

THE PALLIATIVE CARE HANDBOOK

Advice on clinical management

SEVENTH EDITION

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**In association with
Wessex and
Avon, Somerset & Wiltshire Cancer Services
Specialist Palliative Care Units**

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INTRODUCTION

Palliative care:

- is the active total care of patients and their families, usually when their disease is no longer responsive to potentially curative treatment, although it may be applicable earlier in the illness
- provides relief from pain and other symptoms
- aims to achieve the best possible quality of life for patients and families
- responds to physical, psychological, social and spiritual needs
- extends as necessary to support in bereavement.

This handbook contains guidance to help GPs, community nurses and hospital staff as well as specialist palliative care teams. It aims to provide a checklist for the management of common problems in palliative care, with some information on drug treatment. It is **not** a comprehensive textbook. Further advice can be sought from the specialist staff identified on the back cover or from any hospice or specialist palliative care unit. More detailed drug information may be found in the British National Formulary (BNF), or from the Palliative Care Formulary (PCF), see below.

National Service Frameworks for heart failure, renal failure and other conditions are increasingly emphasising the importance of providing good palliative care to these patient groups as well as to those with cancer. The material in this Handbook is intended to apply across a range of diagnoses.

Cautionary note: some of the drug usage recommended is outside product licence, whether by way of indication, dose, or route of administration. However, the approaches described are recognised as reasonable practice within palliative medicine in the UK. The rINN names for drugs are used throughout.

Abbreviations

Routes:	csci	= continuous subcutaneous infusion (via a syringe driver).
	sl	= sublingual.
	sc	= subcutaneous injection.
	po	= by mouth.
	pr	= per rectum
Timings:	om, nocte	= each morning, each night.
	od, bd	= once, twice daily.
	tds, qds	= three, four times daily.
	q4h, q6h	= every four, six hours.

Further reading/drug information

- The Oxford Textbook of Palliative Medicine (4th ed. Hanks GW et. al.), considers all aspects of palliative care in greater detail.
- The Palliative Care Formulary (3rd ed. Twycross R, Wilcock A), also online at www.palliativedrugs.com and www.pallcare.info, gives more detailed advice on the drugs used in palliative care.

GENERAL PRINCIPLES OF SYMPTOM MANAGEMENT

- Accurate and full assessment is essential for both diagnosis and treatment.
- Be aware of the importance of non-physical factors in symptomatology - emotional, psychological, social and spiritual problems are often mixed together with physical symptoms.
- When symptoms are difficult to control there may be more than one cause, or there may be hidden emotional, psychological, social and spiritual factors.
- Use appropriate therapies to maintain the best possible quality of life and independence, and to allow patient and carers to focus on other important issues.
- Be careful that drug side effects do not become worse than the original problem.
- Sensitive explanation and inclusion of patient and carers in decision making are essential parts of symptom management.
- A multiprofessional approach is essential, and may be facilitated by the use of a patient held drug card/shared information card.
- Consider referral for a specialist palliative care opinion:
 - if there is a problem which does not respond as expected
 - in complex situations which may benefit from specialist expertise
 - for support for the hospital or primary health care team.
- **Continually reassess.**

GUIDANCE FROM NICE ON SPECIALIST PALLIATIVE CARE

The National Institute for Clinical Excellence (NICE) has made the following statements in its Supportive and Palliative Care Guidance (2004). The full Guidance can be seen at www.nice.org.uk.

A significant proportion of people with advanced disease experience a range of complex problems that cannot always be dealt with effectively by generalist services. Hospices and specialist palliative care services have been established across the country over the past four decades to help minimise these problems.

Areas of expertise within specialist palliative care to which patients and carers may need access include:

- unresolved symptoms and complex psychosocial issues for patients with advanced disease
- complex end of life issues
- complex bereavement issues.

Specialist palliative care should be available to those with any diagnosis, not only those with cancer. Services should as a minimum include specialist palliative care inpatient facilities and hospital and community teams. Advice should be available on a twenty-four hour, seven days a week basis.

PAIN

Diagnosis

Accurate diagnosis of the cause(s) of pain is necessary for a rational approach to therapy. There are many components to pain and all relevant physical, psycho-social and spiritual factors need to be taken into account. It must not be assumed that pain has been caused by the primary diagnosis: debility, previous treatment and unrelated causes must also be considered.

The analgesic ladder approach (see over) is the basis for prescribing in all types of pain, but careful choice of appropriate adjuvant drugs will increase the chance of effective palliation.

Causes / Risk Factors

- | | |
|----------------|--|
| 1 Physical | Nociceptive pain caused by somatic, visceral or bone injury.
Neuropathic pain caused by nerve injury. |
| 2 Non-physical | Anger, anxieties, fears, sadness, helplessness.
Spiritual, social and family distress. |

Assessment

Obtain the patient's own description and assessment of their pain(s):

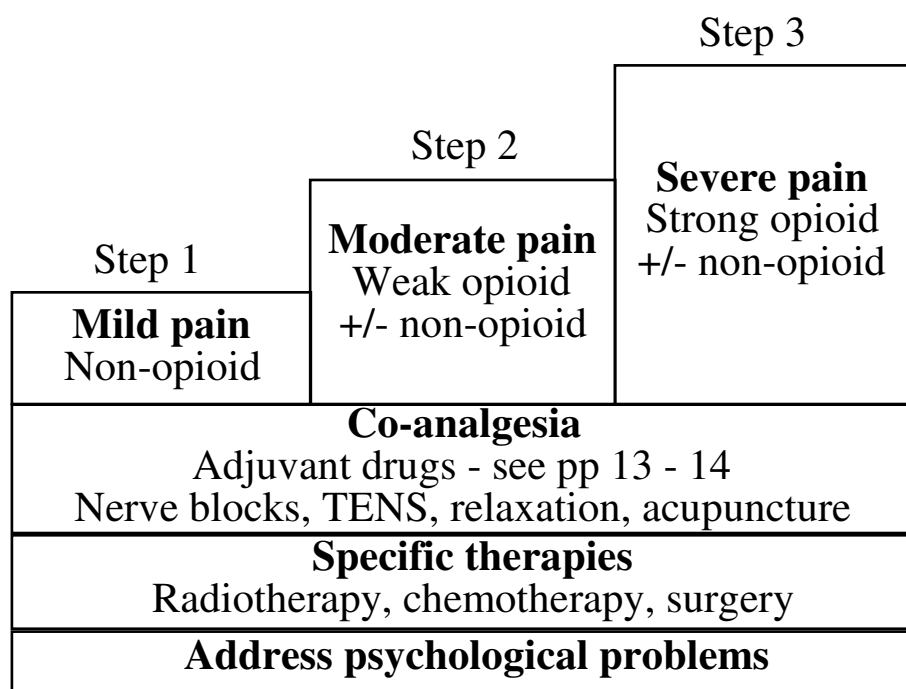
- | | |
|----------------------------------|---|
| 1 What is the pain like? | <ul style="list-style-type: none">• site and radiation – a body diagram is helpful• character – list the patient's descriptors• intensity – use a severity or rating scale• exacerbating and relieving factors• effect on function and sleep. |
| 2 What is causing the pain? | <ul style="list-style-type: none">• the disease, by direct invasion, pressure, etc• the treatment, eg constipation, mucositis• debility, eg pressure sores, muscle stiffness• unrelated pathologies, eg vascular disease. |
| 3 Is it a specific type of pain? | <ul style="list-style-type: none">• bone – worse on movement, weight bearing• nerve – burning or shooting, radiates• liver – hepatomegaly, RUQ tenderness• raised ICP – headache worse lying down• colic – intermittent, cramping. |
| 4 Other factors | <ul style="list-style-type: none">• psychological, social and spiritual distress. |

All pains have a significant psychological component, and fear, anxiety and depression will all lower the pain threshold. Remember also the likely effects of life changes associated with terminal disease including loss of financial security, altered body image and compromised sexual function. Together with more existential and religious uncertainties, these factors can have a major impact on the way a person perceives and copes with pain.

Management

The World Health Organisation (WHO) ‘analgesic ladder’ emphasises that:

- analgesics should be given regularly
- it is essential to use an analgesic appropriate to the severity of the pain
- a patient whose pain does not respond to weak opioids needs a trial of management with strong opioids
- all patients taking opioids should also be prescribed laxatives
- the oral route is preferred for all steps of the ladder
- additional methods of pain control **must** be considered in all patients.



Step 1 Non opioids

Paracetamol: Oral, rectal or iv (500mg - 1g qds, maximum 4g per day).

NSAIDs: Useful for pain aggravated by movement or inflammation, risk/benefit balance must always be considered, gastric protection is strongly advised eg PPIs, misoprostol, renal impairment is not uncommon, relatively contra-indicated in heart failure, choice of NSAID is largely dictated by local preference:

- ibuprofen (200 - 400mg tds or qds)
- diclofenac (tabs SR 75mg bd, supps 100 - 150mg daily)
- naproxen (tabs 500mg bd).

Step 2 Weak opioids

Codeine 30mg with paracetamol 500mg (co-codamol 30/500), 1 - 2 qds.

Tramadol 50 - 100mg qds or tramadol MR 100 - 200mg bd.

Other weak opioids, including dihydrocodeine, offer no advantages.

Step 3 Strong opioids (see following pages).

USE OF STRONG OPIOIDS

Morphine remains the first-line strong opioid of choice.

- 1 To gain control of the pain:
 - A Usually start with immediate release morphine (liquid or tablets), every 4 hours, 2.5 - 10mg, with prn doses equal to the 4-hourly dose. (The eventual effective dose will rarely be more than 30mg 4 hourly).
 - B If using modified release morphine, give 10 - 30mg bd, depending on previous weak opioid, with prn doses of immediate release morphine each up to 1/6th of the total daily dose. Note that pain control may take longer to achieve.

Elderly patients and those with renal or hepatic impairment (see p12) are likely to need lower or less frequent doses

- 2 Reassess pain control at least daily, recording severity if helpful:
Titrate the dose to achieve pain relief, increasing the dose by 30 - 50% every 2 - 3 days, or sooner if needed. A typical dose sequence is:
5 - 10 - 15 - 20 - 30 - 40 - 60 - 90 - 120 - 150 - 200mg.
- 3 Once pain is controlled, the 4-hourly regime is usually changed to modified release morphine: the 12-hourly dose will be three times the 4-hourly dose.
- 4 The prn dose for breakthrough pain will be up to the same as the 4-hourly dose ie 1/6th of the daily dose. Wait for 30 minutes after breakthrough medication to assess response. If pain continues, further breakthrough medication may be allowed but the pain will require reassessment.
- 5 Review doses regularly: if using two or more breakthrough doses per day (with benefit), consider increasing the regular dose as suggested in 2 above.
- 6 Continuing pain, particularly with persisting side effects eg drowsiness, nausea or confusion, may indicate that this pain is not fully opioid responsive – other approaches may be more appropriate, rather than increasing the opioid dose (see pp13 - 16). If side effects occur but pain is well controlled, reduce dose.
- 7 To avoid confusion between preparations with names that seem similar to patients, and to ensure consistent bioavailability, we recommend that both immediate release and slow release preparations, as well as transdermal analgesics, are prescribed by their **brand name**.

Instructions to the patient and carer

- 1 Emphasise the need for regular administration.
- 2 Explain about breakthrough medication.
- 3 Warn about possible side effects.
- 4 Reassure that when used for pain relief, morphine is not addictive and that its use does not prejudice future pain relief.

Unwanted effects of strong opioids

- 1 **Constipation** is virtually inevitable – use prophylactic laxatives (see p25).
- 2 **Nausea** is fairly common when initiating opioids, particularly with higher doses or rapid dose escalation. Slow titration usually avoids this. If antiemetic needed – metoclopramide 10mg tds, cyclizine 50mg tds or haloperidol 1.5mg nocte.
- 3 **Drowsiness** implies too high a dose; if persistent, reduce dose and/or consider other options.
- 4 **Hallucinations** also imply too high a dose, often preceded by vivid dreams.
- 5 **Other troublesome symptoms** include dry mouth, hiccups, sweating.
- 6 **Respiratory depression** is very rarely seen if opioids titrated sensibly.

Signs of excess opioid/opioid toxicity (seek advice):

- increasing drowsiness
- vivid dreams/hallucinations
- pinpoint pupils
- muscle twitching/myoclonus/jerking*
- hyperalgesia on light touch.*

These problems may occur with any opioid, especially morphine, when there is significant renal or hepatic impairment (see p12), dehydration or infection. Naloxone should only be considered (in small aliquots up to 100mcg) if significant respiratory depression, because pain control will be dramatically reversed.

Changing from one strong opioid to another

When oral administration is not possible because of dysphagia, vomiting or weakness, consider changing to a transdermal patch (see p11) or to csci using a syringe driver (see pp10, 25).

Other reasons for changing strong opioids can be: reduction in side effects eg constipation (fentanyl, buprenorphine less constipating), problems with oral compliance etc.

If there is difficulty achieving good pain control without unacceptable side effects, changing the strong opioid may be appropriate. However, most problems can be solved by improving the titration, or using adjuvant drugs.

The dose conversion (total daily or prn dose) from oral morphine to sc morphine is normally 2:1, and from oral morphine to sc diamorphine 3:1 (see p10), but allow flexibility depending on the need for increased or decreased analgesia.

Seek specialist advice when:

- converting from higher doses of one opioid to another, because conversion ratios may be different at higher doses*
- pain persists but there is opioid toxicity*
- converting to or from methadone.*

Morphine preparations

Immediate release oral morphine:

- Oramorph liquid 10mg/5ml, oramorph concentrated solution 100mg/5ml.
- Sevredol tablets 10mg, 20mg, 50mg.

Modified release oral morphine:

- Zomorph capsules† 10mg, 30mg, 60mg, 100mg, 200mg (12 hourly).
- MST Continus tablets 5mg, 10mg, 15mg, 30mg, 60mg, 100mg, 200mg (12 hourly).
- MST Continus suspension 20mg, 30mg, 60mg, 100mg, 200mg (12 hourly).
Contents of sachets to be mixed with water. Expensive.
- Morphesic SR tablets 10mg, 30mg, 60mg, 100mg (12 hourly).
- MXL capsules† 30mg, 60mg, 90mg, 120mg, 150mg, 200mg (daily).

Morphine sulphate injection 10mg, 15mg, 20mg, 30mg per 1ml ampoule.

Morphine can be used in syringe drivers, as cheaper than diamorphine, but volume limitations at higher dose.

Morphine suppositories 10mg, 15mg, 20mg, 30mg.

Other oral and injectable strong opioids

See overleaf for the Table of Opioid Equivalents.

Diamorphine has been the strong opioid of choice for parenteral use at higher doses because of its greater solubility than morphine, but is more expensive.

Subcutaneous diamorphine is up to 3 times more potent than oral morphine.

Maximum recommended concentration is 250mg/ml.

a) Ampoules 5mg, 10mg, 30mg, 100mg, 500mg. Dissolve in water for injection.

Oxycodone is available for oral and injectable use, as an alternative to morphine, with slightly different side effect profile.

a) OxyNorm liquid 5mg/5ml, 50mg/5ml (immediate release, 4 hourly).

b) OxyNorm capsules 5mg, 10mg, 20mg (immediate release, 4 hourly).

c) OxyContin tablets 5mg, 10mg, 20mg, 40mg, 80mg (12 hourly).

d) OxyNorm injection, 10mg/ml, 50mg/ml.

Hydromorphone is also available for oral use, as an alternative to morphine, with slightly different side effect profile. It may be safer in mild to moderate renal failure.

a) Palladone capsules† 1.3mg, 2.6mg (4hourly).

b) Palladone SR capsules† 2mg, 4mg, 8mg, 16mg, 24mg (12hourly).

Methadone* may be useful in patients with pain, particularly neuropathic, poorly responsive to morphine or with unacceptable side effects. However, it has a variable metabolism and **dangerous accumulation** can occur. Steady state potency of oral methadone to morphine ranges from 3:1 to 10:1. Dose titration involves a prn regime over 5 - 8 days before switching to a 12hourly regime. **Its use is best restricted to those with extensive experience.**

† indicates that capsule can be opened and contents sprinkled on food or drink

Fentanyl is most commonly used as a transdermal patch (see p11) or in short acting buccal, sublingual or intranasal formulations for pains of short duration (see pp15/16) but, like alfentanil, can be used sc and via syringe driver particularly for pain in patients with severe renal failure (see p55). Csci dose is similar to patch eg 600mcg/24h = 25mcg/h patch, at higher doses alfentanil is preferred because of volume. Fentanyl injection 50mcg/ml.

Alfentanil* has a rapid onset but short duration of action. It may be useful for treatment of procedure pain such as dressing changes either by subcutaneous injection or as a buccal spray (see pp15/16). It can be given by syringe driver particularly in patients with renal failure who exhibit toxicity reactions with other opioids. It is approximately ten times more potent than sc diamorphine. Alfentanil injection 500mcg/ml, 2ml amp.

We do **not** recommend pethidine for regular use in chronic cancer pain. For conversion from pethidine to morphine seek specialist advice.*

Table of relative potencies of oral and subcutaneous opioid analgesics

This table provides only an **approximate** guide to opioid equivalents, because comprehensive data are lacking. Doses **always need to be re-titrated** after a change of opioid. Breakthrough dose is normally up to 1/6th total daily dose.

Drug and route of administration	Dose ratio to oral morphine	Approximate dose equivalents (examples) in mg		
Oral codeine	10 - 12	300 - 360	-	-
Oral tramadol	7 - 10	200 - 300	-	-
Oral morphine	1	30	90	240
Subcutaneous morphine	1 / 2	15	45	120
Subcutaneous diamorphine	1 / 3	10	30	80
Oral oxycodone†	1 / 2	15	45	120
Subcutaneous oxycodone†	1 / 3	10	30	80
Oral hydromorphone	1 / 7.5	4	12	32
Subcutaneous hydromorphone	1 / 15	2	6	16
Subcutaneous alfentanil	1 / 30	1	3	8

† oxycodone oral:sc is not the manufacturers 2:1 because oral ratio to morphine is more correctly 2:3. However, sc oxycodone: sc diamorphine is 1:1.

Strong opioids available for transdermal use (patches)

Patches can be useful especially when there is vomiting or other problems with the oral route, intractable constipation despite laxatives, or other side effects are a problem with opioid responsive pain. They are unsuitable for acute or variable pain, and for the opioid naïve (with the possible exception of BuTrans).

Note that:

- patients converting from 12hrly modified release morphine should apply the first patch at the same time as taking the final 12hrly dose
- patients converting from 4hrly immediate release morphine must continue regular morphine for the first 12 hours
- oral immediate release or sc opioid should always be prescribed for breakthrough pain (see table below)
- laxatives should be reduced by up to 50% and then titrated to need
- reassessment of pain control should take place at a minimum of 36 and preferably 72hrs. Any upward titration in dose should be in steps of no more than 25-50%.
- there is a possibility of withdrawal symptoms when converting from morphine, which respond to small doses of immediate release oral morphine
- see p58 for advice on the use of patches at the end of life.

Fentanyl

There are now a number of different brands of fentanyl patches – use matrix rather than reservoir.

a) Patches 12, 25, 50, 75 and 100mcg/hr (every 72 hours).

Buprenorphine

Current patches are either low dose BuTrans (weekly) or higher dose Transtec (twice weekly). Dose increments are smaller and safer than with fentanyl patches. Any partial agonist effect is not clinically apparent.

a) Transtec patch 35, 52.5, 70mcg/hr (twice weekly)

b) BuTrans patch 5, 10, 20mcg/hr (every 7 days).

Buprenorphine is also available as sl tablet and injection (neither recommended).

Table of approximate equivalents of patches and prn opioid doses

Oral morphine (total mg/24 hrs)	30	60	120	180	240
Transdermal fentanyl (microgram/hr)	12	25	37	50	75
Transdermal buprenorphine (microgram/hr)	20 - 35	35	70	105	140
Oral morphine for breakthrough (mg)	5	10	20	30	40
sc diamorphine for breakthrough (mg)	2.5	2.5 - 5	5 - 7.5	10	15
sc morphine for breakthrough (mg)	2.5	5	10	15	20

Opioids and renal or hepatic impairment

Metabolites of morphine and some other opioids accumulate in renal impairment (of which eGFR is a better indicator than serum creatinine in patients with loss of muscle bulk), leading to opioid toxicity manifested as:

- increasing drowsiness or confusion
- vivid dreams/hallucinations
- muscle twitching/myoclonus/jerking*
- hyperalgesia on light touch or on being turned.*

This is an important cause of ‘terminal agitation’. It may respond to a reduction in the dose and/or frequency of administration, but it is often better to switch to an opioid which does not accumulate in renal impairment such as fentanyl, buprenorphine or alfentanil (see p55).

Opioid toxicity may also occur in hepatic impairment, but clinical difficulties do not usually arise unless the impairment is severe: prothrombin time (or INR) is a more sensitive indicator of severe impairment than standard liver function tests. All opioids can precipitate confusion and encephalopathy, but oral opioids will be particularly affected by the loss of first pass metabolism. Careful re-titration is necessary using both a reduction in the dose and a lengthening of dose interval, while considering an alternative opioid. In the dying patient, maintenance of good analgesia remains very important.

Opioid	Renal impairment		Hepatic impairment	
	Moderate	Severe*	Moderate	Severe*
morphine	Reduce dose	Avoid	Normal dose	Reduce dose
diamorphine	Reduce dose	Avoid	Normal dose	Reduce dose
fentanyl	Normal dose	Normal dose	Normal dose	Reduce dose
hydromorphone	Reduce dose	Reduce dose	Normal dose	Reduce dose
oxycodone	Reduce dose	Avoid	Normal dose	Reduce dose
methadone	Normal dose	Normal dose	Normal dose	Reduce dose
alfentanil	Normal dose	Normal dose	Normal dose	Reduce dose
buprenorphine	Normal dose	Normal dose	Normal dose	Reduce dose

*Always seek specialist advice in cases of severe renal or hepatic impairment.

Opioids and driving

Doctors have a legal responsibility to advise patients if a disability is likely to make them a danger when driving. Taking morphine for medicinal reasons does not automatically disqualify from driving, but the following advice should be given:

- Do not drive for at least two days, and preferably five, after starting or increasing morphine
- Check fitness to drive by taking a trusted passenger and driving for 10 - 15 minutes on quiet roads
- Inform the insurance company. If this is not done the patient may find they are not covered, irrespective of fault. It is illegal to drive uninsured.

ADJUVANT TREATMENTS FOR SPECIFIC PAINS

A Bone pain

- 1 Consider early referral for palliative radiotherapy - usually a single fraction is effective. Radioactive isotope treatment may be used for multiple sclerotic metastases.
- 2 NSAIDs may be effective but beware side effects: discontinue if not helping. Gastro-protective agents should usually be prescribed.
- 3 IV infusions of bisphosphonates may reduce pain in patients with bone metastases, especially from breast and prostate cancer and myeloma: drugs and doses as per hypercalcaemia (see p51).
- 4 Consider referral to an orthopaedic surgeon for internal fixation for metastases in long bones at risk of fracture.
- 5 Vertebroplasty or cement fixation may be appropriate for isolated vertebral collapse in selected patients.

B Abdominal pain

Exclude/diagnose oesophago-gastritis, peptic ulcer, perforation, urinary tract infection or ureteric obstruction.

- 1 Constipation is a common cause; for treatment see p25.
- 2 For colic (bowel or ureteric) use an anticholinergic. Hyoscine butylbromide is more effective by sc injection 20mg or csci 40 - 120 (-240*)mg/24hrs. Other oral agents include mebeverine, alverine and propantheline.
- 3 For liver capsule pain consider dexamethasone 4 - 8mg/per day (see p52) and/or NSAIDs.
- 4 For pancreatic pain consider coeliac plexus block (see p15).
- 5 For pain arising from retroperitoneal lymph nodes consider dexamethasone 4 - 8mg/per day (see p52), gabapentin or other neuropathic analgesics (see p14) or nerve blocks (see p15)
- 6 For bladder spasm consider oxybutynin 2.5 - 5mg bd-qds or tolterodine 2mg bd, amitriptyline 10 - 50mg nocte, or NSAIDs. If catheterized and no response to the above, intravesical bupivacaine 0.25%, 20mls for 15 mins tds.

C Rectal pain

Exclude constipation by abdominal and rectal examination. Tenesmus and deep seated pelvic pains may respond to:

- 1 Local steroid (Colifoam, Predsol etc) or systemic steroids, NSAIDs, amitriptyline or gabapentin (see below).
- 2 Drugs for relief of muscle spasm:
 - nifedipine immediate release capsules 10 - 20mg orally or sl after opening
 - glyceryl trinitrate ointment 0.1 - 0.2% bd
 - benzodiazepines, eg diazepam 2 - 10mg nocte
- 3 Local radiotherapy for tumour especially if steroid treatment is successful.
- 4 Nerve blocks (see p15).

D Muscle pain

- 1 Physiotherapy, aromatherapy, relaxation, heat pad.
- 2 Muscle relaxants: diazepam, baclofen, clonazepam, dantrolene, tizanidine.

E Neuropathic pain

Often aching in nature, sometimes burning or shooting, and may be worse after movement or at night. May not respond in a predictable way to pain-relieving medication. May presage cord compression. Usually due to compression or damage of the spinal cord, nerve roots, nerve plexi or peripheral nerves; occasionally originates in the thalamus or cortex.

Specialist palliative care team or chronic pain team will be happy to advise and referral is suggested at an early stage.

The following treatments may be effective:

- 1 Dexamethasone 4 - 8mg daily (see p52) for short term relief of pressure.
- 2 Try opioid titration, but be aware that this sort of pain is often not very opioid sensitive and opioid toxicity is a risk whichever opioid is tried.
- 3 Tricyclic antidepressants eg amitriptyline 10 - 75mg or dosulepin 25 - 75mg nocte. Venlafaxine* and mirtazapine have also been used. SSRIs do not appear to be of benefit.
- 4 Gabapentin titrating from 300mg/day (100mg/day in elderly) in divided doses up to maximum 2700mg/day, or pregabalin initially 75mg bd max 300mg bd.
- 5 Other antiepileptics can be tried: sodium valproate 400 - 800mg/day, carbamazepine 200 - 1200mg/day.
- 6 Clonazepam starting at 500mcg nocte or diazepam 2 - 10mg/day sometimes help.
- 7 Other drugs used by specialists include baclofen*, clonidine*, ketamine* and methadone*.
- 8 Other approaches include TENS, acupuncture and nerve blocks (see next page).

Pains amenable to nerve blocks

Many pains are amenable to intervention by a pain management specialist anaesthetist. Neural blockade can be temporary with local anaesthetic or semi-permanent with neurolytic agents such as phenol. Injected steroids are particularly useful when pain is due to compression of the nerve.

- 1 Back pain due to metastases often responds to epidural injection of high dose steroid and local anaesthetic. Caudal injections are easily performed and are useful for sacral pain. Thoracic and cervical epidurals are more difficult.
- 2 Pancoast tumour or other brachial plexopathy : brachial plexus block.
- 3 Rib pain may be temporarily abolished by intercostal injection of local anaesthetic proximal to the lesion. Longer term benefit may result from infiltration with depot steroid. If helpful, permanent block may be obtained with cryoprobe.
- 4 Chest wall pain can be very difficult to control, especially when it occurs as a result of mesothelioma. Intercostal and paravertebral blocks can be effective, but if ineffective, early referral for percutaneous cervical cordotomy (Portsmouth or Exeter) is recommended. Some specialists perform thoracic epidurals or even intrapleural infusions.
- 5 Upper abdominal pain, especially due to pancreatic tumour, responds to coeliac plexus block in around 80%. This can be performed under direct vision at laparotomy, or under CT control.
- 6 Lower abdominal and pelvic pain : lumbar plexus block can give worthwhile benefit but with a lower success rate.
- 7 Perineal pain : saddle anaesthesia using intrathecal phenol (as with all neurolytic techniques this is the province of the specialist).
- 8 Hip pain may be helped by a variety of procedures, including direct injection of local anaesthetic and steroid into the joint, psoas compartment block, and block of the obturator nerve together with the nerve to quadratus femoris.
- 9 Intrathecal or epidural opioid and local anaesthetic infusions may help in difficult pains.

Acute pain of short duration and Breakthrough pain

There are some pains which are often of quite short duration, either predictable from specific incidents eg moving a fractured limb or changing a painful dressing, or unpredictable.

Breakthrough pain is usually defined as transient flare up of pain from generally controlled background pain.

The principles for management are the same as for any other pain ie correct diagnosis, remove causes where possible, and assess whether opioid sensitive, and whether NSAID more appropriate.

- Treatment options are, usually, shorter acting immediate release preparations
- The dose required is not necessarily predictable from background dosage and requires individual titration
- When the incident is predictable give 20 - 30mins beforehand

Drug options:

- 1 Morphine, immediate release oral or sc; diamorphine or oxycodone sc.
(Effect may last a lot longer than duration of the pain episode).
- 2 Fentanyl preparations: short acting buccal, sublingual or intranasal.
(Quicker acting and usually lasting 1 - 2 hours)
- 3 Alfentanil* by sc injection or buccal spray (special order) 250 - 500mcg if opioid naïve.
- 4 Nitrous oxide (as Entonox), not for regular use as it is addictive.

NON-PHARMACOLOGICAL APPROACHES TO PAIN CONTROL

A Emotional and spiritual support (see also pp62, 68)

- 1 Within a careful assessment of the pain:
 - assess what the pain means for the patient
 - assess their general emotional, psychological and spiritual state
 - assess their current coping style – is it helpful, is this their usual approach or has it changed with the disease/pain?
 - assess impact on family/carers
- 2 Identify and communicate (to patient & family, health professionals):
 - causes of pain and management plan
 - the correct use/expectations of medications and other treatments
 - understanding of the patient's personal situation
 - practical and emotional support available

B Help to develop coping strategies

Coping strategies developed for chronic pain may be useful within the palliative care setting. They are based on living with pain, adapting living to the new requirements and the maintenance of normal activity as far as possible. Many chronic pain clinics have clinical psychologists who specialise in this field.

C Relaxation and distraction techniques and creative/complementary therapies

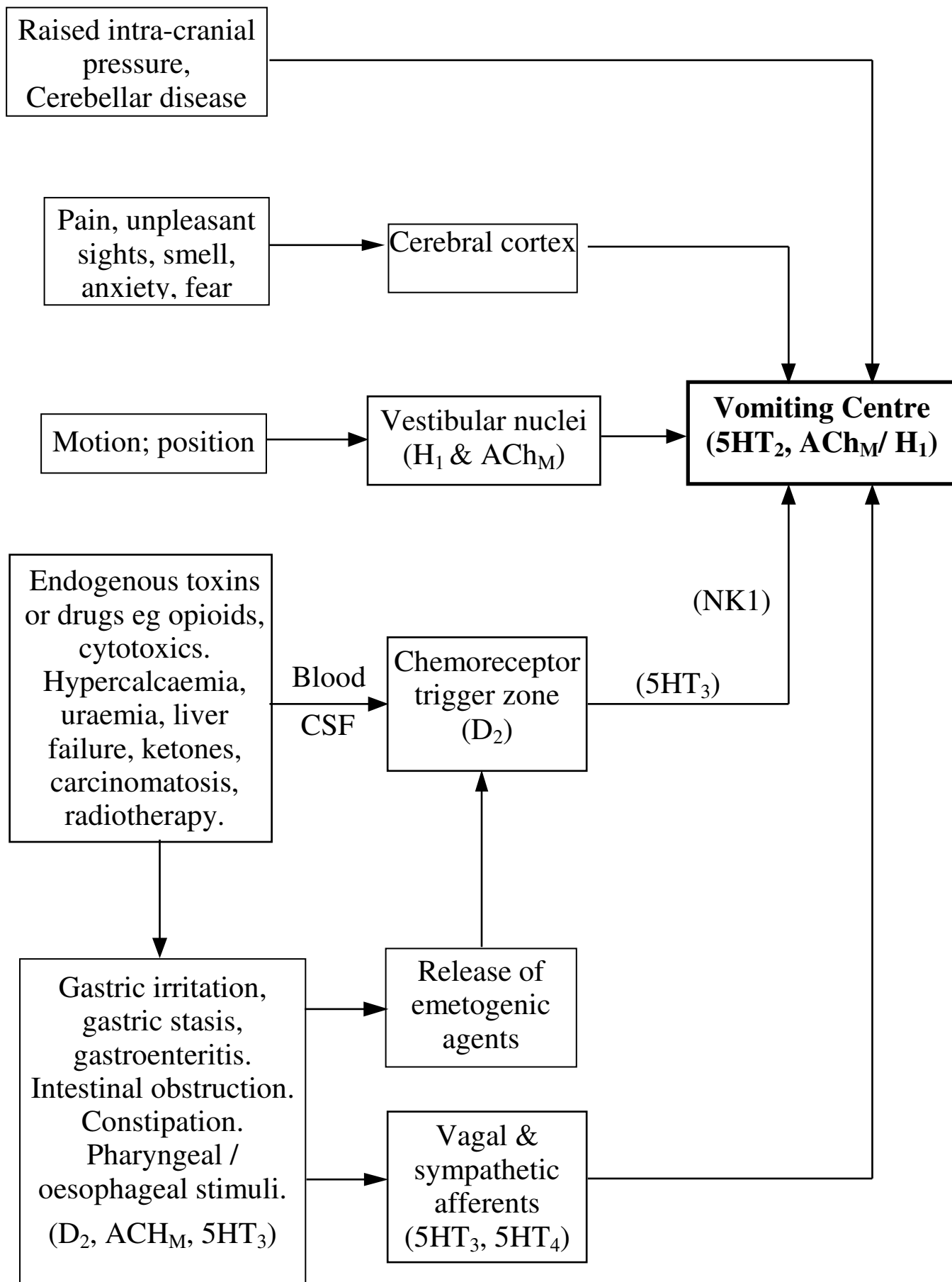
There are a number of techniques and therapies, provided by a wide range of professionals, which aim to encourage relaxation, finding distraction and other interests. Most patients will find at least some of these approaches will help.

D Transcutaneous electrical nerve stimulator (TENS) or Acupuncture

** indicates that this is best managed by specialists*

NAUSEA AND VOMITING

Mechanisms



Causes / Risk factors

There are many causes of nausea and vomiting and often more than one cause is present. Mechanisms are outlined on the previous page. See next page for profiles of antiemetics.

Management

1. Treat cause if possible eg stopping/changing/reducing drugs.
2. Non-drug measures include relaxation and psychotherapeutic techniques, acupuncture, ginger and Seabands.
3. In established nausea and vomiting may need to use antiemetics via non-oral routes for initial control eg csci via syringe driver.
4. Drug therapy (see next page for drug profiles):

Cause	Drug therapy
Raised intracranial pressure, & cerebellar disease	Dexamethasone (see p52) Cyclizine or levomepromazine
Anxiety	Levomepromazine, benzodiazepines (see p37)
Motion, positional	Cyclizine Hyoscine hydrobromide
Drugs, endogenous toxins	Metoclopramide Haloperidol, prochlorperazine Levomepromazine
Chemotherapy, and radiotherapy	Consult oncology colleagues Early: 5HT ₃ antagonists or prokinetics Delayed: dexamethasone, levomepromazine
Gastric stasis	Metoclopramide, domperidone Erythromycin*
Gastric irritation	Review medication Antacids Proton pump inhibitors Misoprostol 400mcg bd if caused by NSAIDs
Intestinal stasis	Metoclopramide 40 - 80mg daily
Intestinal obstruction	See separate section p20
Constipation	See separate section p25
Indeterminate	Metoclopramide Levomepromazine or Cyclizine Dexamethasone 4 - 8mg om Trial of others

Antiemetic drug profiles (see also p57):

- Cyclizine**
- H₁ antihistamine with anticholinergic action
 - 50mg tds orally or by sc injection
 - 100 - 150mg over 24 hours by csci (skin irritation)
- Dexamethasone**
- reduces intracerebral swelling, other modes of action uncertain
 - may help emesis of indeterminate cause
 - 4 - 8mg od for 5 day trial
- Domperidone**
- dopamine D₂ antagonist and prokinetic
 - unlikely to cause sedation / extrapyramidal effects
 - 10 - 20mg tds - qds orally
 - 30 - 60mg suppositories bd rectally
- Haloperidol †**
- pure dopamine D₂ antagonist, not prokinetic
 - often used for opioid induced nausea
 - may cause extrapyramidal effects
 - 1.5 - 5mg nocte, oral or sc
 - 2.5 - 5mg over 24 hours by csci
- Hyoscine hydrobromide**
- antimuscarinic anticholinergic (ACh_M)
 - 0.3 - 0.6mg up to qds sl (Kwells) or sc
 - 0.8 - 2.4mg over 24 hours by csci (sedating)
 - 1mg every 72 hours by transdermal patch
- Levomepromazine †**
- activity at multiple sites (5HT₂, D₂, ACh_M/H₁)
 - can cause hypotension in susceptible patients
 - antiemetic at modest doses 5 - 25mg daily, use lowest effective dose unless sedation required, usually given as single oral dose nocte or by csci
- Metoclopramide †**
- dopamine D₂ antagonist and prokinetic
 - 10 - 20mg tds - qds oral or sc; can be by csci
 - 5HT₄ agonist (bowel prokinetic) (40 - 80mg daily)
 - 5HT₃ antagonist at high doses (>100mg daily)
- Prochlorperazine †**
- predominantly D₂ antagonist, weak anti-ACh_M/H₁
 - 5 - 10mg tds orally or 3 - 6mg bd as buccal tablets
 - 12.5mg tds by deep im injection - do not give sc
- 5HT₃ antagonists**
- ondansetron and others (see Section 4.6 of BNF)
 - used to control early emesis after chemotherapy and abdominal radiotherapy
 - avoid prolonged use, cause constipation
- Neurokinin1 antagonists***
- used as an adjunct with emetogenic chemotherapy

† avoid in Parkinsonism and dystonia

INTESTINAL OBSTRUCTION

Intestinal obstruction in association with advanced cancer is often complex and difficult to control. Early discussion with specialist palliative care team is recommended. Has both mechanical (intestinal narrowing) and functional (poor motility) elements.

Diagnosis

- 1 Range of symptoms depends on level of blockage, but these include:
 - vomiting often with little preceding nausea
 - constipation, although some flatus and/or stool may still be passed
 - abdominal distension and generalised discomfort
 - colic may or may not be a feature
 - bowel sounds may be hyperactive or scanty.
- 2 Examine previous operation notes; abdominal x-ray may be helpful.
- 3 Exclude simple constipation by rectal and abdominal examination.

Causes / Risk factors

- 1 Most common with primary tumours of ovary and colon, but may occur with almost any primary site, including breast and lung.
- 2 Tumour mass within lumen.
- 3 Tumour on peritoneal surface causing oedema or adhesions.
- 4 Infiltration within muscle coats preventing normal peristalsis.
- 5 Damage to autonomic nerve plexuses by tumour infiltration of mesentery.
- 6 Pancreatic carcinoma may cause gastric stasis by unknown mechanism.
- 7 Adhesions, radiation fibrosis, metabolic disturbance, constipation, sepsis.

Management

This will depend on the site of obstruction; whether complete or incomplete; bowel motility; and the patient's wishes and general condition.

- 1 Consider surgery or stenting if there are clinical features to suggest a single site of obstruction, especially where colic is a prominent symptom, or where distension is such as to require venting.
- 2 If inoperable, aim to control symptoms without the need for continuous 'drip and suck' but:
 - a) nasogastric intubation or percutaneous venting gastrostomy may be preferred by patients with gastroduodenal obstruction where drug treatment has been unsuccessful;
 - b) hydration with 1+ litre per day iv or sc may relieve thirst (not dry mouth), but may increase vomit volume.
- 3 Treat dry mouth (see p23).
- 4 Treat symptomatic gastro-oesophageal reflux.

5 Drug therapy:

Constant abdominal pain

- Strong opioids, eg morphine, diamorphine by csci.

Colic

- Avoid/stop stimulant and bulking laxatives.
- Avoid prokinetic antiemetics (metoclopramide, domperidone).
- Hyoscine butylbromide 40 - 120 (- 240*)mg daily by csci.
- Mebeverine, alverine po may help if only intermittent partial obstruction.

Nausea and vomiting

Aim to abolish nausea and to reduce vomiting to a minimum.

- Cyclizine - see p19
- Levomepromazine - see p19
- Haloperidol - see p19
- Metoclopramide (see p19) may help where there is gastric stasis or ileus but is contra-indicated in the presence of colic; the response is unpredictable if there has been a gastro-jejunostomy
- Anti-secretory agents
 - a) If high (gastroduodenal) obstruction:
 - hyoscine butylbromide 40 - 120 (- 240*)mg daily by csci reduces secretions
 - H₂ blocker (ranitidine) may reduce volume of gastric secretions.
 - b) If small bowel obstruction consider:
 - hyoscine butylbromide (see above)
 - octreotide* initially 300 - 500mcg per day by csci: reduces volume of intestinal secretions and inhibits motility. Effect may take several days to appear. The final effective dose is likely to be 200 - 800mcg per day.

Laxatives

- Check that lower rectum is empty.
- Do not use if there is complete obstruction.
- If there is partial intermittent obstruction, can use faecal softeners with caution:
 - docusate sodium up to 200mg tds
 - magnesium hydroxide mixture 20 - 30 ml od or bd
 - macrogols (eg Movicol) 1 sachet up to tds.

Shrinkage of tumour masses

- Dexamethasone 4 - 8mg daily may help to relieve peri-tumour oedema and so relieve obstruction, particularly at the gastric outlet.
- Hormone/cytotoxic therapy is occasionally indicated if the patient's overall condition is good, especially in primary tumours of ovary, colon or breast.
- Radiotherapy is occasionally appropriate for low large bowel tumours.

MOUTH PROBLEMS

Good mouth care is essential to the well being of debilitated patients. Although mouth problems are very common (up to 90% of patients in some surveys), it is often a neglected area of care.

Diagnosis

- 1 Assess oral cavity daily using a pen torch and spatula. Note the state of the lips, teeth/dentures (remove the dentures for examination), mucous membranes and tongue, and also the type/volume of saliva.
- 2 Assess nutritional status - quality of diet and adequacy of fluid intake.
- 3 Assess mental state - will determine the patient's ability and willingness to participate in his or her care.

Causes / Risk factors

- 1 Dry mouth (xerostomia) especially from drugs (opioids, tricyclic antidepressants, antimuscarinics), dehydration (reduced intake or diuretics) and local radiotherapy.
- 2 Poor oral and dental hygiene.
- 3 Poor oral intake leading to decreased mastication.
- 4 Poor nutritional state, especially if leading to vitamin deficiencies.
- 5 Infections: viral, bacterial and fungal.
- 6 Some cytotoxics can cause mucositis and acute ulceration; radiotherapy can cause mucositis.
- 7 Corticosteroids and diabetes predispose to oral candidosis.
- 8 Oral tumours.

Management

- 1 Review medications causing dry mouth or other oral problems.
- 2 Treat oral infections.
- 3 Maintain frequent attention to good oral hygiene.
- 4 Alcohol-free chlorhexidine mouthwash may be used in debilitated patients - inhibits plaque formation and is antiseptic.
- 5 Maintain good denture care by cleaning and rinsing thoroughly. Dentures can be named by writing on them with a pencil and applying a coat of nail varnish.

Specific problems

Lack of good quality saliva

- 1 Salivary stimulants
 - Sugar free chewing gum
 - Pilocarpine 5 - 10mg tds (or 1 - 2 drops 4%, flavoured to taste), bethanecol 10mg tds
- 2 Saliva substitutes
 - Spray eg Xerotin (non-acidic, no animal products)
 - Gels eg Biotène oral balance
- 3 Sips of water or ice cubes may give short term relief.

Oral Thrush

- 1 Increase the flow of saliva as described above.
- 2 Nystatin oral suspension 1 - 5ml qds for at least 7 days.
- 3 Fluconazole 50mg daily by mouth for 7 days. Less effective in xerostomia. Note that there is increasing resistance to triazole antifungals.
- 4 Ensure that dentures are thoroughly cleaned and disinfected.

Painful mouth

- 1 Treat infections - metronidazole for fungating tumours in the mouth, herpes orogingivitis is extremely painful (may need aciclovir).
- 2 For symptomatic relief use Difflam or soluble aspirin gargle, flurbiprofen lozenges or systemic NSAIDs by other routes.
- 3 Aphthous ulcers may respond to local steroid, eg hydrocortisone pellets.
- 4 For chemotherapy induced mucositis try Mugard or sucralfate suspension.
- 5 Other analgesic options: oramorph liquid held in the mouth, local anaesthetic (lidocaine) spray, may cause initial stinging.

Excessive salivation or drooling with swallowing problems

- 1 May be helped by hyoscine hydrobromide patch 1mg / 72hrs, atropine drops 1% sub lingual, glycopyrronium or hyoscine butylbromide via csci (see p57), or amitriptyline (low dose) via gastrostomy. These may make the saliva unacceptably sticky, in which case propranolol can be considered.
- 2 Some units offer botulinum toxin injection to the salivary glands to reduce salivation.
- 3 In severe cases, radiotherapy to the salivary glands may be considered.

ANOREXIA

Diagnosis

- 1 A reduced interest in food which at its most severe may manifest as nausea.
- 2 Often associated with taste changes.
- 3 May increase (appetite diminishes) as the day goes on.
- 4 Distinguish from mouth problems, difficulties with swallowing, and early satiety due to gastric stasis.

Causes / Risk factors

- 1 Extensive malignancy (but occasionally occurs as a presenting symptom).
- 2 Uncontrolled symptoms.
- 3 Psychological, emotional and spiritual distress eg anxiety and depression.
- 4 Drugs, especially cytotoxics, digoxin.

Management

- 1 Treat nausea, pain and other symptoms.
- 2 Reduce psychological distress with support and counselling.
- 3 Treat depression, preferably not using SSRIs as can increase anorexia.
- 4 Review drugs.
- 5 Aim to provide frequent, small, attractive portions within pleasant and social surroundings.
- 6 Drug therapy - if drugs are needed and there are no contra-indications:
 - alcohol before meals
 - megestrol acetate 160 - 320mg daily: may take 2 - 3 weeks to respond (increased risk of thrombosis)
 - dexamethasone 2 - 4mg or prednisolone 10 - 30mg om (see p52).

ANOREXIA/CACHEXIA/FATIGUE SYNDROME

Diagnosis

- 1 A syndrome of loss of appetite, fatigue, and profound weight and muscle loss.
- 2 There is usually an associated rise in acute-phase proteins, eg CRP.

Causes / Risk factors

- 1 Usually associated with cancer but may occur with heart failure and chronic infection or inflammation.
- 2 Cytokine release leading to proteolysis, lipolysis, increased resting energy expenditure, and hypothalamic disturbances including anorexia.

Management

- 1 Correct associated problems (see above).
- 2 Fatigue management programme - gentle but regular exercise programme to reduce muscle loss and promote adaptive behaviour.
- 3 Dexamethasone 2 - 4mg om or NSAIDs to reduce inflammatory process.
- 4 Anecdotal evidence for methylphenidate* or modafinil* to improve fatigue.
- 5 Evidence is unclear on the place of fish oils (eg Maxepa), nutritional supplements (eg Prosure) and anabolic steroids.

CONSTIPATION

Constipation is common in patients with advanced disease. It can cause abdominal pain and urinary retention. Even if not eating, patients can become constipated due to accumulation of faecal matter formed from gut secretions, cells and bacteria. It is far better to anticipate and prevent constipation than to wait until treatment is urgent.

Diagnosis

- 1 Passing harder and/or less frequent stools than normal.
- 2 Faecal impaction may present with overflow ('spurious diarrhoea').
- 3 Rectal examination: empty or impacted, collapsed or cavernous?
- 4 Exclude intestinal obstruction.

Causes/Risk factors

- 1 Drugs, especially oral opioids, antidepressants, antispasmodics, ondansetron.
- 2 Inactivity, immobility, weakness, lack of privacy.
- 3 Dehydration due to poor fluid intake, vomiting, polyuria, fever.
- 4 Hypercalcaemia.
- 5 Concurrent disease including painful anal conditions, neurological disorders.

Management

- 1 Reduce or eradicate underlying cause(s) as far as possible.
 - 2 If general condition allows, mobilise and encourage fluids.
 - 3 Drug treatments:
 - a) Use softeners if stool is hard, stimulants if soft stool is not expelled.
 - b) Patients taking regular opioids will usually and routinely need both, although macrogols alone are often sufficient.
- | | |
|------------------------------|---|
| <i>Stimulants</i> | Senna 2 - 4 tablets nocte or bd.
Bisacodyl tablets 5 - 20mg nocte or bd.
Sodium picosulphate solution 5 - 10ml od/bd. |
| <i>Softeners</i> | Docusate sodium capsules 200mg nocte or bd.
Macrogols (eg Movicol) 1 sachet od or bd. |
| <i>Osmotics</i> | Magnesium hydroxide 20 - 30ml od or bd.
Lactulose 10 - 15ml bd (not advised, excess wind). |
| <i>Combined preparations</i> | Codanthramer liquid or capsules (two strengths).
Codanthrusate liquid or capsules. |
- 4 Often, patients need suppositories or enemas for established constipation. If rectal faeces, glycerol or bisacodyl suppositories usually given. If the rectum is empty but colon loaded with hard stool, use arachis oil retention enema overnight (check no peanut allergy) followed by phosphates enema. If opioid related constipation consider methylnaltrexone sc (dose according to weight).
 - 5 Manual evacuation should be a last resort, and consent obtained after full explanation. Sedation may be required.

DIARRHOEA

Diagnosis

The patient who speaks of 'diarrhoea' may be referring either to the frequency or to the looseness of bowel motions. An accurate history and examination are crucial: assess for watery/liquid stools usually with an increased stool frequency.

Causes / Risk Factors

- 1 Excess laxative use.
- 2 Impacted faeces with overflow (spurious diarrhoea).
- 3 Side effects of some drugs, eg chemotherapy, antibiotics, PPIs, NSAIDs.
- 4 Infections, including *C. difficile*, upper GI bacterial overgrowth, giardia.
- 5 Partial intestinal obstruction.
- 6 Previous treatment: pelvic radiotherapy, extensive bowel resection.
- 7 On initiation of enteral feeding.
- 8 Pancreatic insufficiency, characterized by bulky, offensive stools which float.
- 9 Effects of some tumours, eg carcinoid, mucus secretion in rectal cancer.
- 10 Other - eg inflammatory bowel disease, bile salt malabsorption, secondary lactose intolerance, autonomic neuropathy (diabetes, paraneoplastic), IBS.

Management

- 1 Review all drugs, including laxatives and non-prescription drugs.
- 2 Screen for infections and prescribe antibiotics as appropriate.
- 3 Address dehydration if appropriate.
- 4 *Specific treatments*
Steroids given locally or systemically for radiation induced diarrhoea.
Pancreatic enzymes (Creon capsules; 3 strengths) for steatorrhoea.
Metronidazole for bacterial overgrowth/blind loop syndrome.
Octreotide* (see pp21, 57) for faecal fistulae, carcinoid syndrome.
Colestyramine for bile salt malabsorption.
- 5 *Symptomatic treatments*
Loperamide 2 - 4mg every 6 hours; binds to opioid receptors in gut.
Codeine phosphate 30 - 60mg tds - qds.
Co-phenotrope (Lomotil) 2 tablets up to qds.

FISTULAE

Management

- 1 Assess fistula size, site and type, and patient's overall condition.
- 2 Prevent excoriation with a barrier product.
- 3 Collect effluent in a closed stoma bag. A good seal is needed to minimise leakage and odour. If necessary seek advice from stoma care nurses.
- 4 Metronidazole may be helpful if there is blind loop or overgrowth of anaerobes.
- 5 Surgical intervention may be appropriate.
- 6 Octreotide* by csci may be helpful in reducing effluent, see pp21, 57.

ASCITES

Diagnosis

- 1 Clinical assessment: progressive distension, shifting dullness, fluid thrill.
- 2 Abdominal ultrasound (with marking for paracentesis if appropriate).
- 3 Exclude tumour masses, organomegaly, distended bladder, intestinal obstruction.

Causes / Risk factors

- 1 Peritoneal metastases - may be associated with extra-abdominal primary sites.
- 2 Tumour obstructing retroperitoneal/diaphragmatic lymph system.
- 3 Hypoalbuminaemia, usually associated with extensive liver metastases.
- 4 Secondary sodium retention.
- 5 Venous compression or thrombosis of inferior vena cava or hepatic vein.
- 6 Other concurrent disease, eg heart failure, cirrhosis.

Management

- 1 If symptoms are minor, explanation and reassurance may be sufficient.
- 2 Paracentesis may be appropriate for patients with a tense, uncomfortable, distended abdomen, especially if associated with breathlessness. Can use ultrasound to identify suitable location. Drain up to 5 litres of fluid per day, but sudden release of abdominal tension may lead to venous decompression, hypotension and collapse. Remove drain after 1 - 2 days, there is no advantage in draining to dryness. If leakage continues after drain is removed, place stoma bag over puncture site.
- 3 Peritoneo-venous shunt (eg Denver or LeVeen shunt) may be considered for selected patients who require frequent paracentesis as electrolytes and albumin are conserved, or indwelling drainage systems eg PleurX.
- 4 Drug therapy
 - Analgesia* (from paracetamol up to strong opioids) for abdominal pain or discomfort of distension.
 - Antiemetics*: domperidone or metoclopramide for gastric stasis.
 - Diuretics*: furosemide (especially if dependent oedema) 40 - 80mg od; spironolactone (especially if low albumin) 50 - 200mg od. Diuretics are less likely to be effective if due to peritoneal metastases. Monitor electrolytes, renal function and blood pressure.
 - Corticosteroids*: dexamethasone 2 - 4mg om may reduce lymph blockage.
 - Laxatives* as appropriate to treat constipation.
 - Cytotoxic chemotherapy* (local or systemic) may be appropriate, especially for primary carcinomas of ovary, breast or colon - seek oncological advice.

BREATHLESSNESS

Breathlessness is usually multifactorial. There is inevitably a psychological component – being breathless is always frightening and patients often have unspoken fears about how they will die.

Investigations eg chest x-rays, scans and blood tests may be needed to exclude reversible causes but are often of limited value; oxygen saturation will guide the use of oxygen. A therapeutic trial of treatments, either singly or in combination, is often necessary to find out what works in an individual patient.

Causes / Risk factors

A Impaired gas exchange.

1 *Airflow obstruction*

a) Large airways:

tumour
extrinsic compression
laryngeal palsy
radiation stricture

b) Small airways:

lymphangitis carcinomatosa
COPD, asthma

2 *Decreased effective lung volume*

effusions
pneumothorax
extensive tumour
collapse
infection

3 *Increased lung stiffness*

gross abdominal distension
pulmonary oedema
lymphangitis carcinomatosa
fibrosis

4 *Decreased alveolar gas exchange*

pulmonary embolism
pericardial effusion
thrombotic tumour
fibrosis

5 *Pain*

pleurisy
chest wall infiltration
rib/vertebral fractures
liver capsule pain

6 *Neuromuscular failure*

paraplegia
chronic neuromuscular diseases
phrenic nerve palsy
cachexia, deconditioning
paraneoplastic syndromes

B Increased demand

1 *Anxiety*

2 *Anaemia*

3 *Metabolic acidosis*

Management

General treatments

Can be employed whilst investigating for an identifiable and correctable cause. General and specific managements should be used in parallel. Consider consulting the respiratory team.

A Non drug treatments

- A fan (hand held or fixed) or cool air across the face is often helpful.
- Proper positioning for easier breathing.
- Explore the patient's fears about breathlessness.
- General and specific reassurance (eg that the patient will not suffocate).
- Explanation of the mechanisms of breathlessness.
- Breathing exercises, relaxation training) 'pulmonary rehabilitation' by Counselling and readaptation) physiotherapist/specialist nurse
- Acupuncture, aromatherapy, reflexology.

B Drug treatments

- Nebulised saline often helps where there are tenacious secretions.
- Opioids often help reduce the subjective sensation of breathlessness; there is no evidence that they shorten life. If opioid naïve, start on 2.5mg of oral morphine 4 hourly prn and titrate upwards. If already on morphine for pain, the dose may need to be increased by 25 - 50% for co-existing breathlessness. Morphine/diamorphine often used via csci when severe breathlessness. Nebulised opioids are no longer advised.
- Benzodiazepines are often used in combination with opioids for their anxiolytic effect. Use diazepam 2 - 10mg daily for background control with option of lorazepam 0.5 - 1mg sublingually (quick-acting) for acute crises and panic. Midazolam 2.5 - 10mg sc stat or 5 - 50mg per 24 hours by csci if patient is not able to take oral medication.
- Oxygen has variable effects; it is difficult to predict who will benefit other than by individual therapeutic trial, but patients with oxygen saturations <90% usually benefit from oxygen. Nasal prongs are often preferred to masks. For some patients the burden of continuous attachment/dependence on oxygen may outweigh its benefit.

C Refractory/severe breathlessness

Refractory/severe breathlessness is distressing for patients and their families, and can result in an exhausted patient who is too frightened to sleep. One can offer csci midazolam (+/- low dose opioid) to provide the required balance between breathlessness and sedation with dose adjustment according to patient's wishes.

D Decisions about ventilation

When a patient may be at risk of respiratory failure, the risks/benefits of mechanical ventilation (invasive or non-invasive) should be considered and, where appropriate, discussed with the patient in order to avoid crisis decisions about ventilation. In the majority of cases invasive ventilation will not be appropriate. Careful documentation of the decision is necessary.

E Sudden major airway obstruction

This is a palliative care emergency requiring urgent sedation, eg midazolam 10mg iv or sc. The cause should then be treated if possible.

Specific treatments

- 1 Extensive lung metastases: dexamethasone 4 - 8mg daily (see p52).
- 2 Lymphangitis carcinomatosa: dexamethasone 4 - 8mg daily (see p52), chemotherapy.
- 3 Large airway narrowing: radiotherapy, endobronchial stents, dexamethasone 4 - 8mg daily (see p52).
- 4 Bronchoconstriction: inhaled bronchodilators, steroids.
- 5 a) Pleural effusion: drainage, pleurodesis, PleurX catheter
b) Pericardial effusion: drainage, sometimes formation of a pericardial window.
c) Ascites: drainage (see p27).
- 6 Infection: antibiotics as appropriate.
- 7 Respiratory secretions: physiotherapy, nebulised saline, mucolytics eg carbocysteine (if thick). (Upper airway secretions – see pp23, 59).
- 8 Pulmonary emboli: anticoagulation as appropriate (see p50).
- 9 Pulmonary oedema: diuretics, low dose opioids.
- 10 Chest wall/pleuritic pain: NSAIDs, steroids, opioids, nerve blocks, radiotherapy, cordotomy (see Pain section).
- 11 MND, other neuromuscular disorders: nasal or mask BiPAP, mainly nocte (seek Respiratory Team advice early).
- 12 Laryngeal obstruction/stridor: urgent ENT opinion, tracheostomy, dexamethasone 4 - 8mg daily (see p52).
- 13 Laryngeal nerve palsy: vocal cord injection, ENT opinion.
- 14 Anaemia: transfusion if appropriate (see p48).

COUGH

Diagnosis

- 1 Ask about sputum (and if possible observe) – quantity, consistency, colour.
- 2 Is cough affected by position?
- 3 Examine chest. Chest x-ray may be helpful.
- 4 PEFV to check for reversibility – bronchospasm may present with cough.

Causes / Risk factors

- 1 Nasopharyngeal – post-nasal drip, candidosis, tumour.
- 2 Laryngeal – tumour, inflammation, infection.
- 3 Bronchial – inflammation, tumour, infection, ACE inhibitors, tracheo-oesophageal fistula.
- 4 Pulmonary – pneumonia, alveolitis/fibrosis, abscess, bronchiectasis, oedema.
- 5 Pleural – pleural effusion.
- 6 Mediastinal – tumour, lymphadenopathy.
- 7 Gastric reflux – with or without frank aspiration.

Management

Treat the cause where possible.

- 1 More upright body position.
- 2 Steam inhalations, nebulised saline, mucolytic for thick secretions.
- 3 Chest physiotherapy where appropriate.
- 4 Treat infections unless the chest infection is a terminal event.
- 5 Radiotherapy may help if cough is caused by tumour.
- 6 Drug therapy

General:

- a Inhalations: benzoin co tincture, menthol & eucalyptus.
- b Simple linctus.
- c Low dose oral opioids: codeine, morphine.

Specific:

- a Nasopharyngeal – post-nasal drip: antibiotics, nasal steroid spray.
- b Laryngeal
 - steroids via inhaler.
 - local anaesthetics* via nebuliser : bupivacaine 0.5%, 5ml tds, at least 30 minutes before any food or drink; risk of idiosyncratic bronchospasm, may be severe.
- c Bronchial
 - bronchodilators in standard doses.
 - steroids orally or inhaled.
 - local anaesthetics* (see above).
- d Gastric reflux
 - antacids containing simeticone or alginate.
 - prokinetic agents (see p19).

HICCUP

Causes / Risk factors

- 1 *Peripheral (diaphragmatic or phrenic nerve irritation)*
 - gastric distension or irritation
 - liver enlargement/involvement
 - intrathoracic nodes/tumour
 - tumour irritation/involvement of diaphragm.
- 2 *Central (medullary stimulation)*
 - raised intracranial pressure
 - brain stem CVA/tumour
 - uraemia (also causes gastric stasis).

Management

- 1 Rebreathing with a paper bag (raises pCO₂ levels).
- 2 Drinking cold water or taking a teaspoon of granulated sugar (pharyngeal stimulation).
- 3 Phrenic nerve block for intractable hiccup.
- 4 Drug therapy

Peripheral causes: metoclopramide 10mg tds - qds
 domperidone 10 - 20mg tds - qds
 antacids containing simeticone
 proton pump inhibitors or ranitidine 150mg bd

dexamethasone 4 - 8mg od

baclofen 5mg od - tds
nifedipine 10mg od - tds

Central causes: haloperidol 0.5mg od - tds
 dexamethasone 4 - 8mg od
 diazepam 2mg od - bd or midazolam by csci
 chlorpromazine* 25mg od - tds (very sedating)
 or levomepromazine by csci

None of these treatments is consistently reliable.

RAISED INTRACRANIAL PRESSURE

Diagnosis

- 1 Severe headache worse when lying down or straining.
- 2 Vomiting, convulsions, mental symptoms, diplopia, restlessness.
- 3 Papilloedema may be present.
- 4 CT/MRI scan may be appropriate.

Causes / Risk factors

- 1 Cerebral metastases (common with some primaries, eg lung, breast, melanoma, and rare with others, eg prostate).
- 2 Primary cerebral tumour.
- 3 Other causes – abscess, cerebro-vascular event, sagittal sinus thrombosis, secondary hydrocephalus following surgery.

Management

- 1 Raise head of the bed.
- 2 Consider cranial irradiation or neurosurgery for malignancy if prognosis/status warrants it.
- 3 Drug therapy:
Dexamethasone up to 16mg per day. Avoid doses after 2pm as may add to insomnia. Gradually reduce dose to minimum effective (see p52), monitoring that symptoms remain controlled. Withdraw dexamethasone if no improvement after 7 days on 16mgs daily. (Phenytoin and carbamazepine may reduce therapeutic effect by up to 50%, and vice versa, by enzyme induction).
Analgesics for headache – eg paracetamol.
Antiepileptics should be considered in the presence of cerebral malignancy, but normally reserved for those who have had fits (see p34).
Acetazolamide* 250 - 500mg od - bd, anecdotal evidence for benefit.

SPINAL CORD COMPRESSION

Diagnosis

Occurs in 5 - 10% of patients with advanced cancer. It is therefore essential to be alert for early signs, which can be subtle (eg heaviness of the legs). Do not wait for signs to become unequivocal: **early diagnosis** and **urgent treatment** within hours are vital to improved outcome, mobility and continence. Once paralysed, only 5% walk again, but some survive more than one year.

- 1 Often back pain with or without radiation in the territory of a nerve root, followed by sensory changes, bladder or bowel disturbance, and leg weakness, but can be any combination of these.
- 2 If at thoracic level, there is likely to be a sensory level with brisk reflexes; if cauda equina compression, reflexes may be diminished.

Causes / Risk factors

- 1 Epidural invasion from vertebral body metastases or paravertebral nodes.
- 2 Bony deformity from vertebral body collapse.
- 3 Blood borne epidural or intradural metastases.
- 4 Primary spinal cord tumour.

Management

Depending on patient's general condition:

- 1 Immediate:
 - dexamethasone 16mg per day
 - emergency MRI scan, or CT scan if MRI unavailable
 - urgent referral to clinical oncologist and discuss with neuro/spinal surgical team.
- 2 a) If gradual onset, or if rapid onset but paraplegia present less than 24 hours, surgical decompression may be possible; otherwise radiotherapy.
b) If rapid onset and established paraplegia, radiotherapy may not help except for pain relief.
- 3 Established paraplegia:
 - pressure area care
 - urinary catheter
 - bowel regulation – allow some constipation and use regular enemas or suppositories
 - physio and OT assessment – wheelchair, home modifications
 - consider prophylaxis against venous thrombosis
 - psychological readjustment.
- 4 Specialist palliative care assessment for management and/or rehabilitation is recommended.

DEPRESSION

It is important to distinguish between clinical depression, profound sadness and dementia. Be aware that many of the usual somatic symptoms of depression such as anorexia, weight loss and sleep disturbance may already be present in patients with malignant disease. Depression may be hidden behind a brave but hollow smile or even overt joking. A therapeutic trial of antidepressants may be acceptable.

Diagnosis

Biological symptoms

- Diurnal variation in mood; may be agitation.
- Sleep disturbance, especially with frequent or early morning waking.
- Anorexia that does not improve with steroids.

Psychological symptoms

- Persistent, pervasive low mood with loss of pleasure and enjoyment.
- Morbid guilt, feelings of helplessness and worthlessness/low self esteem.
- Suicidal ideas and intentions.

Causes / Risk factors

- 1 Past history of depression.
- 2 Need to adjust to many life changes over a short period of time.
- 3 Poor symptom control.
- 4 Immobility and isolation with poor quality of life and lack of support.
- 5 Inadequate or inaccurate information about illness or prognosis.
- 6 Early dementia.
- 7 Drugs – corticosteroids (predominantly on withdrawal), benzodiazepines, some cytotoxics, antihypertensives and neuroleptics.

Management

- 1 Minimise the causes, especially 3 - 5 above.
- 2 Provide psychological support.
- 3 Drug therapy is recommended in moderate to severe depression. NICE guidance is that first line treatment should be with an SSRI. Alternatives within palliative care would include mirtazapine, amitriptyline and dosulepin. If there is a lack of response or unacceptable side effects, consider a switch to another SSRI or to mirtazapine.

ANXIETY

Diagnosis

- 1 Feeling of being on edge, restless or agitated, apprehension.
- 2 Inability to concentrate.
- 3 Physical effects such as sweating, tachycardia, staring eyes with dilated pupils.
- 4 Anxiety may be a presenting feature of an underlying depression.

Causes / Risk factors

- 1 Past history of anxiety.
- 2 Poor symptom control.
- 3 Inadequate/inaccurate information.
- 4 Unfamiliar surroundings.
- 5 Uncertainty about the future.
- 6 Concern for family/finances etc.
- 7 Early dementia.
- 8 Depression
- 9 Steroid treatment/salbutamol therapy.
- 10 Withdrawal of drugs eg opioids/benzodiazepines.

Management

- 1 Support for patient and family.
- 2 Appropriate information and discussion with patient and family.
- 3 Relaxation techniques and complementary therapies.
- 4 Treatment of depression if present (see p36).
- 5 If part of agitation with confusion, see p41.
- 6 Drug therapy:
 - Diazepam 2mg bd and/or 5mg at night – for short term use.
 - Propranolol 40mg bd to tds for somatic symptoms.
 - Lorazepam 0.5 - 1mg given sublingually may be helpful in panic attacks.
 - If the patient is unable to swallow or has a syringe driver for other reasons, consider midazolam 10 - 20mg per 24 hours by csci.

INSOMNIA

Diagnosis

Insomnia is a subjective complaint of poor sleep. This can mean insufficient, interrupted or non-restorative sleep or sleep at the wrong time. It is important to distinguish between an inability to get to sleep (eg anxiety, confusion) and a tendency to wake early or repeatedly (eg depression, urinary problems, pain).

Causes / Risk factors

- 1 Anxiety or depression.
- 2 Poor symptom control.
- 3 Nocturia.
- 4 Environmental changes – inpatient admission, interruptions by staff.
- 5 Fear – eg of going to sleep or of nightmares. Beware of well-intentioned reassurance that ‘you will die in your sleep’.
- 6 Drugs – stimulants (caffeine etc), steroids (worse if given later than 2pm), diuretics, opioids (vivid dreams, hallucinations), fluoxetine, propranolol (nightmares).
- 7 Drug withdrawal – alcohol, benzodiazepines, barbiturates.

Management

- 1 Minimise the causes – control symptoms as far as possible, keep interruptions to a minimum, reduce drug therapy or give stimulants early in the day, counsel about fears and anxieties.
- 2 Establish a good sleep pattern – allow a siesta to prevent going to bed too early.
- 3 Encourage a consistent bedtime ritual, a warm milky drink may help.
- 4 Encourage relaxation techniques.
- 5 Drug therapy:
Benzodiazepines eg temazepam 10 - 20mg
Zopiclone 3.75 - 7.5mg, zolpidem 5 - 10 mg or zaleplon 5 - 10mg may have fewer residual effects than benzodiazepines.
Clomethiazole (1 - 2 capsules) has a short duration of action.
Amitriptyline 10 - 150mg or dosulepin 25 - 75mg if early morning waking.
Melatonin* 2mg for 1 - 3 weeks – increasing anecdotal evidence for use in some sleep disturbances eg day-night reversal.

Note – all as a single dose at night, short term use advised
– hypnotics may increase risk of falls and nocturnal confusion.

DROWSINESS

Causes / Risk factors

Organic

- 1 Disease progression and likely impending death.
- 2 Infection, especially within respiratory and urinary tracts.
- 3 Raised intracranial pressure.

Biochemical

- 1 Metabolic abnormalities:
 - uraemia, especially if on opioids
 - hyper/hypoglycaemia
 - hypercalcaemia
 - hyponatraemia
 - hepatic failure
 - respiratory failure (blood gas analysis likely to be inappropriate).
- 2 Drugs :
Opioids, tricyclic antidepressants, benzodiazepines, antimuscarinics, antihistamines.

Other

- 1 Fatigue.
- 2 Insomnia.
- 3 Psychological withdrawal.
- 4 Post-ictal.

Management

- 1 Assess accurately; if the patient is near to death due to advanced disease, further interventions are unlikely to be appropriate.
- 2 Correct physical causes listed above if indicated.
- 3 Review doses of opioids and other sedative drugs.
- 4 Drug therapy:
Dexamethasone up to 16mg daily for raised ICP.
Antidepressants for retarded depression (see p36).
Dexamethasone 2 - 4mg daily may act as stimulant.
Methylphenidate* 2.5mg bd initially may act as stimulant.

CONFUSION

Delirium is typified by acute confusion, often with visual illusions or hallucinations, together with increased or decreased psychomotor activity and fluctuating level of consciousness or attention. It must be distinguished from **dementia**, which is associated with gradual onset poor short-term memory and no impairment of consciousness, and which will not be considered here.

Diagnosis

- 1 Disturbance of consciousness with reduced ability to focus attention.
- 2 Generalised impairment of cognition affecting memory, orientation, attention and planning and organisational skills.
- 3 Short history (usually hours to days) often with fluctuation during the day.
- 4 Evidence from the history, examination, or investigations that there may be a physical cause.

Causes / Risk factors

- 1 Age and pre-existing cognitive deficit.
- 2 Drugs – eg opioids, tricyclic antidepressants, antimuscarinics, any sedative drug, baclofen; higher dose corticosteroids may cause hypomania.
- 3 Infection, especially within respiratory and urinary tracts.
- 4 Biochemical abnormalities – see list under Drowsiness, p39.
- 5 Intracerebral causes – space-occupying lesions, infections, strokes.
- 6 Environment changes – excessive unfamiliar stimuli, inpatient admission, social isolation.
- 7 Poor symptom control – pain, constipation, urinary retention, anxiety, depression.
- 8 Alcohol or drug withdrawal.

Opioid toxicity exacerbated by uraemia*, dehydration or infection is an important cause of confusion and hallucinations. Look for constricted pupils, myoclonic jerks, skin hyperaesthesia. See p12.

Management

- 1 Treat or minimise the possible causes, especially drugs and infections.
- 2 Minimise stimuli: nurse in a room with diffused lighting, little extraneous noise, and few staff changes.
- 3 Attempt to keep patient in touch with reality and environment – eye contact and touch are often helpful.
- 4 Allay fear and suspicion – explain all procedures, don't change position of patient's bed, if possible have a friend or relative of patient present.
- 5 Stress that patient is not going mad and that there may well be lucid intervals.
- 6 Drug therapy:
 - Oxygen if cyanosed/hypoxic and oxygen saturations are <90%.
 - Dexamethasone up to 16mg per day if cerebral tumour or raised ICP.

If paranoid, deluded, agitated or hallucinating

Haloperidol 1.5 - 5mg up to tds; may be given orally, sc or by csci.

Levomepromazine 12.5 - 50mg up to tds, may be given orally, sc or by csci.

If extrapyramidal problems, try atypical antipsychotics.

Avoid antipsychotics in Parkinson's Disease or Dementia Lewy Body type – can try lorazepam 0.5 - 1mg od - tds if sedation required for disturbed behaviour (hallucinations may respond to reduction in disease-specific medication).

Review early as symptoms may be exacerbated by sedative effects.

Midazolam 10 - 60mg by csci if still very agitated despite above measures (benzodiazepines alone can make delirium worse).

RESTLESSNESS

This may be akin to delirium in someone very close to death, or may occasionally reflect unresolved psychological or spiritual distress, especially if this has previously been a problem.

Causes / Risk factors

- 1 Physical discomfort – unrelieved pain, distended bladder or rectum, inability to move, insomnia, uncomfortable bed, breathlessness.
- 2 Drugs – opioid toxicity (especially in renal, liver impairment), hyoscine hydrobromide (paradoxical agitation), phenothiazines (akathisia).
- 3 Infection.
- 4 Raised intracranial pressure.
- 5 Biochemical abnormalities – hypercalcaemia, uraemia, hypoxia.
- 6 Psychological/spiritual distress – anger, fear, guilt. Beware especially if patient has been unwilling to discuss illness.

Management

- 1 Must be a multi-professional approach involving family or main carers.
- 2 Accurately assess the patient.
- 3 Ameliorate all physical elements if possible, eg analgesia, catheterisation.
- 4 Listen to the patient and discuss anger, fear and guilt if possible.
- 5 May be very distressing for the family who will need much support. Their presence may help or may worsen the patient's agitation.
- 6 If there are hallucinations or frank delirium, see p41.
- 7 Drug therapy (see also p59):
 - Diazepam – 2mg bd and/or 5mg nocte orally, 5 - 10mg pr.
 - Midazolam – 10 - 60mg per 24 hours by csci or in divided doses sc or buccal (may only last ~2 hours).
 - Levomepromazine – 25 - 150mg per 24 hours orally or by csci.
 - Clonazepam* – 0.5 - 2mg per 24 hours by csci.
 - Phenobarbital* – 200 - 1200mg per 24 hours by csci (with water but no other drugs) or sc in divided doses.

ITCH

Causes/Risk factors

Histamine mediated

1 Allergies, acute urticaria, insect bites.

Histamine unrelated (unlikely to respond to antihistamines)

1 Hepatic disease: eg biliary obstruction.

2 Chronic renal failure.

3 Lymphoma.

4 Paraneoplastic phenomenon.

5 Parasites, eg scabies, fleas.

6 Skin diseases, eg eczema, psoriasis.

7 Graft versus host disease after allogenic bone marrow transplant.

8 Iron deficiency.

9 Systemic opioid therapy.

Management

1 Alleviate causes if possible.

2 Avoid provocative influences eg rough clothing, vasodilators, overheating.

3 Try to break the itch/scratch cycle – clip nails, cotton gloves, paste bandages.

4 Add a handful of sodium bicarbonate to a cool bath. Pat rather than rub dry.

5 Avoid washing with soap and bubble bath; use a pH balanced soap substitute or emollient bath additives (see BNF section 13.2.1.1).

6 Apply emollients topically (see BNF section 13.2.1) to combat dryness.

7 Apply topical antipruritic lotions (see BNF section 13.3) or use menthol 2% in aqueous cream.

8 Drug therapy:

- Antihistamines chlorphenamine 4mg qds
loratadine 10mg od (non-sedating).
- In obstructive jaundice stenting for common bile duct obstruction
colestyramine 4 - 8g daily (in intrahepatic stasis)
rifampicin* 150 - 300mg od (enzyme inducer)
naltrexone* 25mg od (but reverses opioid analgesia)
buprenorphine patch* 10 - 35mcg/h.
- In uraemia ondansetron 8mg od
gabapentin (low dose)
naltrexone* 25mg od (but reverses opioid analgesia).
- In lymphoma chemotherapy/radiotherapy; corticosteroids
cimetidine 400mg bd.
- In polycythaemia r v aspirin 75 - 150mg od.
- Paraneoplastic pruritus paroxetine 5 - 20mg od
mirtazapine 7.5 - 15mg nocte.
- Other options paroxetine 5 - 20mg od
gabapentin* 100 - 300mg tds (for neuropathic itch)
UVB phototherapy.

9 Consider early advice from dermatologist or palliative care physician.

SWEATING

Causes / risk factors

- 1 Fever.
- 2 Environmental changes.
- 3 Emotional – fear and anxiety (mainly confined to axillae, palms, and soles).
- 4 Extensive malignancy, lymphomas and carcinoid.
- 5 Autonomic disturbance.
- 6 Intense pain.
- 7 Drugs – opioids, antidepressants (older and newer), steroids, alcohol.
- 8 Hormonal disturbance – eg menopause, tamoxifen, goserelin.

Management

- 1 Treat the underlying disease, including infections where appropriate.
- 2 Stop causative drugs – try alternatives.
- 3 Alter environment – fans, reduce room temperature (unless cold sweats), avoid heavy bedclothes, wear cotton clothes or wicking material rather than synthetic or mixed fibres, use moisture absorbing mattress covers, frequent baths or sponging.
- 4 Psychological support for anxiety.
- 5 Drug therapy:
Various drugs have been used with varying success:
Paracetamol 1g qds (nocte for night pyrexias).
NSAIDs: diclofenac SR 75mg nocte - bd, naproxen 250 - 500mg bd.
Cimetidine 400 - 800mg nocte (be aware of interactions).
Corticosteroids: dexamethasone 2 - 4mg daily.
Beta-blockers: propranolol 10 - 40mg od - qds.
Anticholinergics: propantheline 15mg nocte - tds, oxybutynin 2.5 - 5mg bd, glycopyrronium by csci.
Antidepressants: eg amitriptyline 10 - 75mg nocte.
Clonidine 25mcg od - bd for hormonal disturbance if HRT not appropriate.
Thalidomide* 100 - 200mg nocte (in malignancy).

FUNGATING WOUNDS

Causes/Risk factors

Tumour infiltration of epithelium and its surrounding blood and lymphatic vessels.

General Management

- 1 Assess wound and patient's overall condition. Consider management goal.
- 2 Radiotherapy may reduce bleeding and discharge; surgery and skin grafting may aid healing.
- 3 Oral antibiotics may reduce infection and odour (see below).
- 4 Clean wound with 0.9% sodium chloride at body temperature.
- 5 Ensure adequate analgesia if painful.

Specific management

Examples of different brands of dressings are provided: further information is available in Appendix 8 of the BNF. We recommend that in the first instance the advice of the local tissue viability nurse is sought, as there are likely to be specific local guidelines for the management of wounds.

1 Of wound itself:

light exudate	hydrogel.
heavy exudate	alginate dressing (eg Sorbsan) or fibrous hydrocolloid (eg Aquacel) with absorbent pads.
cavity	alginate rope (eg Sorbsan) with foam dressing (eg Allevyn, Cavi-Care).
bleeding	alginate (eg Kaltostat or Sorbsan); may need to soak dressings with saline before removing; adrenaline 1:1000 either directly to wound or in dressing.
infected	metronidazole gel (eg Anabact) and charcoal dressing (eg Clinisorb, Actisorb plus).
pain	morphine (or diamorphine) 10mg mixed in a hydrogel gel; short acting opioid preparation for dressing changes (see p15/16)

2 Systemic drug therapy:

analgesics	paracetamol, NSAIDs, opioids (see section on Pain).
antibiotics	metronidazole orally to reduce pain and odour.
antipruritic	sedating antihistamine eg chlorphenamine.

LYMPHOEDEMA

Diagnosis

By history and examination. Differentiate from heart failure, immobility, venous insufficiency and obstruction, chronic renal failure, hypoalbuminaemia, limb dependency.

Causes/ Risk factors

- 1 Primary congenital or familial lymphoedema.
- 2 Secondary obstruction from tumour spread, surgery, or radiotherapy.
- 3 Recurrent streptococcal infections.

Management

Management is based on skin care, lymph drainage, compression and exercise.

- 1 Treatment should be undertaken by a trained practitioner.
- 2 Early referral to the local lymphoedema service will give the best chance of maximum improvement and control of the condition as cure is not possible.
- 3 Clear explanation of the lymphatic system, reasons for condition and means of treatment will encourage compliance.
- 4 Treat infections before beginning treatment, according to local protocols. Constant vigilance for and prompt treatment of further infections is essential.
- 5 Instructions on daily skin care of affected limb(s): use aqueous or similar cream; general advice to avoid cuts, sunburn, insect bites and injections in affected limb.
- 6 Monitor progress by regular measurement and assessing condition of tissues.
- 7 Regular simple light superficial and proximal massage may help; should be taught with suitable exercise by trained practitioner.
- 8 Manual lymphatic drainage may help, taught by a trained practitioner.
- 9 Properly measured graduated compression hosiery worn daily except during acute inflammatory episode; remove at night.
- 10 Multi-layered compression bandaging may be appropriate for a limited period initially.
- 11 Occasionally a multi-chambered sequential pneumatic compression unit may help reduce limb volume unless there is quadrant/midline oedema. Use at low pressures and in conjunction with other measures. May help reduce fibrosis.
- 12 With advanced disease and severe obstruction pain may be exacerbated by compression; balance the intervention with the patient's overall condition. Simple lymphatic drainage or supportive bandaging often reduce the pain.
- 13 Drug therapy:
Diuretics may help if there is heart failure or hypoalbuminaemia.
Steroids may shrink lymphadenopathy but can increase fluid retention.
Antibiotics may be needed long term if there is recurrent infection. Choice of antibiotic will be governed by local protocols.

FATIGUE / WEAKNESS

Diagnosis

- 1 Fatigue is characterised by variable physical and mental lethargy, sleep disturbance and perceived weakness; often worse at the beginning and end of the day. Frequently part of anorexia/cachexia/fatigue syndrome (see p24). Fatigue is of central rather than peripheral origin.
- 2 True weakness suggests neuromuscular disorder or cachexia.

Causes / Risk factors

- 1 Advancing cancer.
- 2 Anorexia/cachexia/fatigue syndrome (see p24 for further information).
- 3 Anaemia.
- 4 Infection.
- 5 Emotional distress.
- 6 Metabolic: hyponatraemia, hypokalaemia, uraemia, hypercalcaemia, liver impairment, adrenal insufficiency, hyperthyroidism, hypothyroidism.
- 7 Chemotherapy and radiotherapy.
- 8 Corticosteroids after prolonged use may cause profound proximal myopathy.
- 9 Other drugs: sedatives, diuretics, antihypertensives.
- 10 Neuromuscular damage: by tumour to brain, spinal cord or peripheral nerves, MND, myopathy, peripheral neuropathy, myasthenia gravis, Lambert-Eaton myasthenic syndrome.
- 11 Prolonged bed rest.

Management

- 1 Take a good history to assess functional interference, emotional state, mental capacity and sleep pattern.
- 2 Examine to assess muscle wasting, specific weakness and neurological abnormality.
- 3 Review drug regimen paying particular attention to cardiac medication.
- 4 Check blood count, electrolytes, liver function and calcium levels and correct metabolic disturbances where possible and appropriate.
- 5 Provide support for emotional distress, hopelessness.
- 6 Treat any depression as appropriate.
- 7 Provide dietary support as appropriate.
- 8 Help with coping and acceptance using exercise programmes, energy conservation techniques and advice on rest, sleep and stress reduction – ie a fatigue management programme.
- 9 If part of anorexia/cachexia/fatigue syndrome, see also p24.
- 10 Drug therapy: methylphenidate* 2.5 - 5mg bd may act as stimulant.

ANAEMIA

Diagnosis

- 1 Symptoms – tiredness, weakness, breathless on exertion.
- 2 Blood counts – haemoglobin, RBC indices, platelets and WBC.

Causes / Risk factors

- 1 Increased rate of RBC loss:
 - Bleeding –acute (anaemia may not be revealed immediately);
–chronic (microcytic, reticulocytes, thrombocytosis).
 - Haemolysis – primary, secondary eg autoimmune process, drugs, infection (macrocytosis, reticulocytes, raised bilirubin).
- 2 Reduced RBC production:
 - Chronic disease and renal disease (normochromic, normocytic or microcytic).
 - Bone marrow infiltration – leukaemia, lymphoma, carcinoma (especially carcinomas of prostate or breast).
 - Aplastic – especially drugs (including NSAIDs, antibiotics, anticonvulsants, antipsychotics, hypoglycaemics, but many drugs have been implicated).
 - Sideroblastic secondary to malignancy.
 - Infection, debility.
 - Deficiency of iron (microcytic), B₁₂ or folate (macrocytic).

Management

- 1 Treat cause if appropriate – see Bleeding/Haemorrhage (next page), iron, B₁₂ or folate if deficient, review medication eg aspirin, NSAIDs.
- 2 Consider transfusion if specific symptomatic benefit is anticipated with Hb < 9.5 g/dl and not macrocytic. Transfusion can cause heart failure in debilitated or elderly patients; use 2 - 4 units maximum per day with furosemide cover.

If the anaemia is chronic, patients may adapt even if Hb 8.0 g/dl. Do not transfuse unless a specific benefit is anticipated.

- 3 Reassess one week after transfusion for any symptomatic relief. If little relief then transfusion need not be repeated if the haemoglobin falls again: consider other causes and treatments for symptoms.

BLEEDING / HAEMORRHAGE

Causes / Risk Factors

- 1 Tumour invasion.
- 2 Platelet or coagulation disorders, including disseminated intravascular coagulation, heparin-induced thrombocytopenia.
- 3 Infection – eg haemoptysis, haematuria, vaginal bleed, fungating wounds.
- 4 Drugs – heparin, warfarin, aspirin, NSAID, SSRI antidepressants.
- 5 Peptic ulceration.

Management

General

- 1 Stop anticoagulants and review medication; consider reversing warfarin with fresh frozen plasma (rapid) or vitamin K 5mg iv (acts in a few hours).
- 2 Consider replacement of blood, platelets, clotting factors, fluids.
- 3 Treat any infection which may be exacerbating bleeding.
- 4 Consider radiotherapy when bleeding due to malignancy, especially haemoptysis, haematuria or cutaneous.
- 5 Consider chemotherapy and palliative surgical techniques including endoscopic laser or cautery for tumour where feasible and appropriate.
- 6 Embolisation is occasionally used for liver and renal malignancy.
- 7 Severe terminal haemorrhage – stay with the patient; verbal reassurance and physical touch help.

If slow, use suction as appropriate and consider iv as below.

If rapid, consider im or iv midazolam +/- diamorphine (for relief of distress).

If a terminal haemorrhage is anticipated carers can be given a supply of rectal diazepam 10 mg. Dark towels or sheets may help to mask the blood. Relatives who witness the event will need support.

- 8 Drug therapy:
Tranexamic acid 500mg -1.5g bd - qds orally (stabilises clots); caution in haematuria as may lead to clot retention.
Etamsylate 500mg qds orally (enhances platelet adhesion within capillaries).

Specific

- 1 Nasal bleeding: – packing and cautery.
- 2 Oral bleeding: – sucralfate suspension.
- 3 Haemoptysis: – radiotherapy often helpful in lung tumours.
- 4 Upper GI bleeding: – consider stopping any NSAIDs
proton pump inhibitors.
- 5 Lower GI bleeding: – rectal steroids
tranexamic acid oral (as above) or 0.5g in 5mls
water pr bd.
- 6 GI tumours: – thalidomide* 100 - 400mg od.
- 7 Skin – Kaltostat dressing
topical adrenaline 1 in 1000 to soak dressings.

VENOUS THROMBOEMBOLISM

Diagnosis

- 1 Some degree of venous thromboembolic disease (VTE) is extremely common in patients with cancer and to a lesser extent with other advanced disease.
- 2 Suspect pulmonary emboli in patients with episodic and otherwise unexplained breathlessness or confusion.
- 3 Serological tests such as D-Dimers are unhelpful in advanced cancer.
- 4 Doppler scans will reveal DVTs in large veins.
- 5 CT pulmonary angiography can detect even small pulmonary emboli.
- 6 VQ lung scan will reveal ventilation/perfusion mismatches but may be difficult to interpret in the presence of other pulmonary pathology.

Causes / Risk factors

- 1 Malignant disease.
- 2 Recent chemotherapy or surgery.
- 3 Immobility.
- 4 Pelvic disease.

Management

- 1 Assess whether patient is at risk of VTE. If so, take into account any risk of bleeding and expected prognosis; and then discuss with the patient whether they wish to have active prophylaxis with anti-embolism stockings and low molecular weight (LMW) heparin as appropriate, balancing risks and benefits to optimise quality of life.
If the patient is in the last few days or weeks of life then thromboprophylaxis is often not appropriate, and is not routine.
The best evidence in favour of thromboprophylaxis is in potentially reversible co-existing acute conditions.
- 2 If there is symptomatic or objective evidence of VTE, consider formal anticoagulation with LMW heparin, the preferred option because it is more effective in VTE associated with malignancy, is less likely to cause bleeding but requires daily injections. LMW heparin followed by warfarin is cheaper, but requires blood tests and INR may be very difficult to keep stable in those with advanced disease and variable nutritional intake.
- 3 Regularly re-assess the patient to ensure that the current management strategy is appropriate to the stage of their illness and their wishes.

HYPERCALCAEMIA

Hypercalcaemia is common in cancers with bone metastases (eg breast, prostate, lung) or may be due to ectopic production of PTH-like peptides. It occurs in 10% of cancer patients and 30% of those with myeloma. Amongst solid tumours, it is most commonly associated with squamous carcinomas and breast cancers.

Diagnosis

- 1 Corrected serum calcium > 2.7 mmol/l; symptoms usually only become troublesome above 2.9 mmol/l; levels > 4 mmol/l may be fatal.
- 2 Any combination of the following: nausea, confusion, fatigue, loss of appetite or emotional disturbances, thirst, polyuria, constipation and abdominal pain.

Causes / Risk factors

- 1 Bone metastases.
- 2 PTHrP-secreting tumours, eg carcinoma of lung.
- 3 Dehydration, renal impairment.
- 4 Tamoxifen flare.

Management

- 1 Decide if further treatment is appropriate – is this a terminal event?
- 2 Relieve associated symptoms.
- 3 Stop thiazide diuretics, vitamin D/calcium supplements.
- 4 Correct dehydration using up to 3 litres saline iv over 24 hours.
- 5 If serum calcium >3.0mmol/l or >2.8 still symptomatic after iv rehydration, use iv bisphosphonates:
 - pamidronate 90mg in 500ml saline over 2 - 4 hours (first line), or
 - zoledronic acid 4mg in 50ml saline over 15 mins (most potent).(In renal impairment the above doses need adjustment – see BNF; if eGFR<30 only bisphosphonate licensed is ibandronic acid).

Bisphosphonates can take 72hrs to be effective, so avoid rechecking calcium before day 4. If normocalcaemic, plan to recheck three weeks after treatment. If serum calcium still raised after 7 days, iv bisphosphonate can be repeated. Oral bisphosphonates have no place in the acute treatment of hypercalcaemia but may be used to maintain normocalcaemia and as prophylaxis for myeloma and breast carcinoma.

Calcitonin* 100 units sc 3 times per week is sometimes successful if bisphosphonates have lost effectiveness in maintaining normocalcaemia, but this is usually an indication of entering the terminal phase and aims of treatment should be reviewed.

USE OF STEROIDS

General points

- Dexamethasone is the preferred drug.
- Prescribe as a single or 2 morning doses to avoid sleep disturbance.
- Give a 5 - 7 day trial and stop if there is no benefit.
Be clear about what objective benefit is sought, and keep under review.
- Discuss potential benefits and side effects with patient and give steroid card.
- If benefit achieved, reduce to lowest effective dose and then review regularly.
- Stop if ineffective or when benefit lost (see below).
- Consider monitoring plasma glucose levels.
- Add gastric protective if also on NSAID or longer-term use.
- Increase (up to double) the dose if on phenytoin or carbamazepine.

Indications

Initial dose, dexamethasone

- | | |
|---|----------|
| • Brain tumour, SVCO, spinal cord compression: | 8 - 16mg |
| • Nerve compression pain, liver capsule pain, intestinal obstruction, anti-emesis, bronchial obstruction, lymphangitis carcinomatosa, post-radiotherapy inflammation: | 4 - 8mg |
| • Anorexia, fatigue: | 2 - 4mg |

Stopping steroids

- Can withdraw immediately if less than 3 weeks and < 6 mg dexamethasone.
- Otherwise tail off by 2mg every 5 - 7 days until 2mg od, then by 0.5mg every 5 - 7 days (can substitute with betamethasone 0.5mg tabs).
- After cranial irradiation start reducing 2 weeks after completion of treatment, eg 16 - 12 - 8 - 6 - 4 - 2mg at intervals of 3 days; if symptoms recur, return to previous effective dose.

Common problems (usually related to higher or longer-term doses)

- Early: oral thrush, hyperglycaemia, heartburn, sleep disturbance, mania.
- Late: proximal myopathy, skin atrophy, change in face and body shape.

Steroid equivalents (approximate)

Dexamethasone	Betamethasone	Prednisolone	Hydrocortisone
2mg	2mg	15mg	50mg

DIABETES MANAGEMENT

Aims

- 1 Blood sugars 7 - 15 and asymptomatic.
- 2 No hypoglycaemia, diabetic ketoacidosis, or HONK.
- 3 Avoid unnecessary injections and testing.

Management

Blood sugar testing

- On oral therapy: test 18:00 (premeal)
- If starting/on steroids: test 18:00 (premeal)
- If worried about fasting hypoglycaemia: test before breakfast

Diet controlled

- Blood sugars <15, and no steroids: no further testing
- Blood sugars >17 +/- symptoms: start sulphonylurea (eg gliclazide, glimepiride)

On oral therapy

- Stop metformin and glitazone therapy
- Blood sugars <15: continue. If <5: halve dose of oral therapy.
- Blood sugars >17 +/- symptoms: increase/start sulphonylurea
If still >17: add glargine 10units 08:00 (increase by 2mg every 48h if >17)

Insulin controlled

- If eating, continue usual regimen or contact Diabetes Team
- If not eating, stop short acting insulin, continue long acting or swap to glargine 08:00 (test 18:00), contacting the Diabetes Team

On/starting steroids

- Single dose steroid mane. Test blood sugars 18:00 (premeal)
- If blood sugars >17, add sulphonylurea at 12:00
If still >17: start short acting insulin bd eg Humulin S/Actrapid 8 - 12units at 12:00 & 18:00 premeal (glargine less effective & risk of fasting hypoglycaemia)

Notes

- Avoid bd insulin mixtures (risk of hypoglycaemia), qds regimes (multiple tests and injections), bd steroids (prolonged hyperglycaemia), bolus/prn Actrapid (poor control, risk of hypoglycaemia), metformin, glitazones.
- Treat hypoglycaemia with sugar eg GlucoGel, glucagon less effective if no glycogen stores.
- In the last few days of life, can allow blood sugars >17 if asymptomatic.
- Communicate the above basic principles to patient, family and carers.

END STAGE CONDITIONS

General principles

1. Looking ahead (see also Advance Care Planning p65):
 - prognostic triggers – “Would you be surprised if this patient was to die in the next year?”, repeated hospital admissions, increasing dependency, specific clinical prognostic indicators (see below)
 - to ease the transition from invasive treatment to supportive care
 - discussion with patient (and carer as appropriate) about their understanding of severity of disease and likely prognosis, preferences for future care and treatment, and what to do or where to go in a crisis:
“Thinking ahead – what sort of future care would you want?”
“What would you like to happen or not to happen?”
2. Assessment of patient’s and carers’ needs for physical, psychological/emotional, social/financial and spiritual support (see p60).
3. Symptom control, for restoration or maintenance of dignity/quality of life
 - optimisation of medical management of condition, treatable causes of deterioration and iatrogenic problems
 - disease-specific symptom palliation (see below).
4. Information exchange – ensure that the above information/choices are communicated to the relevant hospital team, GP, community team and support services etc as appropriate.
5. Triggers for Specialist Palliative Care referral:
 - poorly controlled symptoms
 - complex needs or problems that require additional help
 - help required with issues brought up in 1 and 2 above
 - preferred place of terminal care is a hospice.

End stage heart failure

Specific clinical prognostic indicators:

Heart failure NYHA Stage III or IV, ejection fraction $\leq 20\%$, albumin <25 , failure to respond to diuretics, worsening co-morbidities.

Specific symptom control:

- Breathlessness – low dose opioid and/or benzodiazepine (see p29); bronchodilators not advisable if angina or aortic stenosis
- Oedema – balance dose of diuretics against symptomatic hypotension and dehydration, good skin care, cautious hosiery compression of legs
- Low mood/depression – general psychological, social and occupational therapy support; avoid tricyclic antidepressants as arrhythmogenic
- Confusion – emphasis on the use of oxygen, haloperidol and reducing strong opioid dose

** indicates that this is best managed by specialists*

- Nausea – avoid cyclizine as may exacerbate heart failure
- Pain – caution with NSAIDs and steroids because of fluid retention
- Constipation – magnesium hydroxide and lactulose less effective
- Care of the Dying – stop warfarin, statins etc; switch off Implantable Defibrillator.

End stage kidney failure

Specific clinical prognostic indicators:

eGFR <15, decision not to dialyse, contemplating withdrawal from dialysis.

Specific symptom control:

- Pain (often bone) – paracetamol, avoid NSAIDs unless end of life.
Strong opioids (see also pp10 - 12) :
prn opioid will usually be fentanyl sc 12.5 - 25mcg up to hourly
regular background can be fentanyl / buprenorphine patches as p11,
or csci fentanyl* or alfentanil* (will mix with most drugs)
- Neuropathic pain – amitriptyline, gabapentin† or pregabalin†
- Nausea – metoclopramide, haloperidol, levomepromazine†
- Hiccups – metoclopramide
- Itch – aluminium hydroxide mixture 15ml tds, ondansetron, gabapentin†
- Restless legs – gabapentin†, clonazepam 0.5mg nocte
- Care of the Dying – be prepared for significant restlessness (see p59).

† need dose reduction (see BNF). Little difference between dialysed and non-dialysed patients in dosing, although gabapentin often given only on dialysis day.

End stage COPD

Specific clinical prognostic indicators:

On Long Term Oxygen Therapy, episodes of respiratory failure or NIV, right heart failure or cachexia, FEV₁ < 30% predicted.

Specific symptom control:

- Breathlessness – rehab programme, low dose opioid and / or benzodiazepine
- Pain (often from steroid side effects) – higher risk with NSAIDs
- Low mood and anxiety, constipation and muscle deconditioning also common.

SYRINGE DRIVERS

A syringe driver is a small portable battery-powered pump which administers drugs subcutaneously by continuous infusion. It offers an alternative mode and route of drug administration with little impact on patient mobility or independence. By maintaining steady plasma levels a syringe driver **may** improve symptom control.

Indications

For administering medication when the oral route is difficult or inappropriate. If/when problems resolve, consider a return to oral medication.

- 1 Severe vomiting and/or nausea.
- 2 Dysphagia.
- 3 Severe oral tumours, sores, or infection.
- 4 Profoundly weak, unconscious, or sedated patient.
- 5 Poor absorption of orally administered medication.

Practical points

- 1 Syringe drivers in current use are the McKinley, the Graseby MS26 and MS16. The McKinley automatically calculates the rate (mm/hr) and the volume remaining (ml) from the type and size of syringe. For the MS26 and MS16 the rate of infusion has to be set manually: in mm/24hrs for the Graseby MS26 and in mm/hr for the Graseby MS16.
- 2 The line should be primed **before** calculation or measuring length.
- 3 Use a Luerlock syringe in syringe drivers. A 20ml syringe allows greater dilution and less risk of precipitation. For the MS16 driver, the syringe should be filled to a length of 48mm.
- 4 Label the syringe with the patient's name, drug(s) and dose(s), nature of diluent and the date and time commenced.
- 5 The syringe driver and insertion site must be checked **at least** once a day, and preferably every 4 hours in the hospital setting.
- 6 The boost button should not be used to administer breakthrough medication.
- 7 Use as few drugs in the syringe driver as possible (usually maximum of 3).
- 8 Site inflammation may occur as a result of irritant solutions or hypersensitivity to the metal cannula. Management strategies include changing the drug, the diluent, the site or the giving set (from a metal butterfly to a plastic cannula). If problems persist, seek specialist advice.
- 9 Certain drug combinations may cause precipitation within the syringe. This may sometimes be overcome by the following strategies, but do not assume that lack of precipitation necessarily implies compatibility:
 - using a larger syringe to allow greater dilution
 - using water rather than saline for dilution, or vice versa
 - separating drugs into two syringe drivers
 - drawing up dexamethasone last when used in combination
 - substituting drugs with an equivalent alternative
 - avoiding exposure to sunlight as non-observable reactions may occur.

Drugs often used in the syringe driver

- All doses given are **per 24 hours**.
- Water or normal saline may be used as diluents. We usually recommend water, but saline is essential for diclofenac/NSAIDs.
- Not all drug combinations are compatible: check with local Palliative Care Team, pharmacy or the Palliative Care Formulary, www.pallcare.info (see p3).
- Do not use diazepam, prochlorperazine or chlorpromazine – all irritant.

Cyclizine 100 - 150mg

Antihistamine and antimuscarinic antiemetic which acts at the vomiting centre. Often causes site irritation. Limited compatibility.

Dexamethasone Up to 16mg

Used to relieve raised intracranial pressure, liver capsule and neuropathic pain, and as antiemetic. May precipitate when higher doses mixed with other drugs.

Diamorphine 5 - 100mg (or higher*) for use see pp7-12

More soluble (more expensive) than morphine (equivalence see p10).

Diclofenac 75 - 150mg

Use saline as diluent. Does not mix with other drugs.

Glycopyrronium 200mcg - 1.2mg

Used to reduce respiratory secretions if sedation is undesirable.

Haloperidol 2.5 - 10mg

Antidopaminergic antiemetic (see p19). Higher doses occasionally used in confusion (see p41). Extrapyramidal side-effects may occur with high doses.

Hyoscine butylbromide 20 - 120mg (- 240mg*)

Anti-spasmodic used to relieve intestinal colic. Useful for drying secretions and in intestinal obstruction through its antisecretory effect.

Hyoscine hydrobromide 400mcg - 2.4mg

Useful for reducing secretions; some smooth muscle antispasmodic activity. Can be sedative, may cause agitation or confusion (eg in elderly).

Levomepromazine 5 - 25mg (antiemetic, see p19)

25 - 100mg (sedative, see p41)

Metoclopramide 30 - 80mg

Antiemetic (see pp19, 21). Extrapyramidal effects may occur at higher doses.

Midazolam 5 - 60mg

Benzodiazepine: sedative, antiepileptic. May be useful in neuropathic pain. Higher doses are only appropriate for terminal sedation.

Morphine 5 - 300mg, for use see pp7-12

Specialist palliative care referral recommended at the top end of dose range.

Octreotide* 300 - 800mcg

Used in intestinal obstruction (see p21), and for fistulae (see p26). Expensive.

Oxycodone 5 - 200mg

Alternative to morphine and diamorphine (equivalence see p10).

Other drugs are occasionally used eg alfentanil, clonazepam, fentanyl, furosemide, ketorolac, ondansetron, phenobarbital.

THE LAST FEW DAYS OF LIFE

Principles

- Adopt a problem solving approach to symptom control.
- Review all drugs and keep only the essentials.
- Anticipatory prescribing (see below).
- Avoid all unnecessary interventions eg iv infusions.
- Ensure effective communication amongst all involved
- Ensure practical and emotional support offered to family and carers
- Check religious and cultural needs.

Many will use a Liverpool Care Pathway or equivalent to facilitate these principles.

Management

- Anticipate:
Availability of drugs and equipment for treatment of pain, breathlessness, nausea and vomiting, confusion, haemorrhage, terminal restlessness, urinary retention, diabetes management, mouth and skin care.
Family distress and fears.
Practical care requirements.
- Analgesics
- Antiemetics
- Anxiolytics
- Antisecretories
- Administration route.

This will require the use of Anticipatory Prescribing or Just In Case boxes (in the home) for drugs and their route of administration.

Guidance on Medication for Symptom Control

Pain

Opioids and NSAIDs are the main analgesics.

Conversion from oral opioids to csci morphine or diamorphine is often needed: eg morphine po 3mg = 1.5mg morphine sc = 1mg diamorphine sc (see pp8-10).

Prn doses of morphine (po, sc) or diamorphine (sc) should be up to 1/6th total daily opioid dose or 2.5 - 5mg in the opioid naïve (see p10).

If on fentanyl or buprenorphine patch, keep the patch and if further analgesia required add opioid to syringe driver (eg fentanyl 25mcg/hr patch roughly equivalent to csci morphine 30mg or diamorphine 20mg per 24hrs). Prn doses of sc morphine or diamorphine are suggested on p11.

Stiffness, general aches and pains often develop with immobility – NSAID eg diclofenac po, pr or via csci often helpful, or midazolam 5 - 10mg/24h via csci.

Nausea and Vomiting

Usually less of a problem, unless there is intestinal obstruction (see p20).

Available antiemetics should be:

Metoclopramide or haloperidol **and** cyclizine or levomepromazine (see p19).

Prn doses (po or sc): metoclopramide 10mg, haloperidol 0.5 - 1.5mg, cyclizine 50mg, levomepromazine 5 - 6.25mg.

Csci doses (per 24hrs): metoclopramide 30mg - 60mg, haloperidol 2.5 - 5mg, cyclizine 100 - 150mg, levomepromazine 5 - 25mg.

Rarely, a nasogastric tube will be required in intestinal obstruction.

Terminal Restlessness (see also p42)

Usual drugs are midazolam 2.5 - 10mg sc prn or 10 - 60mg per 24hrs via csci and/or levomepromazine 12.5 - 25mg sc prn or 25 - 150mg per 24hrs via csci.

Alternatively, diazepam can be given orally 2 - 10mg or rectally 5 - 10mg.

Excess/Rattling Upper Airway Secretions

Usual drugs to be made available are hyoscine butylbromide 20mg sc prn or 40 - 80mg per 24hrs via csci (also useful for colic and intestinal obstruction) or hyoscine hydrobromide 400mcg sc prn or via csci (see p57) or glycopyrronium via csci (see p57).

Administration Route

Alternatives to the oral route are often needed. Usually drugs can be given rectally or subcutaneously. Syringe drivers have the advantage of giving continuous control of symptoms and are to be preferred to multiple subcutaneous injections (see p56).

Planning for the Death

- To avoid inappropriate resuscitation attempts particularly at home, check that this patient's DNACPR status is known or recorded for visiting health professionals (see p64)
- If the diagnosis is mesothelioma, asbestosis or other industrial disease, remember to warn the family that the Coroner's team will become involved after death
- Check whether cultural or religious rituals are expected to be adhered to after death
- Provide information and/or contact numbers about procedures immediately after death.

PSYCHOLOGICAL, SPIRITUAL AND SOCIAL CARE

The primary task when faced with spiritual questions is to help the person towards some resolution. Palliative care extends far beyond pain relief and the alleviation of symptoms. Psychological, spiritual and social needs of both patient and their family/carers should be addressed. This does not necessarily require specialist help – all health professionals should be prepared to make initial assessments and identify these issues.

This holistic assessment is important in ensuring that the patient and family have optimal support in any care setting. It also ensures that discharge planning is effective (hospital/hospice staff should check that these plans are acceptable to the patient, family, carers and Primary Health Care Team).

The framework for needs assessment should include:

- Psychological needs
- Spiritual issues
- Social needs
- Information needs
- Carers' needs.

Many factors influence the way in which patients and families cope with their illness and the following need to be considered during an assessment:

- The history of the illness and their understanding of what is happening, including their emotional and psychological response
- How the illness is affecting the person's ability to carry out their role, for example as parent, mother, lover, breadwinner etc
- Family history – who is around, where are they, how important are they, how supportive are they? Constructing a family tree (genogram) is often helpful both for establishing relationships and for use as a therapeutic tool in helping people talk about their issues
- Life stresses – what is happening with regard to money, jobs, housing, children, sources of support etc
- Hopes and fears – what is the worst thing that can happen, what are the plans for the future, what losses and disappointments have occurred, what unfinished business is there, and what do they still wish to accomplish?

During assessment it should become apparent whether further expert professional help is required for psychological, spiritual and social care. Those available will include specialist palliative care staff, clinical psychologists, chaplain/spiritual advisors, and adult and child social workers.

CULTURE

In our society there is a wide variety of people of different faiths, ethnic backgrounds and countries of origin. Within these groups, each individual will express their cultural attitudes uniquely, as they are influenced by upbringing, background, environment, beliefs and life experience.

Cultural attitudes can particularly influence:

- Language and the use of colloquialisms
- The roles of the family
- How symptoms or illness are described and understood
- Ethical issues, including autonomy and confidentiality
- Attitudes towards conventional Western therapies, complementary or alternative therapies, food and diet
- Attitudes towards death and dying
- Rituals surrounding death (see 3. below)
- Preferred place of care – home, care home, hospital or hospice
- Acceptance of help and support.

Health professionals should show their awareness by:

- Ensuring that appropriate language interpretation services are used
- Demonstrating willingness to listen and a wish to understand cultural differences and implications
- Meeting specific requirements (such as food, privacy, opportunity to practice religious observances etc) wherever possible
- Being prepared to negotiate boundaries and details of care
- Ensuring that there is access to an appropriate religious advisor.

Do not make assumptions – ASK

Remember that each person is unique, regardless of cultural background and professed faith.

Further reading

1. Neuberger J. Care for Dying People of Different Faiths. Oxford: Radcliffe Medical Press, 2004.
2. Henley Q, Schott J. Culture, Religion and Patient Care in a Multiethnic Society. Age Concern Books, 1999.
3. Multi-Faith Practices. In Standards for Spiritual Care (NHS Wales) 2009: Supporting Guidance p29. www.wales.nhs.uk/sites3/Documents

BREAKING BAD NEWS

Bad news is any information which alters a patient's view of their future for the worse – the bigger the gap between expectation and reality the worse the news. Giving bad news means entering a therapeutic dialogue of listening and responding which will affect how patients and families will cope. The aim is to:

- maintain trust between patient, family/carer and health professionals
- enable appropriate adjustment to the reality of the situation
- encourage informed choice of management options
- reduce uncertainty about the future or at least acknowledge it
- enable patients to regain a feeling of some control over their situation.

The following framework describes one approach.

1. Preparation

- Know the facts and the potential management plan
- Arrange for privacy, sufficient seating and avoidance of interruptions
- Whenever possible offer the patient the chance to have a close family member or friend present

2. Assess understanding (may need repeating as further information given)

- “What do you understand about your illness/what is happening?”

3. Check if more information is wanted and at what level

- “Do you want to go on or is that enough for now?”
- Again, this may need to be repeated as you give further information

4. Allow denial

- Allow the patient to control the pace of information flow, and to whom the information should be given

5. Sharing the information

- Start from where the patient is, give warning shots and further information in small chunks. Know when to stop.
- Be clear and simple, avoiding jargon, and above all be gentle
- Avoid assumptions about their understanding i.e. check that they have heard what you believe you have said

6. Elicit concerns

- What is worrying the patient most?

7. Respond to the patient's feelings

- Identify the patient's feelings and acknowledge them
- Listen for and observe the emotional content and behaviour
- Allow them time to think through the situation and ask questions: “Is there anything else you'd like to say or ask me?”.

8. Summary and plan

- Summarise what has been said, emphasising the positive
- Outline future treatment if appropriate, using written or printed material if possible
- Foster realistic hope, eg “We may not be able to cure you but there are things we can do to make you feel better and cope with your illness”
- Recheck their understanding

9. Make arrangements for further contact

- Ask who may be told about the diagnosis/information

10. Ensure others are informed of what was said

- Tell the General Practitioner and other staff on duty as soon as possible
- Record as exactly as possible what was said, so that it can be repeated later and to avoid misunderstanding
- Giving the patient a recording of the interview is popular and effective.

Remember

- Make sure the patient feels the centre of attention
- Much of what you communicate is by non-verbal means and behaviour
- Move at the patient’s pace, giving information that is appropriate for that time
- If using euphemisms, try to find out what they understand by these words.
- Express your humanity and warmth, and interest in their care
- Breaking bad news does not have to be done at one session, it is often best done in stages
- Do not be afraid of them expressing negative feelings or crying.
- Be prepared for an initial stunned silence or anger
- Ensure that you are answering the question that you are being asked
- Avoid jargon
- Do not tell lies
- Some direct questions are best answered initially by asking “What makes you ask that?”. This may enable them to explain the worry behind the question.
- It is a breach of confidentiality to tell relatives without the patient’s consent, where the patient has the capacity to agree to or refuse disclosure.

Further reading

Buckman R and Kason Y (1992) How to Break Bad News: A Guide for Healthcare Professionals, Papermac.

Peter Kaye (1996) Breaking Bad News a Ten Step Approach: EPL Publications.

DNACPR DISCUSSIONS

A DNACPR (also called DNAR or ‘Allow a Natural Death’) order can be part of an advance decision made by the patient, but is more commonly made when the patient is becoming more ill. Problems may arise because:

- policy documents do not distinguish between an expected death and cardio-pulmonary arrest
- the general public have unrealistic expectations of CPR’s success rate
- there is a lack of understanding of how CPR can lead to adverse outcomes, even where the restoration of cardiac output is successful
- there is a misconception that there is a requirement to discuss the decision with patient and/or carers
- there is a misconception that patients can choose whether or not they will be resuscitated
- it is a well established principle that doctors (and other health professionals) should not offer treatments which they consider to be futile.

The following framework is suggested to overcome these difficulties:

- recognise that while discussion is best practice, it is **not mandatory**, and indeed should not be undertaken if it might cause harm
- do not withhold information just because it is difficult to convey
- discuss what care **will** be given, rather than what will not be done; emphasise (and ensure) that a DNAR decision only relates to CPR and does not involve withholding other appropriate treatments
- emphasise that any decision is based on clinical judgement, not on age or ‘worth’ of the patient’s life
- consider framing any discussion with a patient and/or their carers around the fact that the illness is progressing and death will naturally happen, rather than specifically around CPR
- can point out that if death occurs (heart stops) then family can stay with patient, allowing a dignified death, rather than having to leave while CPR attempted (and unlikely to work)
- be aware that discussing CPR might imply that you believe that it could be successful; if appropriate, explain the likely adverse outcomes of CPR
- if necessary, negotiate a limited range of resuscitative interventions which may be carried out in the event of sudden collapse.

Further reading

BMA/Resuscitation Council Guideline: www.resus.org.uk/pages/dnar

ADVANCE CARE PLANNING

Advance Care Planning (ACP) is the process of discussions between an individual and their health care professional about future needs. Helping a patient establish their priorities in End of Life Care enables them to plan their future and prepare for death, allowing them to maintain control over their wishes and preferences should they later lose mental capacity.

These preferences should be communicated to all professionals involved and documented appropriately (with the patient's consent). It is usually helpful to encourage the patient to include family/carers in these discussions.

ACP takes place in anticipation (preferably) or in recognition of deterioration in condition. Triggers for ACP include:

- enquiry by the patient, or from care needs assessment
- the Surprise Question: "Would I be surprised if this patient was to die in the next year?"
- clinical prompts eg repeated hospital admissions, shift in treatment focus, loss of function, care home admission.

The healthcare professional needs to:

- have sensitivity about when and how to instigate discussion
- recognise when to stop
- have knowledge of likely disease events, treatment options and local resources/services available
- communicate them effectively.

Judgement must be used as to whether ACP is likely to provide overall benefit to the individual at that time, and no pressure should be applied to take part in ACP.

Initiation of discussion can be aided by introducing the leaflet "Planning for your Future Care – A Guide" (www.endoflifecareforadults.nhs.uk).

ACP discussions include exploring patient and carers' insight into disease, future expectations, and future plans/choices for treatments and place of care etc.

ACP spans a spectrum from open conversations to formal, legally binding documents. Outcomes therefore may be:

- 'no wish to discuss further at this time'
- a statement of wishes and preferences
- DNACPR decision (see previous page)
- making an Advance Decision to Refuse Treatment
- registering a Lasting Power of Attorney.

Challenges – family conflict or exclusion, lack of support for potential consequences of discussion, denial or collusion etc.

The patient's permission is required for recording the discussions and sharing the information/documentation with healthcare teams (and, in the future, an End of Life Care Register) or the family.

All ACP should be regularly reviewed to check that it still accords with preferences as wishes often change with worsening condition.

DEALING WITH DENIAL AND COLLUSION

Denial

Denial is a basic coping mechanism that allows us to continue to function when faced with information or events with which we cannot cope. It may be practised by the patient, family or professionals. Denial is not necessarily unhealthy and can be normal, as in the first stage of accepting bad news. However, if taken to extremes or creating situations that are harmful, such as preventing appropriate treatment, adequate symptom control or future planning for dependents, it may be appropriate to explore the denial.

Assessment

- Is it healthy or unhealthy? That is, is it reducing or increasing distress?
- Is there an appropriate reason for challenging the denial?
- Is it really denial? Many people have a good understanding of the situation but do not wish to talk about it.
- Is other health professionals' denial contributing?

Management

1. Gently explore what the person understands of what they have been told.
2. Using the framework outlined in Breaking Bad News (see p62), gently move the person towards a better understanding of reality, particularly with regard for the particular need identified for challenging the denial. It is often helpful to use such phrases as "What if?" or "Let's look at the worst scenario even if it may not happen".
3. Be prepared to modify denial in stages and as far as possible at the patient's pace; and accept that it is unrealistic to expect all patients to come to terms with their mortality.
4. Ensure that extra support is available following the challenging of denial.
5. Support family or carers who may be finding the patient's denial stressful.
6. Alert other health professionals involved of any changes in the patient's understanding.

Collusion

Collusion usually occurs when the family conspire among themselves or with professionals to withhold information from or lie to the patient. It is often well intentioned, acting in what is believed to be the best interests of the patient. However, this inevitably creates tension because, ethically and legally, the patient has the right to information and to authorise disclosure of information to the family.

Management

1. Explore the family's understanding and reasoning:
 - establish whether they are trying to protect themselves or the patient
 - recognise that they may have valid concerns about the patient's capabilities and past behaviour patterns
 - show understanding of their situation.
2. Reassurance and explanation:
 - reassure that you will not walk in and impose information
 - explain that the patient has a right to information, if requested, and honesty is an important part of maintaining trust in a doctor-patient relationship
 - explain the stressful consequences of living out an ever increasing lie
 - explain that if the patient asks direct questions, their understanding and wishes will be explored before answering the question appropriately and sensitively
 - offer to facilitate a joint conversation between the family and patient if they are finding it too difficult.
3. Gently explore the patient's understanding, and assess their desire for further information. Pass this on to the family, with the patient's consent, to enable more open communication.

Occasionally patients collude with professionals to withhold information from their family. This is more difficult as the patient has to give permission for disclosure of information, but the principles are the same as above – exploration of reasoning; explanation about consequences; reassurance of sensitive handling; and offer of facilitation.

SPIRITUAL CARE

Introduction

Spiritual care is one of the central aspects of palliative care. It is difficult to define, but any problem, conversation or contact may contain spiritual as well as physical, psychological or social issues. Spirituality is to do with how we live, what we treasure and value, and peace of mind. Spirituality is relational in its expression, i.e. feeling a need to connect with someone or something. All patients have spiritual needs while only some will have religious needs.

Spiritual distress

When a person experiences a life crisis they will look to their spiritual values, beliefs, attitudes or religious practices to make sense of it. If these do not enable them to cope with the crisis, then they may experience spiritual distress.

Expressions of spiritual distress include:

- **fear** about the future, about dying and what happens after death
- **loss** of identity or roles (parenthood, work etc)
- **helplessness** and loss of control over what is happening
- **anxiety** about relationships, body image or sexuality
- **suffering** excessively from physical symptoms, especially pain
- **anger**
- **guilt** or shame
- **hopelessness**, despair, feeling alone or unloved
- **exploration** of meaning and purpose of their life
- **breaking** with religious or cultural ties.

Dealing with spiritual distress

The primary task when faced with spiritual questions is to help the person towards some resolution and understanding. Accept that there is unlikely to be a specific answer – it's OK not to know.

Listen attentively and be prepared to face uncertainties – just by “being there” you can help the patient to make connections and embark on their own search for meaning.

Do not be afraid to ask simple questions about their fears, losses, feelings, “the future”, sense of control, past regrets, values, beliefs and religious needs. Offer a particular group or person such as a chaplain if you feel out of your depth or there is a requirement for a religious input.

Basic principles

1. Provide a safe caring environment.

- Good symptom control
- Show willingness to listen
- Value their role and appearance, and belief systems

2. Attend to:

- Signs of their wishing to explore spiritual issues
Ask yourself “Why am I being told this? And why now?”
- Your own verbal and non-verbal behaviour and reactions (patients can be reluctant to embarrass professionals if they sense that they are causing discomfort)

3. Listen to:

- Questions
- Expressions of fear, anger, loss etc
- Their story

4. Assess in terms of :

- Past, present and future. Ask simple questions as outlined above.
- What help is needed

5. Reassure and help with:

- Good physical care in illness and dying
- Respect for their integrity, worth and values
- Information as requested
- “Unfinished business”
- Personal support – “being alongside”
- Care for family and carers
- Reviewing of life
- Arranging provision of spiritual counselling if needed eg to help face mortality
- Arranging provision of religious and sacramental care, according to faith

Above all – be there.

6. Attend to yourself:

- Facing intense feelings or distress can leave us feeling uncomfortable, inadequate, helpless or vulnerable. The task is to live with our own uncertainties. It is therefore important to explore difficult issues or share concerns with colleagues, eg through individual or group supervision.

Further reading

Speck P. Being there: pastoral care in times of illness. London: SPCK, 1988.

Stanworth R. Recognising the spiritual needs in people who are dying. Oxford: OUP, 2004.

BEREAVEMENT

Grief is a natural process experienced by anyone who has to adjust to a significant loss. An appreciation of what is 'normal' is required in order to recognise when and what type of intervention is needed. Parkes describes bereavement in terms of **phases of grief**:

- 1 **Initial shock**, numbness and disbelief before emotional reality of the loss is felt. Seeing the body after death, attending the funeral or visiting the grave are often important in facilitating acceptance of the reality of the death.
- 2 **The pain of separation** which affects behaviour and emotions. The bereaved usually suffer overwhelming periods of sadness as they are faced with the day-to-day reality of their loss. They may try to reduce this by avoiding reminders of the deceased. They may also find themselves 'searching' for the bereaved, dreaming about them or actually seeing or hearing them. Visual or auditory hallucinations at this time are normal. Agitation, restlessness and an inability to concentrate can result from the conflict between this searching and avoiding behaviour – attempts to avoid the reality of the situation.
A range of emotions other than sadness may be experienced. Anxiety may be due to loss of the familiar routine and feelings of insecurity. Anger may be directed towards the deceased for abandoning them, towards God, or (justly or unjustly) towards professionals. It may simply manifest as general irritability. Feelings of guilt may occur when anger is directed internally.
It is common for physical symptoms related to over-activity of the autonomic nervous system to be experienced, eg palpitations, insomnia, diarrhoea and fatigue. A transient hypochondriasis can occur, but it is abnormal if it persists.
- 3 **Despair or depression**. As the pangs of grief and anxiety reduce in frequency and severity the bereaved may lose interest and purpose in life. They feel hopeless and become withdrawn. This may last for months.
- 4 Eventually the loss is **accepted** and life without the deceased is adjusted to.
- 5 The final phase of **resolution and reorganisation** is entered as emotional energy is reinvested in new relationships and activities, although anniversaries often trigger renewed grief.

For some, part of the work of grieving may be undergone before the actual death of the deceased (anticipatory grieving). **Although described in sequence, bereavement reactions usually oscillate between phases.**

For most people, no formal psychotherapeutic intervention is needed as their personality, previous life experiences, social network and loving relationship with the bereaved enables them to come to terms with their loss, and often to grow personally through it. All that is often required is a watchful eye to check that their grief is continuing normally.

- 6 For those with **unresolved/abnormal grief** further intervention is required. The needs of children and adolescents are often quite complex and they may also benefit from specialist support. Recognition of those likely to develop an abnormal grief reaction can also allow early supportive intervention and prevent its development. Risk factors include:
- an unexpected/untimely death
 - an unpleasant death
 - an ambivalent relationship
 - an excessively dependent relationship
 - a child/adolescent (may be protected/excluded)
 - social isolation
 - excessive use of denial, preventing anticipatory grieving
 - unresolved anger
 - previously unresolved losses
 - previous psychiatric illness
 - a history of alcoholism/drug abuse
 - other concurrent stressful life events.

For many, a trained volunteer who listens may address the need of the bereaved to recognise and express their feelings and fears, enabling them to make sense for themselves of the events which have occurred. Reassurance that what they are experiencing is 'normal' is extremely helpful. A chaplain may also be helpful to those whose faith is shaken, destroyed or awakened.

Some find meeting with a group of individuals who have undergone a similar experience can be supportive. These groups may or may not have a trained facilitator.

Written information explaining what may be experienced and giving useful contact numbers is often appreciated.

UNRESOLVED/ABNORMAL GRIEF

There is no clear boundary between what is 'normal' and what is 'abnormal' grief, and it is often a question of unusual intensity, of reaction or timing. The following guide indicates when professional intervention may be required.

- 1 **Delayed grief** is defined by an absence of grieving within the first weeks or months after the death. It is often precipitated many years later by further loss. It is more likely to be severe and chronic when it finally occurs. Help is often needed in emotionally accepting the reality of the past loss.
- 2 **Inhibited grief** occurs when all reminders of the bereaved are avoided. This mechanism of avoidance may work for some, but can present as irritability, restlessness or depression. Guided mourning is employed to encourage the bereaved to face the reality of the loss.
- 3 **Chronic grief (mummified grief)** may be severe and occurs when a person fails to progress through all the tasks of mourning. There is no fixed time period. Assistance is needed in helping the bereaved to move on in the grieving process.
- 4 **Persistent hypochondriasis** can occur and may block grief. The bereaved may take on the symptoms of the deceased or develop symptoms related to anxiety or depression. Explaining to the patient what is happening may be all that is required. However, note that mortality and morbidity of widows and widowers is increased in the first year after the death, mainly due to cardiovascular disease.
- 5 **Psychiatric disorder.** A severe depressive illness may develop with delusional ideas of guilt and suicidal intent. It can require hospitalisation. **Mania** can be precipitated as can **phobic disorders**, and **alcoholism** and addiction to drugs, especially hypnotics.

Some of these abnormal grief reactions can be dealt with by the primary health care teams, social workers or trained counsellors. In addition, many areas have their own voluntary bereavement and counselling groups including branches of CRUSE (www.crusebereavementcare.org.uk tel 08444779400). Health centres, hospitals or Citizens' Advice Bureaux should also have information, as will The National Association of Bereavement Services, 10 Norton Folgate, London E1 6DB (tel 02072471080). Others require specialist help from psychotherapists or psychiatrists, and it is important for all professionals to realise their own skills and limitations.

INDEX OF DRUGS, DRESSINGS ETC

This list of drugs, dressings and other preparations recommended in this Handbook is intended as an aid to pharmacists and others. The list is neither exhaustive nor exclusive, and other products may be recommended or be more appropriate in some circumstances. Often, only one drug is listed from a whole class of compounds: this should not be taken to imply that other preparations may not be equally effective. Generic names are given for drugs with single constituents, proprietary names for most compound formulations and for dressings.

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** indicates that this is best managed by specialists*

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