain

Breathlessness

Fear of symptom exacerbation by patient and/or partner

Relationship factors

Treatment effects :

- Surgery
- Chemotherapy
- Hormone therapy
- Immunotherapy

How you can help

There are many ways in which health and social care professionals can help. Often just having the chance to talk without embarrassment is enough.

- Integrate discussion about sexual issues into routine assessment
- Focus on broad aspects of sexuality unless specific sexual dysfunction is identified, in which case more detailed discussion will be necessary
- Assess effect of cancer on relationships, role function, body image and physiological function
- Always provide information about possible effects of treatment on sexual functioning
- Ensure that, if possible, there is privacy for the discussion
- Never make assumptions regarding the patient's sexuality
- Consider including a partner in discussions
- Avoid the use of medical jargon
- Consider using patient education literature as a focus for discussion
- Consider the limits of your expertise and refer on to specialists where appropriate

A useful model for the stages of sexual assessment in palliative care is the PLISSIT model (Annon, 1976)

Permission -	Encourage open discussion about sexuality at all stages in patient's journey
Limited Information -	Give information about the effects of the illness and treatments on Sexuality, to the extent judged appropriate for the particular patient at that point in time
Specific Suggestions -	Give specific suggestions on how to overcome sexual problems related to aspects of the cancer journey
Intensive Therapy -	Refer to specialist services if, following on from the above, more intensive therapy is judged to be necessary

Specialist Resources

- NHS Forth Valley Psychosocial Oncology Service. Consultant Clinical Psychologist – Dr Shirley Anderson. Tel: 01324 404199
- Dr Susan Carr, Consultant in Family Planning and Reproductive Health. Sandyford Initiative. 6, Sandyford Place, Glasgow G3 7NB Tel: 0141 211 8609

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[Contents page](#)

8.10 - Spiritual Care in palliative care

Aspects of spiritual care

Spiritual Care is an integral part of holistic palliative care.

Everyone, whether religious or not, needs support systems, especially in times of crisis.

True healing involves not only the body and the mind but also the spirit.

Many patients, carers and staff, especially those confronting serious or life-threatening illness, have spiritual needs and welcome spiritual care.

Spiritual care is usually given in a one-to-one relationship, is completely person-centred and makes no assumptions about personal conviction or life orientation. It is not necessarily religious.

The function of spiritual care

Spiritual care in a palliative setting facilitates an individual's coming to terms with the past, the present and the future.

Spiritual needs include :

- The need to explore meaning and purpose in life, death and suffering
- The need for love and harmonious relationships
- The need to be understood and valued
- The need to reminisce and reflect
- The need to explore forgiveness
- The need to explore sources of hope and strength to cope with fear, anger, guilt, loss etc.
- The need to explore ethical dilemmas
- The need for trust – to express feelings honestly in a safe environment
- The need to express personal beliefs or values
- The need to be involved in religious worship

Identification and assessment of spiritual need

Spiritual pain or distress may be presented in verbal or non-verbal form.

Regular assessment must be carried out as needs change according to circumstances.

Responding to spiritual distress

Spiritual care is given at one level by staff, carers and friends and informally by patients to each other but a distinctive contribution is given by trained personnel, usually a chaplain.

Effective response requires :

- Time
- Communication skills
- Listening
- Confidentiality
- Openness
- Impartiality
- Sensitivity
- Integrity
- Compassion
- Self-awareness
- Multi-cultural awareness

Forth Valley Spiritual Care Service

Contact details for the Spiritual care service in Forth valley are as follows;

Stirling Royal Infirmary – 01786 434000 Falkirk Royal Infirmary – 01324 624000

Faith and other community contacts

Where an individual belongs to or wishes contact with a particular community further support may be sought from that community's leader or representative. Some contact numbers are as follows:

Bahá'í	0800 0381844 or 0131 554 2446
Buddhist	0141 3330524 or 0131 2283333
Church of Scotland	01786 449522 or 01324 471656
Episcopal	0131 2256357
Jehovah's Witness	01786 448007 or 07813 298095
Jewish	0141 5778200 or 0131 6681279
Hindu	0141 3320482 or 0131 6676064
Humanist	07010 714776 or 01786 842239
Mormon	01324 613586 or 0131 6642510
Muslim	01786 474324
Roman Catholic	01786 473749 or 01324 623567
Salvation Army	01786 489219 or 01324 720430
Sikh	0141 4238288
Unitarian	0141 2213154 or 0131 6674360

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[Contents page](#)

8.11 – Steroids in palliative care

Background

Corticosteroids (commonly known as 'steroids') can provide effective palliation for many specific, and non-specific conditions, in palliative care (see table below). Specific effects are secondary to a reduction in tumour associated oedema and/or inflammation.

Specific conditions

- As a component of chemotherapy regimes
- Raised intracranial pressure from either primary or secondary brain tumours
- Spinal cord compression
- Lymphangitis carcinomatosa
- Superior vena cava obstruction

Non-specific conditions

- Low mood or decreased sense of wellbeing
- Fatigue or weakness
- Anorexia
- Pain e.g. liver capsular pain or nerve root compression
- Dyspnoea
- Nausea and vomiting

Choice of steroid

Steroids can essentially be divided into two main groups:

- Predominant glucocorticoid action (e.g. dexamethasone)
- Predominant mineralocorticoid action (e.g. fludrocortisone)

Those with mainly glucocorticoid activity have potent anti-inflammatory and immunosuppressive effects. However, metabolic effects can cause hyperglycaemia, muscle wasting and osteoporosis. Those with mineralocorticoid activity affect fluid and electrolyte balance causing sodium and water retention.

Dexamethasone is generally the steroid of choice in palliative care. It has high glucocorticoid activity with minimal mineralocorticoid effects. As it has little or no effect on sodium and water retention it is particularly suitable for high dose therapy. In comparison to other steroids, it is relatively potent (Dexamethasone 1mg is approximately equivalent to Prednisolone 7.5mg).

Dexamethasone preparations are available for oral and parenteral use. Although dexamethasone is not licensed for subcutaneous (sc) use, it is common practice for it to be given by this route in palliative care patients. Due to a long half-life it may be administered once daily as a sc injection. Higher doses may need to be divided or administered as a sc infusion. Seek specialist advice if considered mixing dexamethasone with other drugs in a syringe.

Typical doses of Dexamethasone

- Liver capsular pain 6-8mg daily
- Shortness of breath 4-8mg daily (up to 16mg daily if lymphangitis carcinomatosa)
- Promotion of general wellbeing 2-6mg daily
- Spinal cord compression 16mg daily
- Nausea 2 –6mg daily
- Raised intracranial pressure 8-16mg daily
- Neuropathic pain 6-8mg daily

Doses may be given as a single daily dose, or in divided doses if the number of tablets is problematic.

The last daily dose should not be given after 6pm.

Dose reduction and withdrawal

When initiating steroid therapy it is important to document :

- Reason for initiating treatment
- Plan for review
- Proposed duration of treatment
- Plan for reduction.

Steroid use should be supervised to ensure that any benefit from treatment is not outweighed by side effects or toxicity. There are many potential side effects associated with steroids and evidence suggests that the incidence and severity of side effects increase with dose and duration of treatment. It is important therefore, to reduce the dose to the lowest effective dose, and to remain on that dose for the shortest time possible. Dose reduction and withdrawal should be gradual and be medically supervised.

There are great variations in practice regarding dose reduction and steroid withdrawal. There is also concern over what is considered by some to be "uncontrolled use" in palliative care where patients stay on steroid therapy long after benefits are obvious and side effects become troublesome.

Recurrence of symptoms can be a limiting factor for dose reduction. Suppression of the body's naturally occurring steroid can occur at relatively low levels, and return to normal function can be slow, especially in prolonged suppression.

All patients on steroid therapy should be given a steroid card and advised not to stop treatment abruptly. Characteristic symptoms of abrupt withdrawal include fever, myalgia, arthralgia and malaise, which could be mistaken for progressive disease. Nevertheless, abrupt withdrawal in end of life care may be unavoidable if the oral route becomes compromised and clearly no benefit is to be gained by continuation of a futile treatment.

Management of common side effects

The most common side effects and their management are contained in the table below.

Side effect	Management
Reduced inflammatory and immune responses. Increased risk of infection and impaired wound healing.	Avoid close contact with people with infectious diseases.
Gastric irritation/perforation. Increased risk if concurrently prescribed NSAID.	Oral preparations should be taken with or after food. Gastric protection (e.g. omeprazole) is often required prophylactically
Oral candida.	Encourage effective oral hygiene. Be vigilant for evidence of oral candida and treat appropriately.
Ankle swelling and peripheral oedema.	Elevate legs when sitting.
Steroid induced hyperglycaemia.	Monitor blood sugars if high dose of steroid. Seek advice from diabetic management teams if persistent hyperglycaemia occurs. Diet and oral hypoglycaemics may not be adequate in treating steroid induced diabetes but there is often a dilemma associated with the commencement of insulin therapy in end of life care.
Increased appetite and weight gain.	Often a desirable effect.
Thin skin, fragile capillary wall.	Requires vigilance of pressure areas and the need for sensitive moving and handling.
Muscle wasting and weakness, especially of arm and thigh muscles.	Results in difficulty getting out of chairs or climbing stairs. Compounds the physical effects of advanced disease. Occupational therapist and physiotherapists can help maintain and restore function or assist with adaption to disability.
Euphoria, agitation, restlessness, insomnia.	Severe psychological disturbance is rare. Avoid steroid given after 6pm. In some cases, steroids may be unsuitable.

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[Contents page](#)

8.12 – Travelling with controlled drugs

Introduction

Patients with a diagnosis of cancer may want to go abroad to have a holiday or visit friends or relatives and they may meet a number of difficulties when travelling abroad. These difficulties can include obtaining travel insurance and taking controlled drugs abroad.

The Cancer BACUP website www.cancerbacup.org.uk provides helpful information and guidance. A fact sheet for patients and carers is available through the website.

Travel insurance

Even when medical professionals judge that a patient is well enough to travel, the patient may find difficulty in obtaining travel insurance.

Different insurance companies will use different criteria to decide if they will issue insurance or will increase the premiums for some patients. Patients in a poor physical condition are more likely to be refused. Also, insurance companies may be unwilling to provide insurance to places where health care is more expensive or where a long haul flight is required. It may be therefore be worthwhile 'shopping around' for suitable cover as costs and exclusions will usually vary from company to company.

A medical certificate completed by both patient and doctor is usually required and some companies may require a doctor's letter confirming that the patient is fit to travel. It is important that the doctor provides a clear indication of the patient's condition and prognosis in this letter in order to provide the insurer with all the relevant facts. Some insurers may require an assessment from their own doctor before issuing any policy.

Some insurance companies will require the patient to carry a EHIC card for travel to Europe (available through Post Offices or at www.dh.gov.uk for on line applications). An image of this card is shown below. This card entitles the carrier to free or reduced emergency treatment in European Union countries.

EHIC card image



Taking controlled drugs abroad

Patients should have enough medication for their needs while travelling.

In addition to the requirements for leaving and entering the UK, it is important to check with the relevant embassy about any restrictions on taking certain medicines in or out of the country being visited (for example, Diamorphine is not licensed for use in many countries).

Requirements for leaving the UK

If controlled drugs are to be taken in or out of the UK, a letter is needed from the patient's doctor containing the following details :

- Patients name and address in the UK, date of birth,
- Country of destination, dates of departure and return
- Drug name, form and strength and total quantity (in words and figures)
- Doctors signature

Dosages above set levels (1200mg of morphine) will need a licence from the Home Office. To provide a licence, the Home Office Action Against Drugs department will require that the doctor's letter (on headed notepaper) above is faxed to the Home Office (fax number 020 7035 6161) and that the application form is completed. A sample doctor's letter is included at the rear of this section. The application form can be found at www.drugs.gov.uk/publication-search/drug-licences/206452.

It is important to note the following :

- The Home Office will normally require at least 2 weeks to process applications for a licence for taking drugs outside the UK
- All letters and licences for controlled drugs should be carried in the patients hand luggage in case customs officers wish to examine them
- Medicines should be contained in their original packaging and clearly labelled
- Where medication is not classed as a controlled drug, it may be helpful to carry two sets of medication, one in hand luggage and another in the suitcase. This will ensure that if one set goes missing, the other will still be available.
- Medicines should normally be stored in a cool place at less than 25°C but refer to manufacturers instructions

The Home Office Action Against Drugs department can be contacted at the address below :

- Room 230, Action Against Drugs Unit, Home Office, 50 Queen Anne's Gate
London SW1H 9AT Telephone – 0870 0001585

Requirements for entering the country being visited

Specific entry requirements for the country being visited should be verified by making contact with the relevant embassy, consulate or high commission. Where possible, a letter from the embassy, consulate or high commission should be obtained and carried with other items of correspondence in the patients hand luggage.

Resources

1. Cancer BACUP website www.cancerbacup.org.uk
2. European Health Insurance Card website www.ehic.org.uk
3. Home Office Action in Drugs unit website <http://www.drugs.gov.uk/drugs-laws/licensing/personal>

[Contents page](#)

Sample Doctors letter

Doctors Address
Date

Drug Licensing Unit
Room 230
Home Office
50 Queen Anne's Gate
London
SW1H 9AT

Dear Sirs,

The following patient is intending to travel abroad and is currently using medication above the current acceptable levels for travelling.

I would therefore be grateful if you could issue a licence for this patient to carry the medication as specified below.

Patients Name –
Diagnosis –
Date of Birth –
Country of Destination –
Dates of departure and return –
Drug name, form, strength (words and figures) and total quantity –

Yours faithfully,

Doctors Name and signature

8.13 - Using medicines outwith their marketing authorisation or without a marketing authorisation in palliative care

Background information

The Medicines and Healthcare products Regulatory Agency (MHRA, previously the Medicines Control Agency) in the United Kingdom grants a Marketing Authorisation (formerly known as a product licence) to pharmaceutical companies to market and supply a product for the specific indications mentioned in the data sheet or summary of product characteristics (SPC). Since January 1994, it has also been possible to receive an EC wide marketing authorisation through the European Medicines Evaluation Agency (EMA).

Restrictions are imposed by the licensing authority if evidence of safety and efficacy is unavailable in particular patient groups e.g. children or in pregnancy. For the use of the drug in such excluded patient groups to become licensed, further evidence needs to be submitted by the pharmaceutical company. This may not be economically viable as the new patient group may be small compared to the cost of conducting further clinical trials and the company may choose not to pursue this route.

The existence of a marketing authorisation guarantees the quality, safety and efficacy of medicinal products, and to a certain extent, places liability on the marketing authorisation holder for adverse effects arising from the use of their product.

Information for prescribers

The licensing process regulates the activities of pharmaceutical companies and not the prescribing practice of a qualified medical practitioner.

In palliative care off-label use of medications is extremely common (i.e. for an unlicensed indication, by an unlicensed route or in an unlicensed dose). Such use can be justified by clinical practice and primary reference sources such as The Oxford Textbook of Palliative Medicine or the Palliative Care Formulary (2nd Edition). Less commonly, use of an unlicensed medicine (a medicine with no marketing authorisation for use in this country) may be necessary e.g. thalidomide for night sweats.

The Medicines Act (1968) allows a doctor to legally prescribe unlicensed medicines or to use/advise a licensed medicine for indications or in doses or by routes of administration outside those specified in the marketing authorisation. However, doctors also have a duty to act with reasonable care and skill in a manner consistent with the practice of professional colleagues of a similar standing. They must balance potential benefit and harm of using any medicine in a patient. This responsibility also applies to the prescribing of unlicensed or off-label medicines.

Legal responsibility for the effect of a prescribed medicine lies with the doctor who signs a prescription. If an untoward incident is caused by a product defect or occurs with use of a licensed medication in an approved clinical situation, any liability may, in part or whole, be transferred to the license holder. This is not the case for unlicensed medicines or off-label use of licensed medicines.

Information for pharmacists

A pharmacist, when making a supply of any medicinal product, also assumes a duty of care to the patient. If a product without a marketing authorisation is supplied, or a product supplied outside its marketing authorisation and an adverse reaction is suffered to it, the supplying pharmacist may assume some liability with the doctor who prescribed it. The extent of the liability depends on the facts of every case.

The law expects a pharmacist to take the steps that a reasonably competent pharmacist would take, judged in accordance with the accepted standards of his profession regardless of his or her relative experience. The pharmacist must ensure that the supply is made in the best interests of the patient and the potential risk to the patient of making the supply has to be weighed against the detriment to the patient of not making the supply.

Information for nurses and midwives

Nurses and midwives can administer unlicensed and off label drugs. As with all medicines, the nurse should be satisfied that they have sufficient information to administer the drug safely and wherever possible, that there is an acceptable justification for the use of that medicine in the specified way. The prescriber will retain responsibility for any adverse events that occur.

Informed consent

Recommendations from the General Medical Council and the Medical Defence Organisations suggest that informed consent should be gained from the patient and that this should be recorded in the patient's notes before prescribing off-label or unlicensed medicines. In palliative care where use is so widespread, such an approach is impractical and could be burdensome for the patient as well as increasing their anxiety if they did not fully understand the explanation given to them. This could result in refusal of a potentially beneficial treatment.

The Association of Palliative Medicine and The British Pain Society issued a statement in 2002 recommending that organisations should tackle this issue through their clinical governance structure and that staff should be supported and educated to take responsibility for their own decisions.

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[Contents page](#)

Glossary of Terms / Abbreviations

A

ADL – Aids to daily living

B

BP – blood pressure
BNF – British National Formulary

C

COPD – Chronic Obstructive Pulmonary Disorder
CVA – Cerebrovascular accident
CT – Computerised Tomography
CNS – Clinical Nurse specialist
CSCI – Continuous subcutaneous infusion
CMHT – Community Mental Health Team
CHP – Community Health Partnership
CCP – Cancer Clinical Psychology
COSCA – Counselling & Psychotherapy in Scotland

D

DIC – Disseminated intravascular coagulation
DVT – Deep vein thrombosis
DN – District nurse
DNAR – Do not attempt resuscitation
DLA – Disability living allowance
DVLA – Driver and Vehicle Licensing Agency

E

ECG – Electro cardiogram
EHIC – European Health Insurance Card

F

FBC – Full blood count
FDRI – Falkirk & District Royal Infirmary
FVF – Forth Valley formulary
FVPCOD – Forth Valley Primary Care Operating Division

G

GI – Gastro intestinal
GP – General practitioner

H

HIT – Heparin induced thrombocytopenia

I

IV – Intravenous
IM – Intramuscular
ILS – Independent living services

J

JLES – Joint Loan Equipment Service

L

LFTS – Liver function tests
LAA – Local authority area
LCP – Liverpool Care Pathway
LMWH – low molecular weight heparin
LEMS – Lambert Eaton myasthenic syndrome

M

MCN – managed clinical network
MG – milligram
MND – motor neurone disease
MS – multiple sclerosis
MRI – Magnetic resource imaging
MECS – Mobile emergency care services
MUST – Malnutrition Universal Screening Tool

N

NHS – National Health Service
NHSFV – NHS Forth Valley
NSAIDS – Non steroidal anti inflammatory drugs
NOCTE – at night
NG – nasogastric

O

OOH – Out-of-hours
OT – Occupational therapy

P

PD – parkinsons disease
PRN – as required
PTE – pulmonary thrombo embolism
PPI – proton pump inhibitor
PO – oral route
PHCT – Primary health care trust
PF – Procurator Fiscal
PM – Post mortem

Q

QID – four times per day

S

SD – syringe driver
SLT – speech and language therapists
SRI – Stirling Royal Infirmary
S/C – sub cutaneous
SST – Saliva stimulating tablets
SVCO – Superior vena cava obstruction
SIGN – Scottish Intercollegiate Guidelines Network
SSRI – Serotonin specific reuptake inhibitors

T

TID – three times per day
TNF – tumour necrosis factor
TDS – three times per day
TIA – transient ischaemic attack
TENs – Trans electronic nerve stimulator

V

VPF – vascular permeability factor
VTE – venous thrombo-embolism

W

WHO – World Health Organisation

X

XRT – Radiotherapy

[Contents page](#)