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THE PALLIATIVE CARE HANDBOOK

Guidelines on clinical management

FOURTH EDITION

PORTSMOUTH HEALTHCARE NHS TRUST
PORTSMOUTH HOSPITALS NHS TRUST
THE ROWANS (PORTSMOUTH AREA HOSPICE

in association with all the Wessex Specialist Palliative Care Unit

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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 highest 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 guidelines 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; more detailed drug information may be found in the British National Formulary.

The former term 'radiotherapist' is used in place of 'clinical oncologist', for reasons of clarity and brevity.

Cautionary note: some of the drug usage recommended is outside product licence, either by way of indication, dose, or route of administration. However, the approaches described are recognised as reasonable practice within palliative medicine in the UK.

Abbreviations

csci = continuous subcutaneous infusion (via a syringe driver)
sl = sublingual
sc = subcutaneous injection

*** indicates that these drugs or conditions are best managed by specialist staff**

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 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 drug card and/or a 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**

PAIN

Pain is a common, although not inevitable symptom in cancer and successful treatment requires **an accurate diagnosis of the cause and a rational approach to therapy.** There are many components to cancer pain and all relevant physical and psycho-social factors need to be taken into account. Pain in the cancer patient need not be caused by the **cancer**, and can be due to **previous treatment** or to an **unrelated cause.**

Most pains arise by stimulation of nociceptive nerve endings; the characteristics may depend on the organ involved. The analgesic ladder approach (see over) is the basis for prescribing but careful choice of appropriate adjuvant drugs such as anticholinergics for colic, NSAIDs for bone pain and benzodiazepines for muscle spasm, will greatly increase the chance of effective palliation.

A burning or shooting component to the pain is likely to be due to nerve entrapment or infiltration resulting from compression or erosion respectively.

Diagnosis

There is no easy way of measuring pain in a clinical situation; as such, it is generally held that **pain is what the patient says it is.**

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

If pain is difficult to control, remember:

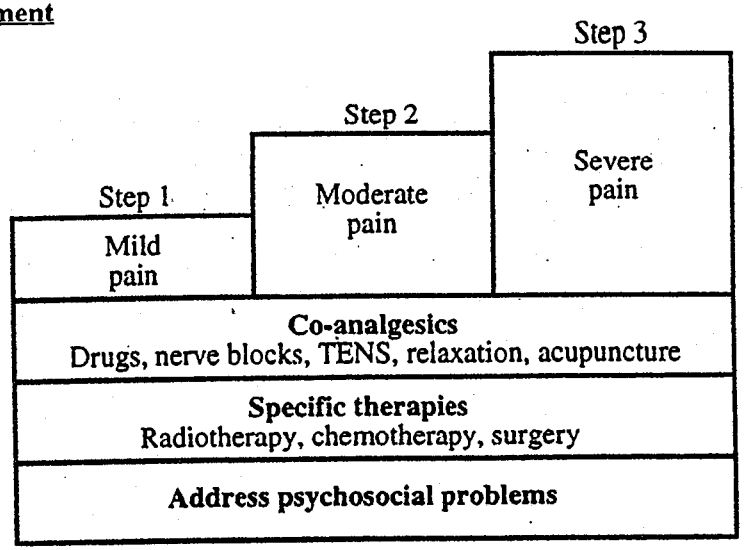
> All pains have a significant psychological component, and fear, anxiety and depression will all lower the pain threshold. Remember also the likely effects of life changes associated with terminal disease including loss of financial security, loss of body image and compromised sexual function. Together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

Assessment

1 Identify the site (with any radiation), severity, duration, timing and aggravating and relieving factors

2 Use a body diagram with the patient's own words

Management



The WHO analgesic ladder

The WHO analgesic ladder has been adopted to emphasize that it is essential to use an analgesic which is appropriate to the severity of the pain; patients whose pains do not respond to weak opioids warrant and deserve to be managed with strong opioids. However, alternative methods of pain control as indicated in the boxes at the base of the diagram **must** be considered in all patients, whatever the severity of their pain.

Step 1 **Non opioids**

Paracetamol	oral or rectal 500mg - 1g qds (maximum 4g / day)
NSAIDs	diclofenac (tabs SR 75mg bd)
	naproxen (tabs/susp/suppos 500mg bd)
	ibuprofen (maximum 2.4g per day)

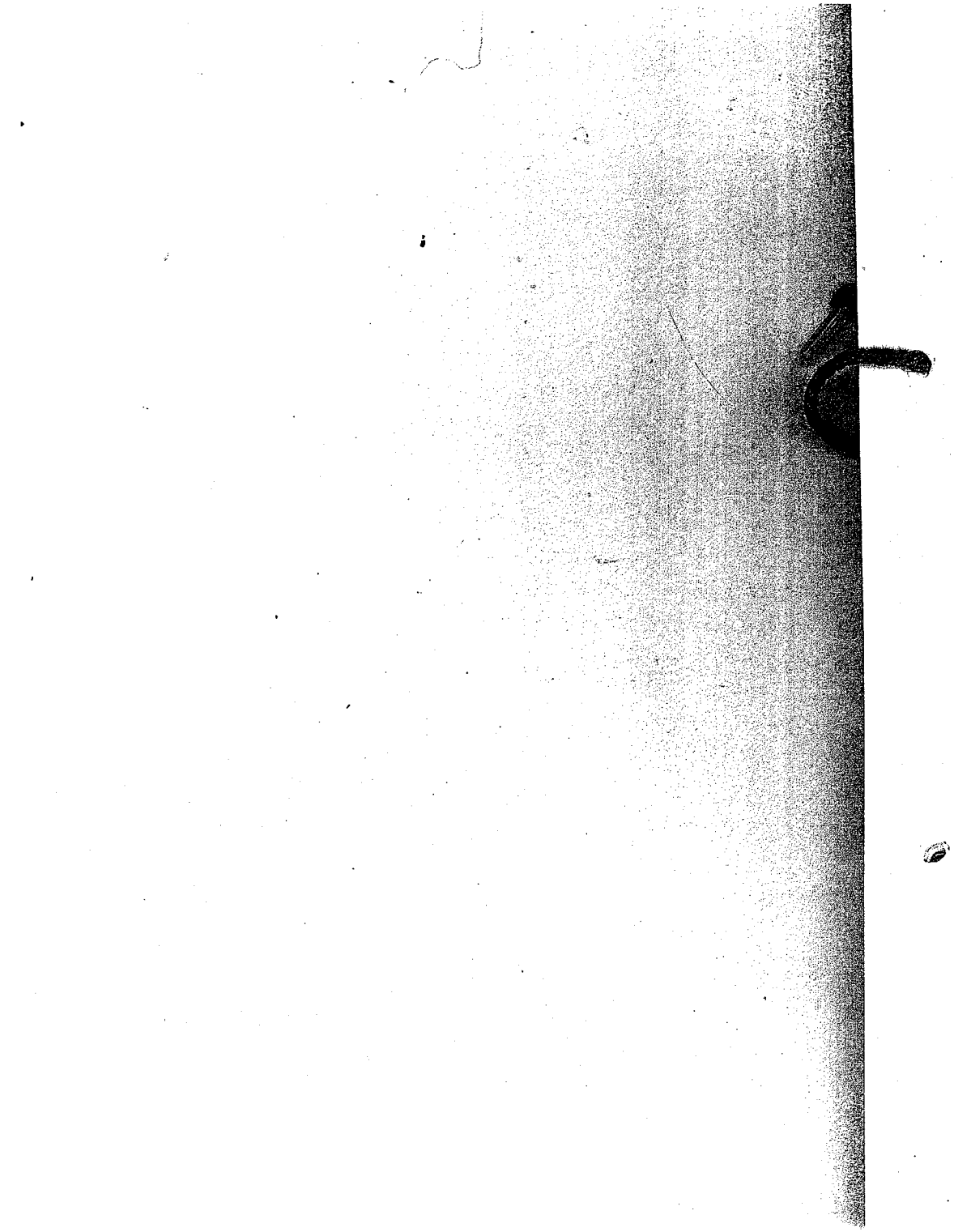
Step 2 **Weak opioids**

Dextropropoxyphene 32.5mg with paracetamol 325mg (coproxamol)
Codeine 30mg with paracetamol 500mg (cocodamol 30/500)

Several other drugs are available in this category including dihydrocodeine and tramadol (avoid in epilepsy or if on antidepressives) although none has any particular advantage over the two preparations listed above

Step 3 **Strong opioids**

See following pages



Strong opioids

1 **Morphine** is the strong opioid of choice for oral use

Several preparations are available including:

Immediate release oral morphine
a) Oramorph liquid 10mg/5ml, 100mg/5ml (4 hourly)
b) Oramorph unit dose vials 10mg/5ml, 30mg/5ml, 100mg/5ml (4 hourly)
c) Sevredol tablet 10mg, 20mg, 50mg (4 hourly)

Sustained release oral morphine tablets and capsules
a) MST Continus 5mg, 10mg, 15mg, 30mg, 60mg, 100mg, 200mg (12 hourly)
b) Oramorph SR 10mg, 30mg, 60mg, 100mg (12 hourly)
c) MXL 30mg, 60mg, 90mg, 120mg, 150mg, 200mg (24 hourly)
d) Morcap SR 20mg, 50mg, 100mg (12 or 24 hourly)

Sustained release oral suspensions
a) MST Continus 20mg, 30mg, 60mg, 100mg, 200mg (12 hourly)

Morphine suppositories are available if the rectal route is preferred - consult local pharmacy for availability

2 **Diamorphine** is the strong opioid of choice for parenteral use because of its greater solubility - maximum recommended concentration 250mg/ml

3 **Phenazocine*** is useful if there is genuine morphine intolerance. One 5mg tablet is equipotent with 25mg morphine but has a longer duration of action
a) Narphen 5mg (6 - 8 hourly)

4 **Fentanyl TTS patch.** Useful especially when there is difficulty swallowing, vomiting or intractable constipation; dose titration is more difficult and expensive. Possibility of withdrawal symptoms when converting from morphine - responds to small doses of immediate release oral morphine
a) Durogesic 25mcg/hr, 50mcg/hr, 75mcg/hr, 100mcg/hr (72 hourly)

Conversion from oral morphine to transdermal fentanyl

Morphine (mg/day)	<135	135 -224	225 -314	315 -404	405 -494	495 -584	585 -674	675 -764	765 -854
Fentanyl (mcg/hour)	25	50	75	100	125	150	175	200	225

5 **Hydromorphone*** has recently become available in this country; it may be useful if there is genuine morphine intolerance
a) Palladone capsules 1.3mg, 2.6mg (4 hourly)
b) Palladone SR capsules 2mg, 4mg, 8mg, 16mg, 24mg (12 hourly)

6 **Dextromoramide** (Palfium) and **pethidine** have a short duration of action. They are useful for painful procedures but should **not** be used regularly for chronic cancer pain

Use of morphine

1 Instructions to the patient
- Emphasise the need for regular administration and explain about breakthrough medication
- Warn about possible side effects
- Reassure that when used for pain relief, morphine is not addictive and that there is a very wide range of doses available so that they are not prejudicing future pain relief by starting treatment now

2 Start by using an immediate release morphine (liquid or tablet) for dose titration giving it every 4 hours. The eventual effective dose may range from 2.5mg to more than 200mg but only a minority of patients will need more than 30mg 4 hourly. Give a double dose at bedtime to avoid waking at 2 - 3 am but ensure that at least 5 doses are given per 24 hours

3 Start with a low dose and increase by 30 - 50% increments each day until pain controlled or side effects prevent further increase. Doses can be rounded up or down according to individual need. A common dose sequence is:
5 - 10 - 15 - 20 - 30 - 40 - 60 - 90 - 120 - 150 - 200mg
Avoid unwieldy doses such as 22.75mg which will lead to confusion and error

4 Prescribe the same dose as the 4 hourly dose for prn use to be repeated as often as necessary (hourly if necessary) for breakthrough pain while still continuing with the regular dose and review every 24 hours

5 Use continuing pain as an indication to increase the dose and persisting side-effects, eg drowsiness, vomiting, confusion, particularly in association with constricted pupils, as an indication to reduce the dose. If both pain and side-effects are present, consider other approaches

6 Once pain is controlled, consider converting to 12 or 24 hourly sustained release preparation for convenience using the same total daily dose. Always make available immediate release morphine for breakthrough pain (see 4)

7 When oral administration is not possible because of dysphagia, vomiting or weakness, consider changing to diamorphine by subcutaneous infusion using a syringe driver. The conversion from oral morphine to subcutaneous diamorphine (total daily dose) varies between 1/3 - 1/2 allowing some flexibility depending on the requirement for increased or decreased opioid effect

Unwanted effects of morphine

1 **Constipation** is virtually inevitable - use prophylactic laxatives (see p22)

2 **Nausea** normally clears within a week; more common at higher doses. May need antiemetic, eg haloperidol 1.5mg nocte, metoclopramide 10mg tds, prochlorperazine 5 - 10mg tds

3 **Drowsiness** normally clears within 5 days; otherwise suggests overdosage. If persistent reduce dose, consider other forms of analgesia or other opioid

Changing from one opioid to another

There are theoretical proposals in the literature for **opioid rotation***, that is changing from one strong opioid to another if pain does not come under good control without unacceptable side effects. Research evidence is lacking, and most problems can be solved by improving the titration or by using adjuvant drugs

Opioid equivalents

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. The total daily doses shown are broadly equivalent to oral morphine 30mg

Drug	**Total daily dose**
Coproxamol	8 tablets
Codeine	360mg
Dihydrocodeine	300mg
Tramadol	120mg
Buprenorphine#	0.6mg
Pethidine (intramuscular)#	200mg
Morphine	**30mg**
Diamorphine (subcutaneous)	10mg
Phenazocine*	7.5mg
Hydromorphone*	4mg
Oxycodone (only available in UK as suppositories)	20mg
Methadone*	10mg
Dextromoramide#	15mg

Notes

\# We do not recommend for regular use in chronic cancer pain

* Best used by specialist staff

Management of specific pains

A Bone pain

1 Consider early referral for palliative radiotherapy - usually single fraction

2 **NSAIDS** are effective for pain on movement but beware side effects especially when used with corticosteroids; discontinue if not helping

3 Regular iv infusions of **bisphosphonates*** of proven benefit in bone metastases from breast or prostate cancer and myeloma: **pamidronate** 60 - 90mg, **sodium clodronate** 1500mg every 3 - 4 weeks

4 Consider orthopaedic surgery for painful lytic metastases at risk of fracture

B Abdominal pain

1 Constipation is a common cause; avoid assuming pain must be due to cancer

2 For colic use an anticholinergic such as oral **propantheline** or subcutaneous **hyoscine butylbromide** (Buscopan) 30 - 90mg/24hrs usually by syringe driver

3 For liver capsule pain consider **dexamethasone** 4 - 8mg/day +/- NSAID

4 For pain arising from upper GI tumour consider coeliac plexus block (see **H**)

5 NSAIDs are a common cause of iatrogenic abdominal pain

C Neuropathic pain*

Often burning or shooting, and may not respond in a predictable way to pain relieving medication. May presage cord compression. Specialist palliative care team will be pleased to advise but the following approach is suggested

1 Titrate to maximum tolerated dose of opioid

2 **Amitriptyline** 10 - 75mg or **dothiepin** 25mg - 75mg nocte; increase dose to maximum tolerated and stop if no benefit after 7 days at that dose

3 According to response either add or substitute anticonvulsant eg **sodium valproate** 400 - 800mg/day, **clonazepam** 500mcg nocte or up to tds, **carbamazepine** 200 - 1200mg/day (usefulness is often limited by side effects); discontinue if no benefit after 5 days on highest dose tolerated

4 **Dexamethasone** 8mg daily - stop if no improvement after 5 days

5 To consider: TENS, acupuncture, **clonidine***, **ketamine***, **midazolam***, **mexilitine***, neural blockade

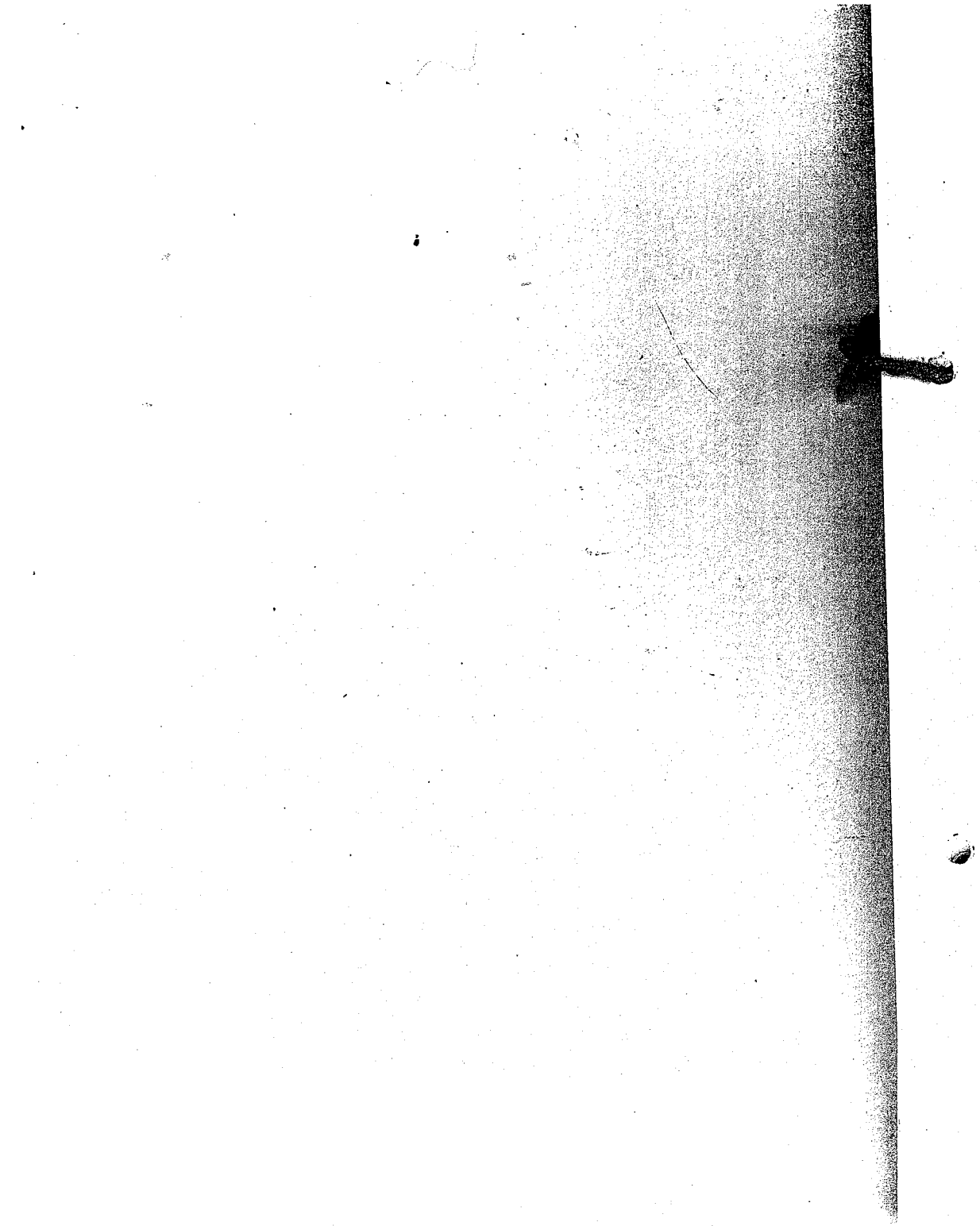
D Rectal pain

1 Rectal drugs: **steroids, diazepam, nifedipine*, baclofen***

2 Local radiotherapy

3 **Tricyclic antidepressives** (amitriptyline, dothiepin - see **C**)

4 If anal spasms, try **glyceryl trinitrate** ointment 0.1 - 0.2% bd



E Muscle pain

1 **Paracetamol, NSAIDs**

2 Muscle relaxants: **diazepam, baclofen, dantrolene**

3 Physiotherapy, aromatherapy, relaxation, heat pad

F Bladder spasm

1 **Oxybutinin** 5mg tds

2 **Amitriptyline** 10 - 75mg nocte

3 If catheterized, intravesical **bupivacaine** 0.25%, 20 mls for 15 mins tds

G Acute pain of short duration

For example pain on moving a fractured limb or changing a painful dressing

1 **Dextromoramide** given sublingually 20 mins prior to procedure

2 **Entonox**

H Pains amenable to nerve blocks

Some techniques are easily learned by the non-specialist whilst others should be performed only by pain management specialist anaesthetist. Neural blockade can be temporary with local anaesthetic or semi-permanent with neurolytic agents such as phenol. By reducing local inflammation, injected steroids are particularly useful when pain is due to compression of the nerve

1 Intrathecal opioid and local anaesthetic infusions may help in difficult pains

2 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 much more difficult

3 Chest wall pain eg due to mesothelioma - can be very difficult to control; intercostal and paravertebral blocks are easy to perform; success claimed for cervical cordotomy or thoracic epidurals in very specialized hands

4 Upper abdominal pain especially due to pancreatic tumour - 80% success claimed for coeliac plexus block

5 Lower abdominal and pelvic pain - lumbar plexus block worthwhile benefit but less successful

6 Hip pain - psoas compartment block

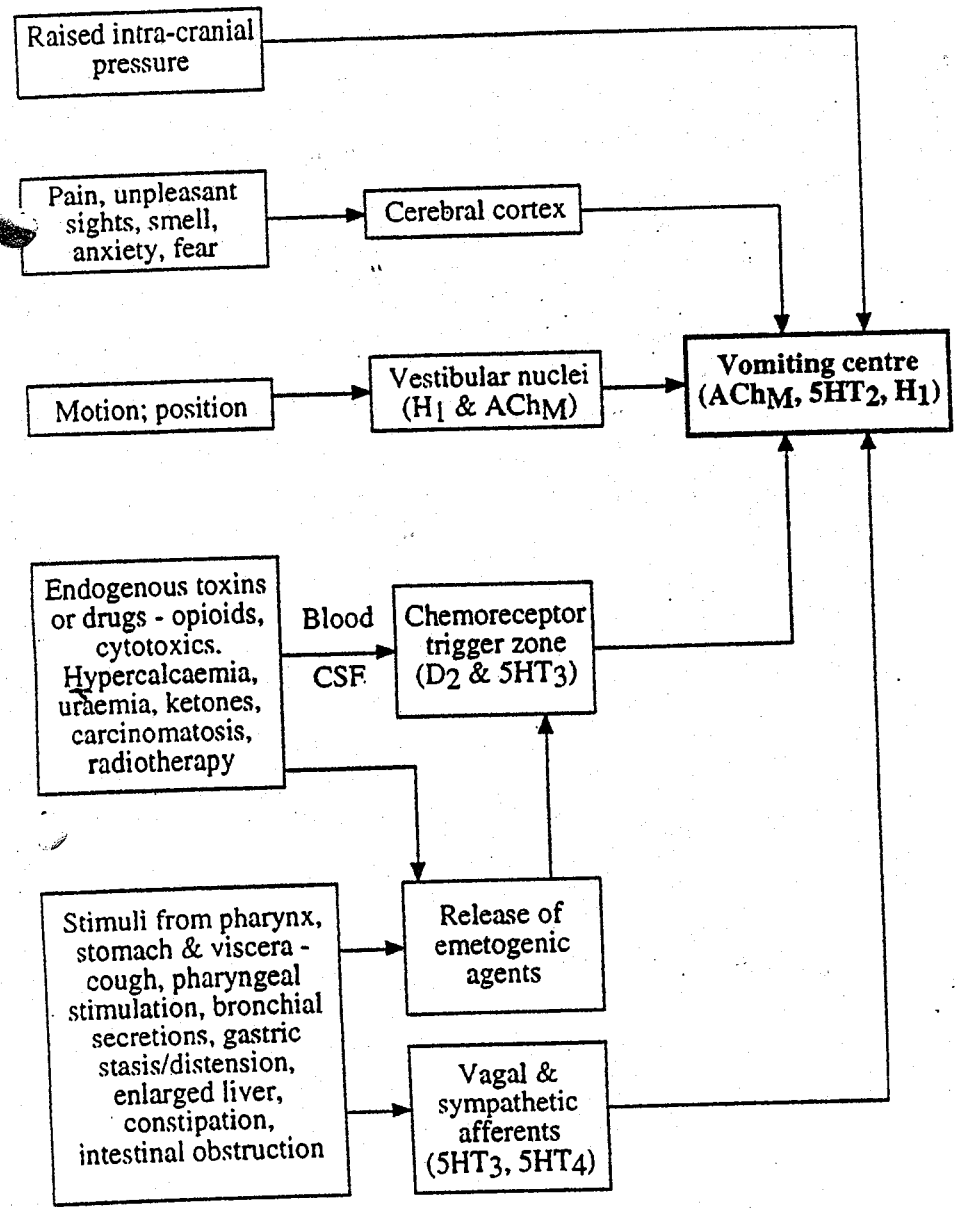
7 Perineal pain - saddle anaesthesia using intrathecal phenol. Like all neurolytic techniques this is the province of the specialist

8 Rib pain - temporarily abolished by intercostal injection of local anaesthetic proximal to lesion. Longer term benefit from infiltration with depot steroid. Care needed but technique well within capability of trained non-specialist

9 Pancoast tumour and similar - brachial plexus block

NAUSEA AND VOMITING

Causes / Risk factors



Management

There are many causes of nausea and vomiting and more than one cause may often be identified in any particular patient. Mechanisms are outlined opposite. See next page for profiles of antiemetics and standard dose regimes

Cause	Therapy
Raised intracranial pressure	1 **Dexamethasone** (see p32) 2 **Cyclizine**
Anxiety etc	1 Benzodiazepines - **diazepam** 2 - 15mg daily 2 **Midazolam** 10 - 30mg/day via syringe driver
Motion, positional	1 **Cyclizine** 2 **Hyoscine**
Endogenous toxins, drugs	1 **Haloperidol** 2 **Prochlorperazine** 3 **Methotrimeprazine** 4 **Metoclopramide**
Chemotherapy (short term)	1 Consult oncology colleagues 2 **Lorazepam** for anticipatory vomiting 3 **Dexamethasone** in reducing doses over 5 days 4 **5HT3 antagonists** only effective in early emesis
Gastric stasis	1 **Domperidone** 2 **Metoclopramide** 3 **Cisapride**
Gastric irritation	1 **Antacids** 2 **Proton pump inhibitors** 3 **Misoprostol** 200mcg bd if caused by NSAIDs
Indeterminate	1 **Cyclizine** 2 **Prochlorperazine** 3 **Methotrimeprazine** 4 **Dexamethasone** 4 - 8mg daily
Constipation	See separate section on p20
Intestinal obstruction	See separate section on p16

Mechanisms of action of antiemetics

Receptor Sites	Type of Receptor
Vomiting centre	Muscarinic (ACh_M) Histamine (H_1) $5HT_2$
Vestibular nuclei	Muscarinic (ACh_M) Histamine (H_1)
Chemoreceptor trigger zone (CTZ)	Dopamine (D_2) $5HT_3$
Upper gastrointestinal tract	$5HT_3$ $5HT_4$ Dopamine (D_2) prokinetic

Antiemetic therapy

In established nausea/vomiting gastric stasis interferes with oral absorption: use other routes. Use oral route for prophylaxis of nausea

Use appropriate non-drug measures and treat basic causes if possible. If nausea/vomiting are caused by other medication consider stopping, reducing dose, changing drug, formulation or route of administration

Caution: most antiemetics have sedative effects

A Anticholinergic/antimuscarinic (ACh_M)

Hyoscine hydrobromide 0.3 - 0.6mg 6 - 8 hourly sl or sc
0.8 - 2.4mg per day by csci
500 - 1500mcg/72 hrs by transdermal patch

B H_1 antihistamines

Cyclizine 50mg three times daily orally or by im or sc injection
100 - 150mg in 24hrs by csci
Also has anticholinergic action

C Dopamine (D2) antagonists

Haloperidol
Antiemetic of choice for opioid induced vomiting
1.5 - 5mg at night, oral or sc
2.5 - 5mg over 24 hours by csci

Methotrimeprazine
Some activity at several sites (ACh_M, D_2, H_1, $5HT_2$)
Sedative at higher doses (25 - 100mg in 24 hours)
Antiemetic activity at low doses (6.25 - 25mg in 24 hours)
Use at lowest effective dose unless sedation required
Dose varies from 6.25 daily to 25mg tds orally or sc
May be given as csci

Prochlorperazine
5 - 10mg tds orally
25mg suppository tds rectally
12.5mg tds by deep im injection
3 - 6mg bd as buccal tablets
Do not give sc

Metoclopramide
Also prokinetic
10 - 20mg three times daily orally or im
In high doses (more than 100mg daily) acts as 5HT3 antagonist and possibly as 5HT4 agonist

Domperidone
Also prokinetic
Less likely to cause sedation or extrapyramidal problems
10 - 20mg tds orally
30 - 60mg suppository tds rectally

D 5HT3 antagonists

Mainly used in early emesis caused by chemotherapy/radiotherapy; no good evidence of efficacy in other situations

Ondansetron 8mg bd - tds orally; may also be used sc, im or iv

E 5HT4 agonists

Cisapride 10mg tds orally
Metoclopramide See above
Domperidone See above

Note: **csci = continuous subcutaneous infusion**
See section on syringe drivers, p25

INTESTINAL OBSTRUCTION*

Intestinal obstruction in the patient with advanced cancer is often a difficult and complex situation and early discussion with the specialist palliative care team is recommended. It is usually a result of multiple incomplete obstructions within a bowel which is tethered and infiltrated by cancer. There are thus both mechanical and functional elements

Diagnosis

1 Vomiting often with little preceding nausea
2 Constipation - some flatus may still be passed
3 Abdominal distension and discomfort
4 Bowel sounds may be hyperactive or scanty
5 Colic may not be prominent, but tends to indicate a single site of obstruction
6 Previous operation notes or abdominal x-ray may indicate site(s)
7 Rectal examination to exclude simple constipation

Causes / Risk factors

1 Most common with primary tumours of ovary and colon but may occur with almost any primary tumour, including carcinoma of breast
2 Tumour mass within the intestinal lumen
3 Tumour outside the intestine causing compression or adhesions
4 Infiltration within the muscular coats, preventing normal peristalsis (pseudo-obstruction)
5 Interference with intestinal motility by tumour infiltration of the mesentery
6 Pancreatic carcinomas may cause gastric stasis by an unknown mechanism
7 Other causes including adhesions, post radiation fibrosis, constipation, metabolic disturbances, septicaemia

Management

1 Consider surgery (or occasionally radiotherapy) if **both**
a) single site, large bowel or marked gaseous distension **and**
b) appropriate depending on patient's condition and wishes - reassess often
2 If inoperable, avoid 'drip and suck' - NG tube increases nausea
3 Treat dry mouth (see p20)

4 **Drug therapy**

Shrinkage of tumour masses

Cytotoxic chemotherapy may occasionally be helpful if the patient's overall condition is good, especially in primary carcinomas of the ovary or colon

Dexamethasone 4 - 8mg daily may help to relieve peri-tumour oedema and thus relieve obstruction; particularly helpful with gastric outlet obstruction. May need to be given im or sc in first instance

Colic

Avoid/stop stimulant and bulking laxatives and prokinetic antiemetics (metoclopramide, domperidone, cisapride)

Hyoscine hydrobromide 0.3mg qds sl

Hyoscine butylbromide 20mg qds orally or 40 - 80mg daily by csci

Mebeverine 135mg tds orally

Loperamide may help

Constant aching abdominal pain

Strong opioids - Diamorphine by csci

Nausea and vomiting

Aim to abolish nausea and to reduce vomiting to a minimum

Cyclizine (see p14)

Haloperidol (see p15)

Methotrimeprazine (see p15)

Prokinetic agents ($5HT_4$ agonists) may help where there is gastric stasis, ileus or pseudo-obstruction but are contra-indicated in the presence of colic or if there has been a gastro-jejunostomy

Laxatives

Use pure faecal softeners to coax stool through narrowed loops of bowel

Docusate sodium up to 200mg tds

Magnesium hydroxide mixture 20 - 30ml od - bd

Anti-secretory agents

H_2 blockers (ranitidine, nizatidine) may be useful in high obstructions to reduce the volume of gastric secretions

Hyoscine butylbromide is a relatively mild anti-secretory agent

Octreotide* (see p18) has powerful anti-secretory properties

OCTREOTIDE*

Octreotide* (Sandostatin) is the longer acting synthetic analogue of the naturally occurring hormone somatostatin. Somatostatin's normal physiological function is to help to regulate pituitary and gastrointestinal endocrine and exocrine secretions, gastrointestinal motility and mesenteric blood flow. Note that experience is limited, efficacy variable, and that octreotide is expensive

Uses in palliative care*

NB These uses are outside the product licence - see cautionary note, p3

1 Intestinal obstruction

Octreotide decreases the volume of intestinal secretions, and thus reduces intestinal distension, itself a potent stimulus of secretion. It does this by reducing fluid and electrolyte secretion. It also reduces gastrointestinal motility. Both actions may reduce nausea, vomiting and abdominal distension

2 Fistulae

Octreotide decreases the output from a variety of fistulae, occasionally leading to closure of the fistula. It has been used in tracheo-oesophageal, pancreatic, entero-cutaneous, entero-vesical and entero-vaginal fistulae

3 Diarrhoea

Octreotide has been used in the management of diarrhoea caused by subacute intestinal obstruction (spurious diarrhoea) or entero-enteric fistulae, as well as in severe secretory diarrhoea and carcinoid syndrome

Dose

1 The effective dose ranges from 200 - 600 mcg per day (carcinoid: 100mcg od)

2 Several days may pass before full effect is seen

3 It may be possible to reduce the dose if control is achieved

Administration

1 Warm drug to room temperature to avoid stinging on injection

2 Octreotide is said to be **compatible** with diamorphine, metoclopramide, haloperidol, midazolam and hyoscine. It is **incompatible** with dexamethasone and cyclizine

Cautions

1 Risk of gallstone formation after prolonged use

2 Insulin requirements in diabetic patients may fall; glucose intolerance in others

3 Side-effects uncommon - steatorrhoea, hepatic and thyroid dysfunction

MOUTH PROBLEMS

Good mouth care is essential to the well being of debilitated patients

Diagnosis

1 Assess oral cavity daily using a pen torch and spatula. Note the state of the lips, teeth/dentures, mucous membranes and tongue, 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 patients' ability and willingness to participate in their care

Causes / Risk factors

1 Poor oral hygiene
2 Poor nutritional state, dehydration, drowsiness, anaemia
3 Oral thrush and other infections
4 Oral tumour
5 Drugs - opioids, tricyclic antidepressives and hyoscine cause dry mouth; some cytotoxics can cause ulceration
6 Local radiotherapy can cause decreased saliva production and oral ulcers

Management

1 Review medications causing dry mouth/ulceration
2 Treat oral infections
3 **Drug therapy**

Frequency of care depends on the patient's condition

General care

Corsodyl mouthwash - antiseptic and inhibits plaque formation. Use regularly after meals and brushing

Betadine and **Oraldene** are antibacterial and antifungal but have little antiplaqu activity

Glycerine thymol has mainly mechanical cleansing properties but is transiently refreshing

Ascorbic acid 1g effervescent tablet - allow a quarter or a half of one tablet to effervesce on coated tongue

Specific care

Lack of Saliva

Sips of iced water

Salivary stimulants - lime juice, fresh melon, pineapple, sugar-free gum

Saliva substitutes - Glandosane spray, Saliva-Orthana

Pilocarpine tablets 5 - 10mg tds for radiotherapy induced dryness

Oral Thrush

Nystatin oral suspension - patients must be instructed on correct usage

Fluconazole - 50mg daily for 7 days

Sodium hypochlorite (Milton) - for soaking dentures overnight

Painful Mouth

Difflam mouthwash - anaesthetic action

Adcortyl in Orobase - apply topically (without rubbing in)

NSAID - Piroxicam melt daily for oral cancer pain

Sucralfate suspension - for chemotherapy induced ulcers

Xylocaine spray

Excessive Salivation

Amitriptyline 10mg at night

Hyoscine by patch, syringe driver, orally or sublingually (see p14)

Glycopyrronium by syringe driver - if hyoscine causes confusion or over-sedation

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, dysphagia, 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, especially 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
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
Medroxyprogesterone 100mg tds
Dexamethasone 2 - 4mg each morning or **prednisolone** 10mg daily to tds
Steroids should always be used with caution, and the dose reduced to the minimum effective at any time, because of the risks of muscle wasting, skir thinning and (rarely) osteoporosis; may also precipitate diabetes. Patients with a history of tuberculosis who have not been treated with triple chemotherapy should receive prophylactic isoniazid

CONSTIPATION

It is extremely important to relieve constipation in patients with advanced disease. Even anorexic patients will need bowel movements to remove faeces formed from gut secretions/cells/bacteria. It is better to anticipate and prevent constipation than to wait until treatment is needed

Diagnosis

1 Passing harder stools, or passing stools less frequently
2 Rectal examination - empty or impacted?
3 Exclude intestinal obstruction (see p16)

Causes / Risk factors

1 Drugs - especially opioids, tricyclic antidepressives, iron, antispasmodics
2 Immobility and lack of privacy
3 Dehydration, due to poor fluid intake, vomiting, polyuria, sweating
4 Diet lacking in fibre
5 Hypercalcaemia
6 Concurrent disease - painful anal conditions, hypothyroidism

Management

1 As far as possible, alleviate cause - encourage fibre intake, keep mobile
2 **Drug therapy:** use softeners if stool is hard, stimulants if unable to expel stool

Patients taking opioids need to be prescribed laxatives as a routine

Combination preparations (stimulant & softener)

Bisacodyl 10 - 20mg nocte with **docusate sodium** 200mg od - tds
Codanthramer (two strengths) susp or capsules 5 - 15ml, 2 - 4 capsules od/bd
Codanthrusate is an alternative

mulants

Bisacodyl 10 - 20mg nocte
Senna 2 - 4 tablets nocte
Sodium picosulphate elixir 10 - 20ml bd

Softener

Docusate sodium 200mg nocte or up to 600mg daily

Osmotics

Lactulose 10 - 15ml bd
Magnesium hydroxide mixture 20 - 30ml od - bd

3 Rectal measures are often needed in established constipation - use suppositories, micro-enemas, phosphate or arachis oil enemas

DIARRHOEA

Diagnosis

The patient who speaks of 'diarrhoea' may either be referring to the frequency of bowel motions, or to the fact that motions are loose; it is therefore important to define the problem by history or examination if a diagnosis is to be reached

Causes / Risk Factors

1 Excess laxative use
2 Infections, including *Clostridium difficile*, *Candida* spp
3 Impacted faeces with overflow (spurious diarrhoea)
4 Subacute intestinal obstruction
5 Previous treatment: pelvic radiotherapy, extensive bowel resection
6 Pancreatic insufficiency, characterized by bulky, offensive stools which float

Management

1 **Specific tretment**

Ensure no excess laxative use

Screen for infections, and prescribe appropriate antibiotics

Octreotide* (see p18) for faecal fistulae, subacute obstruction, carcinoid

Prednisolone enemata or foam for radiation induced diarrhoea

Pancreatic enzymes (Creon capsules; 2 strengths) for steatorrhoea

2 **Symptomatic treatment**

Loperamide 2 - 4mg every 6 hours; binds to opioid receptors in gut

Cophenotrope (Lomotil) 2 tablets four times a day

Codeine Phosphate 30 - 60mg tds - qds

Fistulae

Management

1 Assess fistula size and site, and patient's overall condition
2 A colostomy bag is often needed for collecting effluent. A good seal is needed and advice should be given about skin care and frequent emptying of bag
3 A well-fitted appliance minimizes the risk of odour. **Metronidazole** may be helpful if there is a blind loop or overgrowth of anaerobes
4 **Octreotide*** may be helpful in reducing effluent (p18)

ASCITES

Diagnosis

1 Clinical examination - shifting dullness, fluid thrill, ballot abdominal organs
2 Abdominal ultrasound
3 Diagnostic tap
4 Exclude urinary retention, organomegaly, tumour, gastrointestinal distension

Causes / Risk factors

1 Peritoneal tumour
2 Venous compression or thrombosis
3 Hypoalbuminaemia

Management

1 Take no action if symptoms are not troublesome
2 Perform **paracentesis** if appropriate, unless bowel is distended. Unsuccessful if fluid is loculated (consider ultrasound scan). Drain 2 litres in first hour then 6 litres per day. Monitor carefully: sudden release of abdominal tension may allow venous pooling and rapid reaccumulation of ascites, with hypotension. If leakage continues after drain is removed, consider placing ostomy bag over the puncture site
3 If patient has oedema use stockings and/or massage (see p51)
4 Peritoneo-venous shunt can be valuable in severe recurrent ascites
5 If concurrent intestinal obstruction: see p16
6 **Drug therapy**

Cytotoxic chemotherapy (local or systemic) if appropriate

Diuretics:	**Frusemide** (especially if dependent oedema) 40 - 80mg daily
	Spironolactone (especially if hypoalbuminaemia) 100mg od/bd
	Adjust doses according to response
Steroids:	**Dexamethasone** 2 - 4mg om can help to mobilize fluid
Antiemetics:	**Domperidone** or **metoclopramide** (see p15) for gastric stasis
Analgesics:	If painful stretching of abdominal wall, see pp5 - 11

SYRINGE DRIVERS

A syringe driver is a small portable battery operated pump which administers drugs subcutaneously by continuous infusion. It offers an alternative route of drug administration without limiting patient mobility or independence, and by maintaining very steady blood levels **may** improve symptomatic control

See **cautionary note**, p3

Indications

For administering medication when the oral route is inappropriate or difficult

1 Severe nausea and/or vomiting
2 Dysphagia
3 Severe oral tumours, sores or infection
4 Profoundly weak, unconscious or heavily sedated patients
5 Poor absorption of oral medication

If problems resolve, consider a return to oral medication

Practical Points

1 The syringe driver should be set according to the rate of infusion required
2 Site inflammation may occur for various reasons, and the infusion site should be checked at least daily. Management includes changing the drug, changing t an alternative site or adding a small dose of steroid (hydrocortisone 50 - 100m per day). If the problem persists, seek advice
3 Certain drug combinations are incompatible and cause precipitation. This may be overcome by:
   - 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 the drug with an equivalent alternative
   - avoiding exposure to sunlight as non-observable chemical reactions may occur
4 Use as few drugs in a syringe driver as possible
5 **Diazepam, prochlorperazine and chlorpromazine** should **never** be used in the syringe driver

Drugs used in the syringe driver

Cyclizine 50 - 150mg over 24 hours

Antihistamine and antimuscarinic antiemetic which acts at the vomiting centre in the brain. Often causes site irritation

Dexamethasone Up to 16mg over 24 hours

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

Diamorphine 10mg - 1g over 24 hours

Preferred to morphine for subcutaneous use as it has greater solubility, requiring a smaller volume. See section on opioid equivalents - p9

Glycopyrronium 200 - 600mcg over 24 hours

Used to reduce respiratory secretions if hyoscine causes confusion or over-sedation. Precipitates with dexamethasone. Cheaper than hyoscine

Haloperidol 2.5 - 10mg over 24 hours

Antidopaminergic antiemetic - see pp12 - 15. Higher doses occasionally used for sedation - see p39. Extrapyramidal side-effects occur with high doses

Hyoscine butylbromide 20 - 80mg over 24 hours

Anti-spasmodic used to relieve gastrointestinal spasm, pain and nausea and vomiting. Useful for drying secretions

Hyoscine hydrobromide 0.4 - 2.4mg over 24 hours

Useful for reducing secretions; some smooth muscle antispasmodic activity. An excellent sedative but may cause agitation or confusion (eg in elderly)

Methotrimeprazine 6.25 - 25mg (antiemetic - see p15)
25 - 100mg (sedative - see p39) over 24 hours

Related to chlorpromazine but more potent; also has analgesic activity

Metoclopramide 10 - 30mg over 24 hours

Anti-emetic - see pp12 - 15. Extrapyramidal effects may occur at higher doses particularly in younger women

Midazolam 5 - 60mg over 24 hours

Benzodiazepine sedative with short half-life; anticonvulsant. Higher doses should only be used for terminal sedation

Octreotide* See p18

BREATHLESSNESS

Diagnosis

Breathlessness is usually multifactorial. Investigations such as chest x-rays/scan or blood gases may be of limited value. A therapeutic trial of medications, singly or in combination, is often necessary to find out what works in an individual patient. There is inevitably a psychological component - breathlessness is always frightening

Causes / Risk factors

A Impaired gas exchange

1	Airflow obstruction a) Large airways	tumour extrinsic compression laryngeal palsy radiation stricture
	b) Small airways	chronic obstructive airways disease lymphangitis carcinomatosa
2	Decreased effective lung volume	effusions pneumothorax extensive tumour collapse infection ascites
3	Increased lung stiffness	pulmonary oedema lymphangitis carcinomatosa fibrosis
4	Decreased alveolar gas exchange	pulmonary embolism pericardial effusion thrombotic tumour
5	Pain	pleurisy chest wall infiltration rib/vertebral fractures
6	Neuromuscular failure	paraplegia phrenic nerve palsy cachexia paraneoplastic syndromes

B Increased demand

1 Anxiety
2 Anaemia
3 Metabolic acidosis

Management

General treatments

These can be employed whilst investigating a more specific cause; general and specific managements should be used in parallel

A **Non drug treatments**

General and specific reassurance (that the patient will not suffocate)
Explanation of the mechanisms of breathlessness
Fan or cool air across the face is often helpful
Proper positioning for easier breathing
Explore the significance of breathlessness for the patient
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 are often helpful in easing the subjective sensation of breathlessness; there is no evidence that they shorten life. If opioid naive, start on 2.5mg of oral **morphine** 4 hourly and titrate upwards. If the patient already takes morphine for pain, the dose may have to be increased by up to 50% for co-existing breathlessness. The use of nebulised opioids is not supported by scientific evidence; they may induce bronchospasm

Benzodiazepines are often used in combination with opioids for their anxiolytic effect. Use **diazepam** 2 - 15mg daily for background control with addition of quick-acting **lorazepam** 1 - 2mg sublingually for acute crises and panic. **Midazolam** 2.5 - 10mg sc stat or 5 - 50mg per 24 hours by csci if patient not able to take oral medication

Oxygen has variable effects; it is difficult to predict who will benefit other than by therapeutic trial, but some patients derive psychological benefit rather than any improvement in blood gases. Best used in 10 minute bursts before or after exercise unless hypoxic at rest when continuous use, usually by nasal prongs, may be appropriate

Specific treatments

1 **Steroids** such as dexamethasone 8 - 12mg daily may be useful in airway compression by intrinsic or extrinsic tumour, post radiation stricture/fibrosis, bronchoconstriction, and lymphangitis carcinomatosa
2 **Radiotherapy/brachytherapy, endoscopic laser/diathermy, bronchial stents** may all help large airway obstruction due to intrinsic or extrinsic compression
3 **Antibiotics** for infection, if appropriate - symptomatic medication can be given whether antibiotics are prescribed or not
4 **Drainage of pleural effusion** with or without pleurodesis
5 **Paracentesis** of ascites, and/or diuretics (see p24)
6 **Chest drain** for pneumothorax
7 **Diuretics** for pulmonary oedema
8 **Inhaled bronchodilators** - can be helpful for patients with carcinoma of bronchus who may have previously undiagnosed COAD
9 **Hyoscine/glycopyrronium** - for drying excessive upper airway secretions
10 **Anticoagulation** for pulmonary emboli. Warfarin is potentially hazardous in malignant disease and has many drug interactions.It therefore needs meticulous monitoring. Low molecular weight heparin given by sc injection may be as effective and safer
11 **Aspiration of pericardial effusion** with or without formation of a pericardial window
12 **Analgesics** - pain on respiration can lead to inadequate ventilation. Opioids, NSAIDs, nerve blocks, radiotherapy and rarely cordotomy may be appropriate for pleurisy, tumour infiltration of the chest wall, rib/vertebral fractures
13 **Teflon vocal cord injection** for laryngeal nerve palsy (seek ENT opinion)
14 **Blood transfusion** should be considered if haemoglobin < 9 g/dl
15 **Physiotherapy** for bronchiectatic secretions

COUGH

Diagnosis

1 Ask about sputum (and if possible observe) - quantity, consistency, colour
2 Is cough affected by position?
3 Examine chest

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, abscess, bronchiectasis, oedema, fibrosis
5 Gastric reflux with inhalation

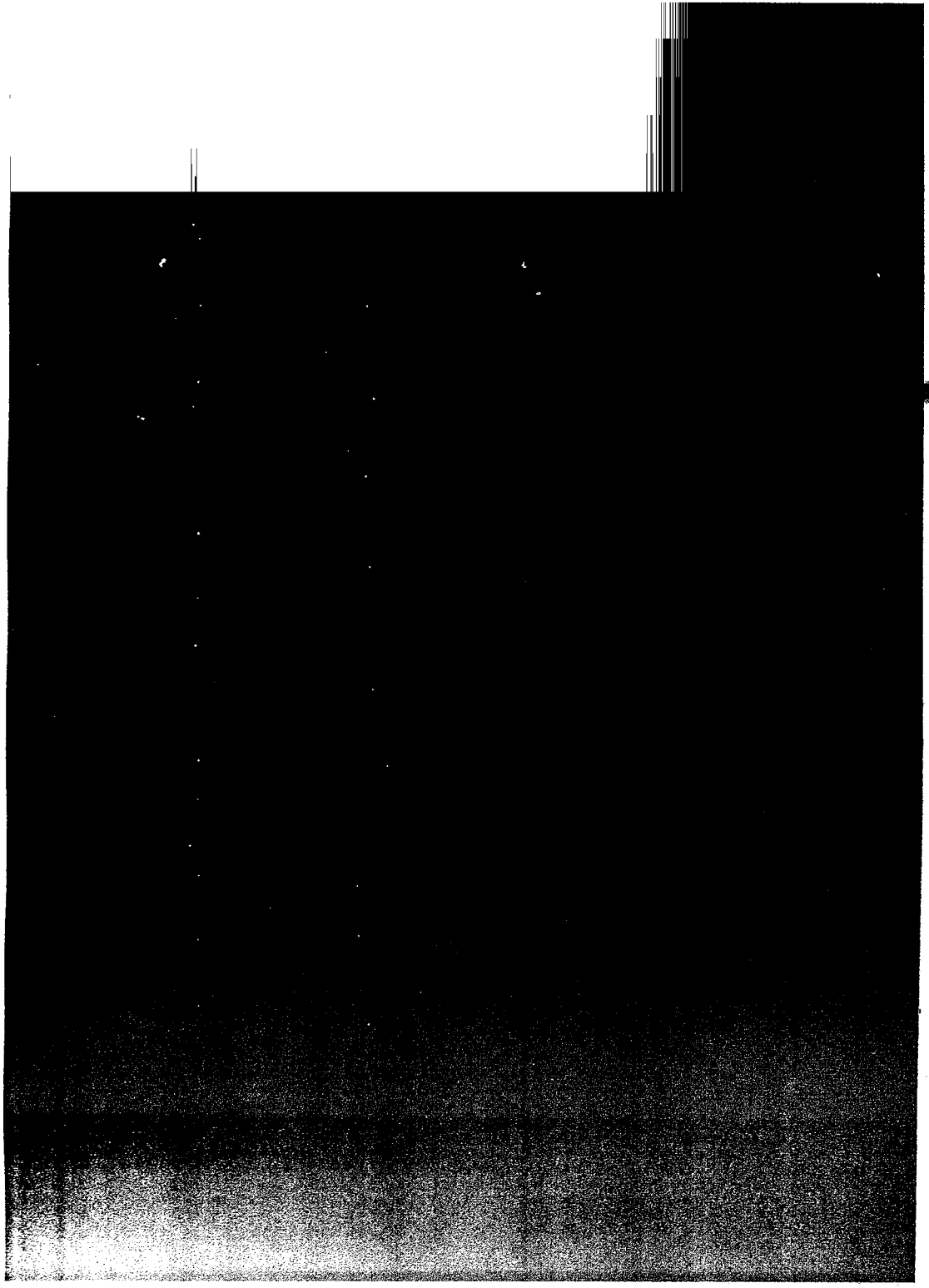
Management

1 More upright body position
2 Steam inhalations, nebulised saline qds 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: Inhalations: **tinct benz co, menthol**
Simple linctus
Low dose opioids: **codeine, pholcodine, methadone, morphine**

Specific:

1 Nasopharyngeal - post-nasal drip: **antibiotics, nasal steroid spray**
2 Laryngeal - **steroids** via inhaler or nebuliser
- **local anaesthetics*** via nebuliser - bupivacaine 0.5%, 5ml tds, at least 30 minutes before any food or drink; risk of idiosyncratic bronchospasm, sometimes severe
3 Bronchial - **bronchodilators** in standard doses
- **steroids** orally, inhaled or nebulised
- **local anaesthetics*** (see above)
4 Gastric reflux - **antacids** containing dimethicone
- **prokinetic agents** (see p15)



HICCUP

Causes / Risk factors

1 Peripheral (diaphragm, phrenic nerve stimulation)
- gastric distension or irritation
- liver enlargement/involvement
- intrathoracic nodes/tumour

2 Central (medullary stimulation)
- raised intracranial pressure
- brain stem CVA/tumour
- uraemia

Management

1 Rebreathing with a paper bag (raises pCO_2 levels)

2 Drinking cold water or taking a teaspoon of granulated sugar (pharyngeal stimulation)

3 **Drug therapy**

Peripheral causes:
- **Metoclopramide** 10mg qds
- **Domperidone** 10 -20mg 4 - 8 hourly
- **Antacids** containing dimethicone (**Gaviscon, Asilone**)
- **Dexamethasone** 4 - 12mg od
- **Ranitidine** 150mg bd

Central causes:
- **Chlorpromazine** 10 - 25mg tds
- **Haloperidol** 0.5mg tds
- **Diazepam** 2mg tds
- **Dexamethasone** 4 - 12mg od
- **Nifedipine** 10mg tds
- **Baclofen** 5mg tds

None of these treatments is consistently reliable

RAISED INTRACRANIAL PRESSURE

Diagnosis

1 Primary carcinoma known to spread to the brain
2 Severe headache worse when lying down
3 Vomiting, convulsions, mental symptoms, diplopia, restlessness
4 Papilloedema may be present
5 CT/MRI scan may be appropriate

Causes/risk factors

1 Cerebral metastases
2 Primary cerebral tumour
3 Other causes - abscess, cerebro-vascular accident, hypertension

Management

1 Raise head of the bed
2 **Drug therapy**

Dexamethasone up to 16mg per day. Avoid doses after 2pm as may contribute to insomnia. Gradually reduce dose to minimum effective, monitoring carefully to check that symptoms remain controlled. Withdraw dexamethasone if no improvement after 7 days on 16mg daily.

Carbamazepine and phenytoin may reduce therapeutic effect by 50%

Anti-convulsants should be considered in the presence of cerebral malignancy, eg phenytoin 200-300mg at night, carbamazepine 0.8-1.2g per day in divided doses (also available as suppositories), sodium valproate 600mg to 2gm daily in divided doses

Midazolam given by csci as an anti-convulsant when oral anti-convulsant can no longer be taken; dose 30 - 100mg by csci over 24 hours titrated to effect

Diazepam suppositories (5 - 10mg) may stop convulsions if they occur

Analgesics for headache

3 Consider cranial irradiation if there is a good response to dexamethasone

SPINAL CORD COMPRESSION

Diagnosis

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 leg weakness, sensory changes and bladder or bowel disturbance, but can be any combination of these

2 If higher 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
- Urgent referral to radiotherapist or neuro/orthopaedic surgeon
- Emergency CT/MRI scan

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
- psychological readjustment

4 Specialist palliative care assessment for management and/or rehabilitation is recommended

DEPRESSION

In palliative care it is important to distinguish between clinical depression, profound sadness and dementia. The diagnosis is further complicated by the fact 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. A therapeutic trial of antidepressives may be acceptable.

Diagnosis

1 Persistent, pervasive low mood with loss of pleasure and enjoyment
2 Diurnal variation in mood; may be agitation
3 Sleep disturbance, especially with frequent or early morning waking
4 Anorexia that does not improve with steroids
5 Morbid guilt, feelings of helplessness and worthlessness/low self esteem
6 Depression may be hidden behind a brave but hollow smile or behind anger

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 Drugs - corticosteroids (predominantly on withdrawal), some cytotoxics, some anti-hypertensives, some neuroleptics, benzodiazepines

Management

1 Minimise the causes, especially 3 - 5 above
2 Provide psychological support
3 **Drug therapy**

for depression with agitation or insomnia
amitriptyline or **dothiepin** 25 - 100mg at night (start at a low dose; higher doses often confuse); **lofepramine** and **mianserin** may be safer in the elderly
for retarded depression
protriptyline 5 - 10mg tds
if no response to above
sertraline (50mg increasing to 100mg daily) or **fluoxetine** (20mg daily), but these may exacerbate anorexia and nausea; dose titration is not required
for depression with neuroses or panic
trazodone (100 - 300mg at night) or **clomipramine** (10-75mg per day)

ANXIETY

Diagnosis

1 Feeling of being on edge, restless or agitated
2 Inability to concentrate
3 Difficulty in getting to sleep
4 Physical effects such as sweating, tachycardia, staring eyes with dilated pupils

Causes/risk factors

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

Management

1 Support for patient and family
2 Appropriate information and discussion with patient and family
3 Relaxation techniques
4 Drug treatment, eg

Diazepam 2mg bd and 5mg at night
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 an inability to get to sleep (part of anxiety spectrum; responds to anxiolytics) and a tendency to wake early or repeatedly (part of depression spectrum; responds to antidepressives)

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 midday), diuretics, opioids (nightmares & 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

4 A warm milky drink at bedtime may help

5 Encourage relaxation techniques

6 **Drug therapy** (all given as a single dose at night):

Lormetazepam (0.5 - 1.5mg) or **temazepam** (10 - 20mg) - for short-term use

Zopiclone (3.75 - 7.5mg) - may have fewer residual effects than benzodiazepines

Chlormethiazole (1 - 2 capsules) - short duration of action

Chloral hydrate (500mg - 1g) - caution with alcohol

Amitriptyline (10 - 100mg) or **dothiepin** (25 - 75mg) if repeated or early morning waking

DROWSINESS

Causes/risk factors

Organic

1 Impending death
2 Infection, especially within respiratory and urinary tracts
3 Raised intracranial pressure

Biochemical

1 Metabolic abnormalities: uraemia, especially if on opioids
hypercalcaemia
hyper/hypoglycaemia
hepatic failure (palpable liver?)
respiratory failure (blood gas analysis likely to be inappropriate)

2 Drugs: opioids, tricyclic antidepressives, benzodiazepines, anticholinergics, antipsychotics, antihistamines

Other

1 Fatigue
2 Insomnia
3 Psychological withdrawal
4 Postictal

Management

1 Assess accurately; if 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 **Drug therapy**
Dexamethasone up to 16mg daily for raised ICP
Protriptyline for retarded depression
Dexamethasone 2 - 4mg daily may act as stimulant

CONFUSION

Delirium is typified by confusion, often with visual illusions or hallucinations with increased or decreased psychomotor activity and fluctuating level of consciousness. It must be distinguished from **dementia**, which is associated with 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 Change in cognition (memory deficit, disorientation, language disturbance) or development of a perceptual disturbance that is not dementia
3 Short history (usually hours to days) with a tendency to fluctuate during the day
4 Evidence from the history, examination, or investigations that there may be a physical cause

Causes/risk factors

1 Drugs - opioids, tricyclic antidepressives, anticholinergics, benzodiazepines, phenothiazines, NSAIDs, cimetidine, some cytotoxics, baclofen, any other drug with sedative effects; corticosteroids may cause a syndrome resembling hypomania
2 Infection, especially within respiratory and urinary tracts
3 Biochemical abnormalities - especially hypercalcaemia, uraemia, liver failure
4 Environment changes - unfamiliar excessive stimuli, inpatient admission
5 Poor symptom control - pain, constipation, urinary retention, anxiety, depression
6 Alcohol or drug withdrawal
7 Intracerebral causes: space-occupying lesions, infections, strokes

Morphine toxicity exacerbated by uraemia* is an important cause of confusion. Look for constricted pupils, myoclonic jerks, skin hyperaesthesia

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**

If paranoid, deluded, agitated or hallucinating

Haloperidol 1.5 - 3mg up to three times a day orally
Thioridazine 10 - 25mg up to four times a day orally

Review early as symptoms may be exacerbated by sedative effects. Watch for extrapyramidal side-effects

If agitated patient and unable to swallow

Midazolam 10mg im stat then 10-100mg over 24 hours sc
Methotrimeprazine 25 - 100mg over 24 hours sc

Dexamethasone up to 16mg per day - if cerebral tumour/raised ICP
Oxygen if cyanosed/hypoxic

TERMINAL RESTLESSNESS

This may be akin to delirium in someone very close to death, or may occasionally reflect unresolved psychological or spiritual distress

Causes/risk factors

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

Management

Must be a multi-disciplinary approach involving family or main carers

1 Accurately assess the patient
2 Ameliorate all physical elements if possible, eg analgesia, catheterisation
3 Listen to the patient and discuss anger, fear and guilt if possible
4 May be very distressing for the family who will need much support. Their presence may help or worsen the patient's agitation
5 **Drug therapy**

Diazepam	20 - 60mg per 24 hours orally or rectally
Midazolam	10 - 60mg per 24 hours by csci or im
Methotrimeprazine	25 - 100mg per 24 hours orally or by csci

WEAKNESS

Causes / Risk factors

1 Cachexia - cancer-related, inadequate nutrition
2 Metabolic - hyponatraemia, hypokalaemia, uraemia, hypercalcaemia, anaemia diabetes mellitus, adrenal insufficiency, hyperthyroidism, hypothyroidism, liver failure
3 Neuromuscular damage - by tumour to brain, spinal cord or peripheral nerves, MND, myopathy, peripheral neuropathy, myasthenia gravis, Lambert-Eaton myasthenic syndrome
4 Drugs - steroids, sedatives, diuretics, antihypertensives (via hypotension)
5 Emotional - anxiety, depression, fear, isolation, apathy
6 Prolonged bed rest
7 Infection

Management

1 Take a good history and examine thoroughly to elucidate and treat possible reversible causes
2 Review drug regimen and minimise possible causes
3 Correct any metabolic/biochemical abnormalities as far as possible
4 Provide dietary support as appropriate (see p21)
5 Rehabilitation for specific weakness by a multiprofessional team. Help with coping and acceptance if appropriate

HYPERCALCAEMIA

Hypercalcaemia is commonly found in the terminal phase of cancer, particularly of breast and squamous carcinomas. It occurs in 30 % of myeloma

Diagnosis

1 Corrected serum calcium of greater than 2.6 mmol/l; symptoms usually only become troublesome above 2.9 mmol/l

2 Any combination of the following: thirst, polyuria, constipation, nausea, abdominal pain, loss of appetite, fatigue, confusion, and emotional disturbances

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 Correct dehydration

Mild to moderate (2.7 - 3.0mmol/L)

initially oral or iv rehydration

Moderate to severe (3.0 - 3.5 mmol/L)

initially iv rehydration with 2-4 litres saline per 24 hours with frusemide (enhances urinary calcium excretion)

3 Relieve associated symptoms

4 Bisphosphonates: **Pamidronate** 30 - 60mg iv over 4 hours or
Sodium clodronate 1500mg iv

These take 48 - 72 hours to be effective, so avoid rechecking calcium before day 4. Their effect lasts 20 to 30 days so recheck calcium three weeks after treatment. Oral **sodium clodronate** has no place in the acute treatment of hypercalcaemia but may be used to maintain normocalcaemia and as prophylaxis particularly for myeloma and breast carcinoma

ANAEMIA

Diagnosis

1 Symptoms - tiredness, weakness, breathlessness

2 Blood counts - haemoglobin, RBC indices, platelets and WBC

Causes / Risk factors

1 Increased rate of RBC loss

- Bleeding - acute or chronic (microcytic, reticulocytes, thrombocytosis)
- Haemolysis - primary or secondary - autoimmune, drugs, infection (macrocytosis, reticulocytes, raised bilirubin)

2 Reduced RBC production

- Chronic disease and renal disease (normochromic, normocytic)
- Bone marrow infiltration - leukaemia, lymphoma, carcinoma (prostate, breast
- Aplastic - especially drugs
- Sideroblastic secondary to malignancy
- Infection, debility
- Deficiency of iron (microcytic), B_{12} or folate (macrocytic)

Management

1 Treat cause if appropriate - see bleeding/haemorrhage, review medication

2 Consider transfusion if symptomatic, specific benefit is anticipated and if Hb < 9 g/dl and not macrocytic. Transfusion carries the risk of causing acute heart failure in debilitated patients and the elderly. If transfusion is appropria use packed cells with diuretic cover at a rate of 2-4 units maximum per day, depending on clinical status

If chronic anaemia, patients adapt even if Hb 8.0 - 9.5 g/dl. Do not transfuse unless a specific benefit has been identified

3 Reassess one week after transfusion to assess any symptomatic relief afforded by the transfusion and review as symptoms may have had other causes. If littl relief then transfusion need not be repeated if the haemoglobin falls again; consider other causes and treatments

BLEEDING/HAEMORRHAGE

Causes / Risk factors

1 Tumour invasion
2 Platelet or coagulation disorders, disseminated intravascular coagulation
3 Infection - eg haemoptysis, haematuria, vaginal bleed, fungating wounds
4 Drugs - heparin, warfarin, aspirin, NSAID (may cause GI bleeds)
5 Peptic ulceration

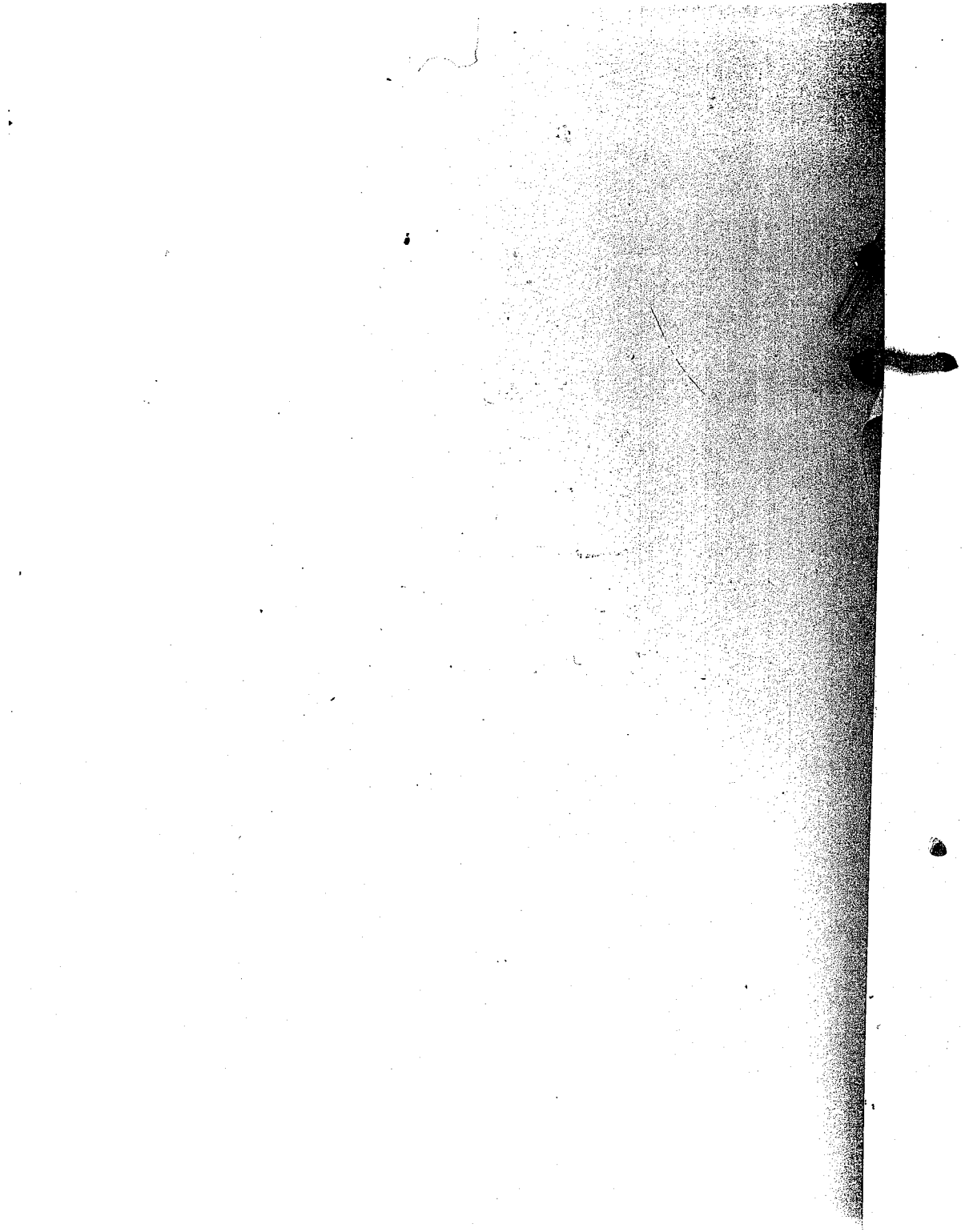
Management

General

1 Stop anticoagulants and review medication; Consider reversing warfarin with fresh frozen plasma (rapid) or vitamin K 1 - 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: helpful in > 75% cases of haemoptysis, also helpful for haematuria, visceral and cutaneous bleeding
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, physical touch helps
If slow, use suction as appropriate and consider iv as below
If rapid, consider im or iv midazolam or diamorphine
If a terminal haemorrhage is anticipated carers can be given a supply of rectal diazepam 10mg. Dark towels or sheets may help to mask the blood
8 **Drug therapy**
tranexamic acid 500mg - 1.5g bd - qds orally (stabilises clots)
ethamsylate 500mg qds orally (enhances platelet adhesion)

Specific

1 Nasal bleeding	• packing and cautery
2 Oral bleeding	• oxycellulose (Surgicell), sucralfate suspension
3 Haemoptysis	• consider radiotherapy
4 Upper GI bleeding	• consider stopping any NSAIDs
	• H_2 blockers or proton pump inhibitors
5 Lower GI bleeding	• rectal steroids
	• tranexamic acid 0.5g in 50mls of water bd rectally
6 Skin	• Kaltostat dressing
	• topical adrenaline 1 in 1000 to soak dressings



ITCHING

Causes/risk factors

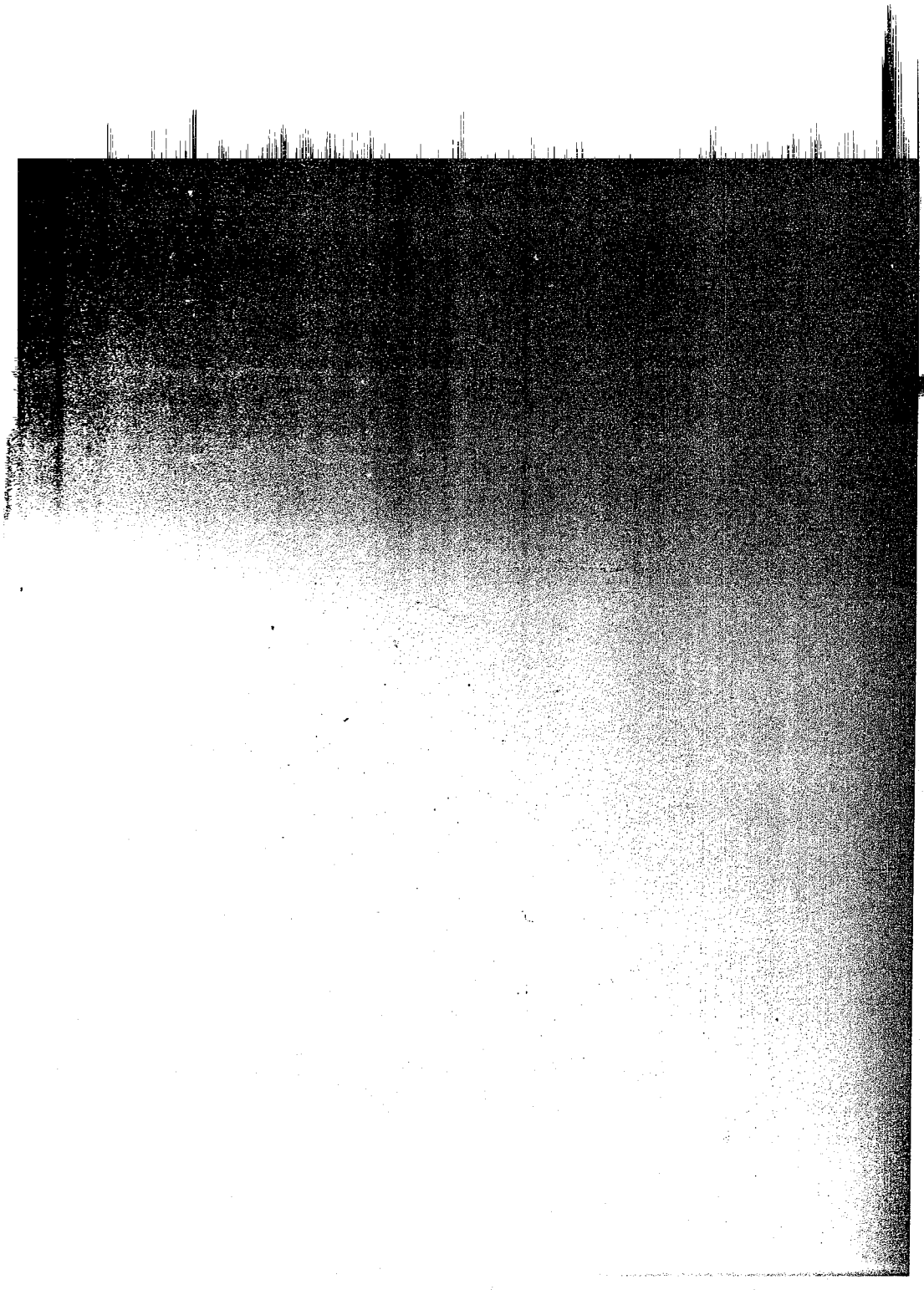
1 Allergies
2 Hepatic disease - biliary obstruction
3 Chronic renal failure
4 Lymphoma
5 Parasites - scabies, fleas
6 Skin diseases - eczema, psoriasis
7 Iron deficiency

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 short, wear cotton gloves, apply paste bandages
4 Avoid washing with soap and bubble bath; add a handful of sodium bicarbonate to a cool bath. Pat rather than rub dry
5 Use emulsifying ointment as a soap substitute, a bath emollient, eg **Oilatum c Balneum** and an emollient after bathing, eg **Aqueous cream** or **Diprobase cream**. Apply surface cooling agents with emollients, eg 0.25% - 1% **Menth in Aqueous cream, Calamine lotion BP**
6 **Drug therapy**

Sedating antihistamines	**Chlorpheniramine** 4mg qds
	Hydroxyzine 25mg nocte
Non-sedating antihistamines	**Loratidine** 10mg od
In obstructive jaundice	Consider referral for stent
	Cholestyramine 6-8 g per day
	Aludrox 10-15 mls tds or qds
	Stanazolol 5mg bd
	Ondansetron 8mg od
Other drugs	**Cimetidine** 400mg bd, **diazepam** 2mg tds
	Chlorpromazine po or **methotrimeprazine** by csci may be needed in intractable itch

7 Consider early advice from dermatologist or palliative care physician



SWEATING

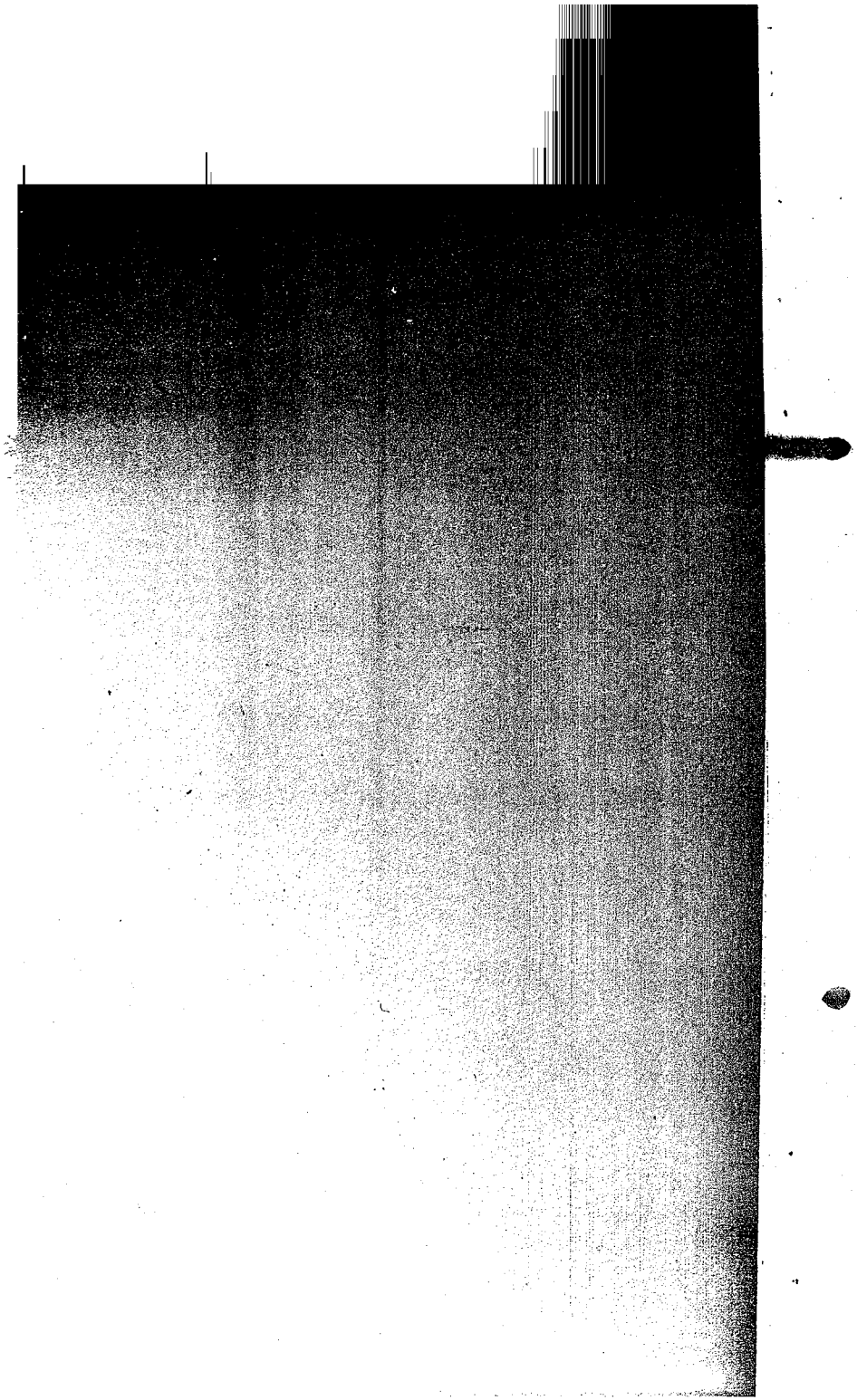
Causes/risk factors

1 Fever & environmental temperature changes
2 Emotional - fear and anxiety (confined to axillae, palms and soles)
3 Extensive malignancy, lymphomas and carcinoid - drenching night sweats
4 Autonomic disturbance
5 Intense pain
6 Drugs - alcohol, tricyclic antidepressives, opioids, steroids
7 Hormonal disturbance - menopause, tamoxifen, goserelin

Management

1 Alter environment - fans, reduce room temperature
2 Treat underlying disease
3 Alleviate other causes as far as possible
4 **Drug therapy** - various drugs have been used with varying success:

Cimetidine 400 - 800mg nocte
Clonidine 50mcg bd
NSAIDs, eg diclofenac SR 100mg nocte
Propantheline 15mg tds
Thioridazine 10 - 30mg nocte
Dexamethasone 4mg daily - effective in lymphoma
Propranolol 40mg once to four times daily



PRESSURE AREA CARE

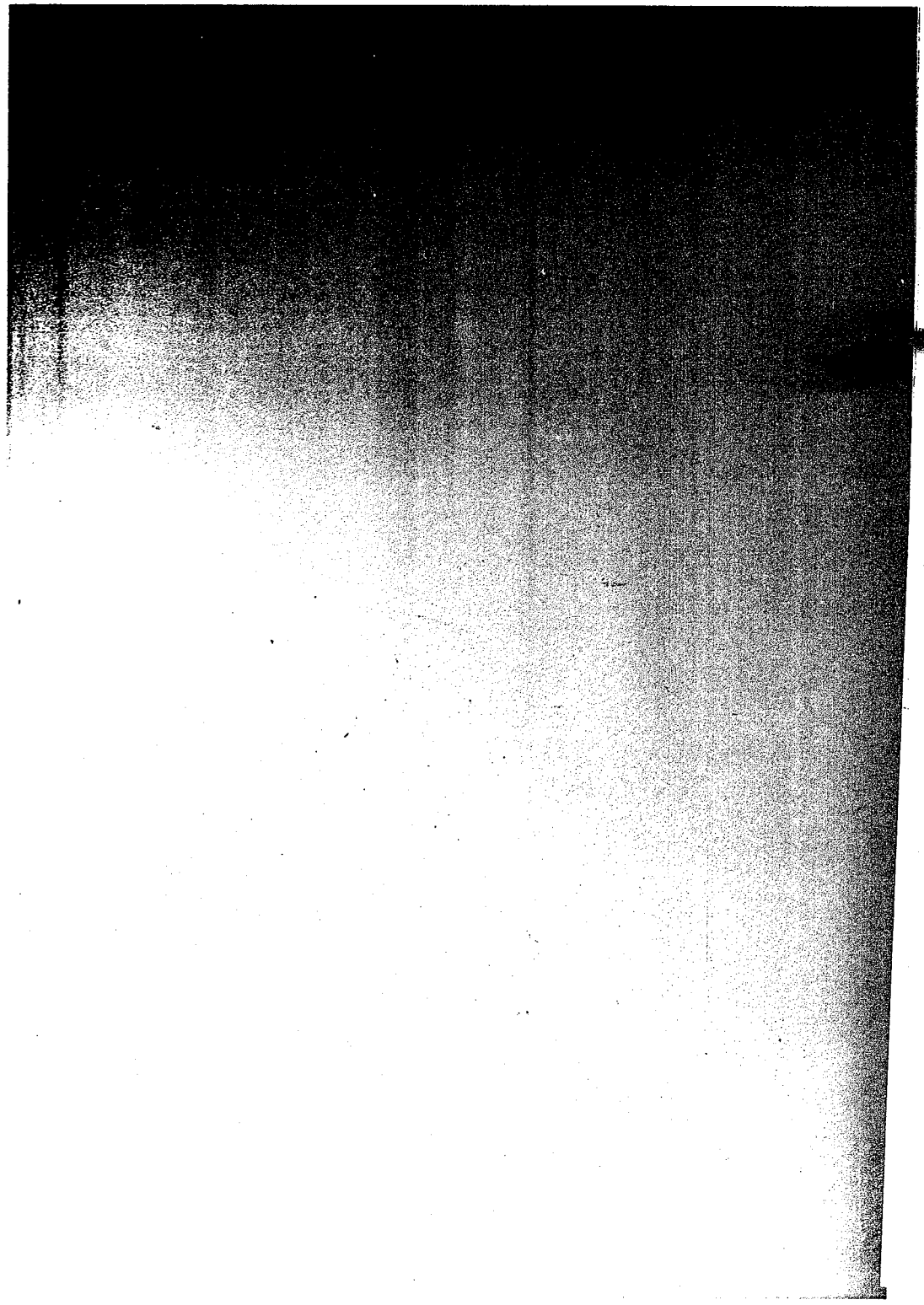
Causes/risk factors

1 Extrinsic factors - pressure, shear, friction, incontinence
2 Immobility, malnutrition, dehydration, old age
3 Contributing medical condition and treatment (eg steroids)
4 Cachexia

Management - General

1 Assess patient using appropriate "risk factor scale" (preferably Waterlow) at regular intervals - daily for high risk, weekly for low risk
2 Assess patient for pressure relieving aids according to risk - static or air mattress, bed cradle
3 Assess for aids to movement as appropriate - monkey pole, cot sides, slings
4 Turn bedbound patients every 4 hours as appropriate, encourage chair-bound patients to stand every 2 hours
5 Improve nutritional state if possible - offer dietary advice, dietary supplemen drugs. Refer to dietitian if appropriate
6 Avoid rubbing pressure areas. Use barrier creams sparingly if patient is incontinent - consider catheterisation
7 Assess pain particularly at dressing changes
8 **Drug therapy**

Ascorbic acid and **zinc** may be useful in sore prevention
Antibiotics may be used as appropriate if infected
Metronidazole (topical or systemic) may be used if offensive (putrid) odo
Flamazine is useful for painful excoriated skin
Paracetamol or NSAID may alleviate wound pain
When dressing changes are painful consider -
short acting **morphine** preparations, **dextromoramide** or **Entonox**
applying **lignocaine gel** to wound or dressings
If wound pain uncontrolled mix **diamorphine** 10mg with **Intrasite gel**



Management - Pressure sores

1 **Grade 1** - skin discoloration, non-blancheable redness
Management - relieve pressure

2 **Grade 2** - partial thickness skin loss or damage
Management - leave blisters intact and apply **Opsite** or **Duoderm**

3 **Grade 3** - extends to subcutaneous fat
Management - dress with alginate (**Sorbsan**) or hydrocolloid (**Granuflex**)
- if sloughy use hydrogel (**Intrasite** or **Granugel**) +/- **Granuflex**

4 **Grade 4** - deep fascia or bony involvement
Management - if necrotic - use hydrogel (**Intrasite** or **Granugel**) + cover with **Granuflex**
- if green - use alginate (**Sorbsan**) and take a wound swab
- if malodorous - use **Intrasite** mixed with **metronidazole** gel, and a charcoal dressing (**Clinisorb**) may be added
- if red - granulating: use **Intrasite** covered with **Granuflex**

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 Consider antibiotics if appropriate
4 Clean wound with 0.9% sodium chloride solution
5 Ensure adequate analgesia

Specific Management

1 Depending on the wound problem:

light exudate	-	use **Granuflex** or **Sorbsan**
heavy exudate	-	use **Sorbsan, Kaltostat or Intrasite** covered with absorbent pads
cavity	-	use alginate rope **(Sorbsan)**, foam dressing **(Allevyn)** or **Dermasorb**, filling 50% of cavity
bleeding	-	use alginate **(Kaltostat or Sorbsan)**
	-	may need to soak dressings with saline before removing
	-	can use adrenaline 1:1000 to stop bleeding
infected	-	use **Intrasite** or **Granugel** mixed with **metronidazole g** and charcoal dressing **(Clinisorb)**
painful	-	see p47

2 **Drug therapy**

Analgesics	-	**NSAID, morphine**
Antibiotics	-	**metronidazole** orally (cheap) or topically (expensive)
Anti-pruritic	-	sedative antihistamine, **eg chlorpheniramine**

LYMPHOEDEMA

Diagnosis

Differentiate from heart failure, low albumin, venous insufficiency

Causes / Risk factors

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

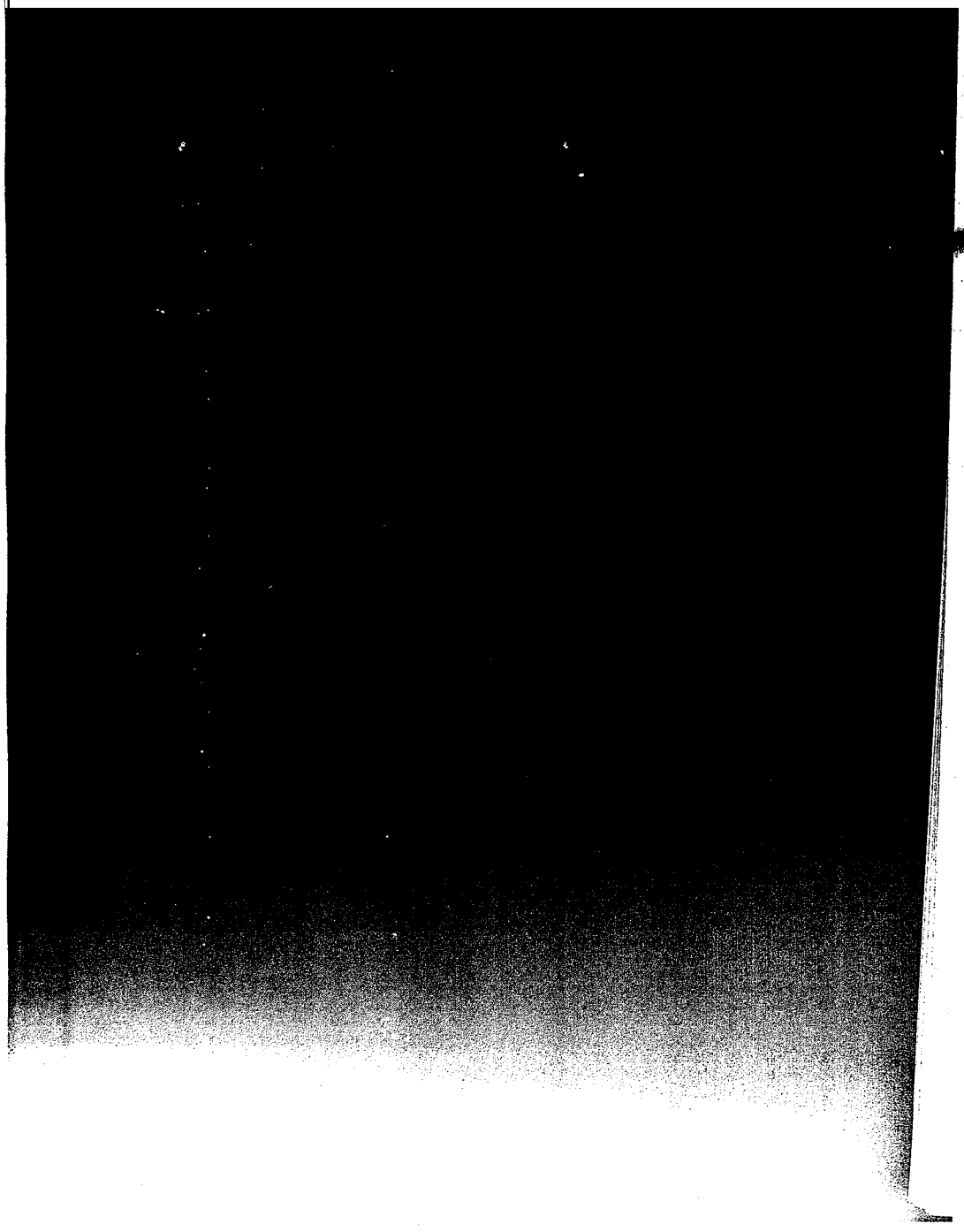
Management

1 Early referral to the local lymphoedema service produces best results in achieving maximal improvement and long-term control (cure is not possible)
2 Explanation of lymph flow and cause of swelling will encourage compliance
3 Clear infections before beginning treatment, usually with at least 2-week course of penicillin V or erythromycin
4 Instructions on daily skin care - often with aqueous or Diprobase cream. Also general advice - avoid injections and any cuts, dry carefully after washing
5 Monitor progress by measuring limbs regularly
6 Regular gentle, superficial, proximal massage can be very effective, with specific exercises where appropriate
7 Containment hosiery of appropriate size and strength should be worn all day
8 Compression bandaging may be necessary initially for a few weeks
9 Occasionally a multi-chamber sequential pneumatic compression is effective in reducing limb volume. This needs to be built up to four hours per day and should be used in conjunction with hosiery and massage/exercises
10 With advanced disease and severe obstruction, pain may be exarcerbated by compression or massage - the level of intervention will need to be balanced against the patient's overall condition and tolerance of the treatment
11 **Drug therapy**

Diuretics may be appropriate in addition to the above, especially where there is an element of heart failure

Steroids may shrink lymphadenopathy or tumour but can increase fluid retention

Antibiotics may be needed long term if there is recurrent cellulitis



PSYCHOLOGICAL AND SPIRITUAL CARE

Palliative care extends far beyond pain relief and the alleviation of symptoms. An essential component of palliative care is the need to address psychological and spiritual needs of both the patient and their family/carers. This does not necessarily require specialist help. All doctors and nurses should be prepared to address these issues and make initial assessments

The way in which patients adapt to their illness will be influenced by several variables including:

- age and stage of family development
- the nature of the disease
- the pattern of the illness
- the individual and family's previous experience with disease and death
- the socio-economic status
- culture
- personality and learned coping mechanisms

Documenting a **family tree** often helps to reveal:

- family dynamics
- family support and location
- the health of the spouse
- previous experience of illness and death
- family history of illness eg cancer of breast
- vulnerability to bereavement

A **social history** is important to ensure that the patient and family have optimal support at home. Aspects to be considered include:

- with whom does the patient live?
- where does the patient live?
  - house, flat, bungalow
  - owner, rented, tied accomodation
  - which floor? (accessibility)
  - are appropriate support services involved?
  - have appropriate allowances been applied for?
  - present or previous occupation and social contacts

Knowledge of these aspects is important for effective discharge planning. Before discharge confirmation should be sought from the patient, family and primary healthcare team that the planned arrangements are both appropriate and acceptable

BREAKING BAD NEWS

Good communication underpins successful patient care, especially if the patient is seriously ill. A key aspect of communication is that of **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 what the patient expects and the reality, the worse the news is. The way in which bad news is given has been shown to affect how the patient and family cope in the future.

Patients often feel that they lack information and thus lack control over their situation. By giving adequate opportunity for discussion it is possible to:

- reduce uncertainty about the future, or at least discuss it
- reduce inappropriate hope (which is demoralising) - but may be difficult
- encourage informed choice of management options
- enable appropriate adjustments to the reality of the situation
- maintain trust between the patient, the carers and the professionals

Remember that **it is impossible not to communicate.** Avoidance of discussion and negative body language usually leaves the patient feeling abandoned, anxious, guilty or depressed. A conspiracy of silence or the raising of false hope may deny the patient the opportunity to use his/her remaining time the way s/he would wish.

When it can be anticipated that bad news is to be given, consider the following points:

1 **The meeting:**
- ensure you have time, and are not exhausted
- arrange for privacy, sufficient seating; avoid interruptions
- whenever possible, offer the opportunity to have a close family member or friend present

2 **Ask** what the patient understands of their situation. 'What do you think is going on?' 'Would you like me to tell you more about your illness?' Do not impose information. If the patient does not want to know, would s/he like you to explain to a family member? Ask them and document this.

3 **Give a warning shot to the patient.** By using the patient's own phrases and avoiding medical jargon wherever possible, start to give a range of possibilities. This may include using euphemisms, eg. shadow, lump, growth - which may subsequently require fuller explanation. Allow the patient to absorb the information at their own pace. If they do not ask questions or deny or protest at information given, do not continue to give more information at this stage: every patient has the right to know about their illness but also has the right not to know. Allow denial.

4 **Avoid assumptions.** If a patient asks a question, never assume that you know what they are referring to. Ask a question to clarify, or you may give an inappropriate answer - 'How long will it be?' may be referring to discharge home, not prognosis. If in doubt, reflect the question back: 'How long will what be?'.

5 **Explanations must be clear and simple,** in terms the patient can understand. Diagrams often help, but may also become a barrier between patient and professional. Avoid detailed explanations and treatment options; these are best discussed at a subsequent meeting. "Once he told me it was cancer, I did not hear anything else."

6 **Be positive:** optimism is supportive, pessimism is not. Say for example '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'.

7 **Confirm** that the patient has understood the information so far. 'Is this making sense?'

8 **Allow ventilation of feelings.** Do not discourage emotions and acknowledge distress - say for example 'have you been surprised by what I have told you?', 'How are you feeling?', 'You look as if you are having a bit of a tough time', or 'I'm sorry' - simple but powerful. Use prompts as necessary, such as 'Is there anything that you are worried about?' or 'Is there anything (else) you would like to ask me - anything at all?'. Listen and allow them time to think how to phrase the questions.

9 **Summarise** the situation and arrange for a follow up meeting, stating the day and time if possible. In summarising, emphasise the positive, and outline future treatment plans if appropriate. Printed information may be useful.

10 **Ask who may be told** about the diagnosis - 'Would you like me to talk to your family?'.

11 **Ensure that the General Practitioner is informed** of what was said, although what was said and what the patient heard may be quite different. Giving the patient a recording of the interview is popular and effective. Offer to speak with other family members.

12 **The Do's and Don'ts of Communicating Bad News** printed on the following two pages is based on advice given by a Macmillan Nursing team and is reproduced with permission, from 'Improving communication between doctors and patients: A working party report', London: Royal College of Physicians, 1997.

The Do's and Don'ts of Communicating Bad News

Do:

- Wherever possible, sit down to be on the same level as the patient - this is reassuring and courteous and signifies that you are 'with' them
- Spend the first part of the interviewing **listening** to what the patient is saying or asking
- Note questions or topics avoided by the patient
- Watch for non-verbal messages, eg posture, eye contact, hands, facial expression
- Respect the patient's right to 'denial'. Patients will often 'selectively perceive' only that information they can cope with at that point in time
- Remember that more than 60% of what you communicate is by non-verbal means, eg posture, eye contact, attitude
- Allow pauses for taking in and digesting what you said - move at patient's pace
- Attempt to give information that is appropriate for that individual patient's needs at that particular point in time
- Realise that most patients become aware of their situation gradually rather than in a 'once off' confrontation
- Realise that it is possible to communicate the 'gentle' rather than the 'bitter' truth by one's attitude and by emphasising positive aspects of the present or future situation
- Realise that patients can and do cope positively with truth about their illness
- Realise that certain euphemisms may be appropriate, eg tumour or growth Try to find out what the patient understands by these words
- Use the word "cancer" if appropriate
- Realise that the patient who 'denied' or did not want the information about his illness in the past may need and be ready for information at another time
- Realise that there is no general rule as to how much to tell
- Try to include all the family (including children) in the sharing of information
- Realise that hope is best communicated by genuine concern and reassurance of continuing care 'no matter how things develop'
- Express your humanity and warmth

- Realise that patients will often be shocked on hearing bad news and that their many questions may only surface later
- End meeting in which bad news is imparted by arranging to meet again in the near future to answer any questions. This also demonstrates to the patient your commitment to them
- Write any information or insight you may have given or received in the patient's notes
- Tell staff on duty what you have said. They may be involved in future discussions

On the other hand:

- **Do not ask the relatives whether or not the patient should be told. (This is unfair both on them and the patient)**
- Do not agree not to tell the patient because the family forbids this
- Do not be afraid of patients or relatives expressing negative feelings or crying. This reaction may be entirely appropriate and not caused by your clumsiness
- Do not tell lies which would lead to a breakdown of trust at a later stage
- Do not give more information than the patient needs or is asking for
- Do not use language that is too technical for the patient or family to understand
- Do not use misleading euphemisms, eg ulcer
- Do not have general rules about "telling", eg "Everybody must be told everything" or "Nobody must be told anything"
- Do not always answer direct questions directly. It may be appropriate to do so but often direct questions such as "It may be cancer" or "Am I dying?" contain a hidden question such as "Will I have uncontrolled pain?" or "Should I make a will?". These hidden questions can be discovered by replying initially with a question such as "I wonder what makes you ask that?". One may discover that the patient already knows, tells you and is, in fact, looking for clarification or reassurance
- Do not talk from the end of the bed with one foot in the door!

And finally:

- **Be aware that it is unethical and technically a breach of confidentiality to tell the relatives without the patient's consent**

DEALING WITH DENIAL AND COLLUSION

Denial

Denial is a basic primitive coping mechanism to protect us from information or events with which we cannot cope. By blotting out unpleasant facts it allows us to continue to function. Denial may be practised by the patient, by the family and/or by the professionals. Denial can be a very normal protective measure but in some situations it can be harmful and should then be challenged.

Professionals who feel that denial is unhealthy need to be sure that they are intervening in the best interest of the patient, not just because they feel the patient and family should fully accept the situation.

It should nevertheless be remembered that, in order for patients to be able to deal with their emotions, they usually need good symptom control.

Management

1 The first step in assessing denial must be to establish that the patient has been told the diagnosis in terms which he/she can understand. Is there written confirmation in the notes? What terms were used?

2 If the patient is in denial, decide if this is healthy or unhealthy. There are two main aspects to consider:

(i) Is the denial reducing emotional distress?

(ii) Is the denial affecting help-seeking behaviour and compliance?

If the patient is functioning well and the denial is not prejudicing treatment, then it may be quite healthy. On the other hand, if the denial acts as a barrier and prevents the patient from seeking treatment (for example, a woman denying the significance of early breast cancer) then it should be tackled. It is also appropriate to intervene in cases where the patient is in denial but is displaying a great deal of distress or pain that is not responding to treatment.

If the patient has dependants for whom provision must be made and planning is blocked by the patient's denial then this too is a situation where the denial should be challenged.

By gently exploring the patient's understanding and helping them to a more realistic view point it may help to resolve distressing symptoms/situations.

3 Denial can be difficult for professionals to work with, particularly when they prefer to communicate openly. However we must respect the needs of the patient and their ability to cope with the information at that particular time. Any attempts to modify denial should be for a specific reason, for example improving compliance with treatment, reducing emotional distress or planning care of dependants.

Phrases such as 'what if"...?' and 'it's sometimes best to plan for the worst and hope for the best' can help to open up the conversation, but it is unrealistic to expect all patients to come to terms with their mortality, indeed some are too ill and too close to death to open up the conversation.

4 Carers may deny the seriousness of the illness and expect too much of the patient. They need extra support to understand that life cannot continue as before.

5 Doctors and nurses may also deny the seriousness of the patient's condition and thus continue with or initiate inappropriate treatments. Teamwork and cross-referral often help in the transition from curative to palliative treatment.

Collusion

Collusion occurs when the family conspire among themselves or with professionals to withold information from, or lie to, the patient.

Collusion is a common probem particularly in the early stages of illness. We must remember that families are often well-intentioned and acting in what they believe to be the best interest of the patient. In trying to shield the patient, the family's actions are of a protective and loving nature attempting to spare their loved one from further pain and distress.

We should also respect the fact that the patient has the right to information about his/her diagnosis first. Has the patient given permission for you to disclose information about their diagnosis to their family? It is important to establish whether the family is trying to protect themselves or the patient.

Management

1 Listen to the family: they know the patient better than you do and may have very valid concerns which should be explored. "What do you think s/he is expecting to hear?" "How has he coped with bad news in the past" "Has anyone else in the family had cancer?'. Having given them an opportunity to express their concerns, show that you empathise with their feelings and help them to understand that the patient has the right to the information. Do not rush this, or the family can become quite antagonistic and this may be hard to reverse.

2 Reassure them that you will not walk in to the patient and impose information, but that if s/he asks questions you should answer them honestly but gently. 'If s/he is brave enough to ask, s/he deserves an honest answer'.

3 Explain to the relatives that if the patient asks a question we often answer it with a question in order to establish exactly what information the patient is seeking, eg. "is it cancer doctor?" If we reply "is that what you think the tests may show?", the patient may then go on to confirm their suspicion or may declare that they do not want all the details, or that they would like their spouse to be present.

4 The relatives are usually distressed and coming to terms with the bad news themselves, with a whole host of concerns and worries for the future. They have often not considered the consequences of their actions and not yet appreciated how difficult it can be to live with a lie and how isolated the patient will become, if the professionals and the family collude and pretend that all will be well. "How many years have you been married? This will be the biggest secret that you have ever tried to keep, they (the patient) may feel more and more lonely and not know who to trust"

5 Usually the family can be reassured that no one is going to blurt out the bad news and that the issue will be handled sensitively. They may initially find talking openly to the patient daunting which is where a joint conversation between patient, family and professionals can help to open up channels of communication.

6 Summarise your perspective:
- The rate and information given will be dictated by cues from the patient
- The patient's questions will be clarified and if they insist on a direct answer, this will be given honestly

Further reading

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

SPIRITUAL CARE

All patients have **spiritual** needs whilst only some patients have **religious** needs. **Religion** pertains to the outward practice of a spiritual understanding and/or the framework for a system of beliefs, values, codes of conduct and rituals. The term **spiritual** can be taken broadly to mean a person's belief in a power outside or other than their own existence. Some people may use the word God, others may be less specific. Strength of belief in this power can, however, be regarded as distinct from any concept held about the precise nature of that power.

When a person experiences a life crisis they will look to their belief system to help them make sense of it. This then becomes a spiritual issue which may be expressed by patients in questions such as 'Why is this happening to me?'.

If a person's spiritual values, beliefs, attitudes and religious practices do not enable him to deal satisfactorily with questions concerning the infinite realities and ultimate meaning and purpose in life, then this may well lead to a state of **spiritual dis-ease** or **spiritual pain.**

Possible indicators of spiritual pain include:

- A break with religious/cultural ties
- Sense of meaning/hopelessness
- Sense of guilt/shame/loss of identity
- Intense suffering
- Unresolved feelings/fear about death and dying
- Anger

Principles of assessing and helping with spiritual pain

There are many ways in which to help directly or indirectly with Spiritual Pain. They include a wide range of aspects of care that all help the patient to find meaning and purpose. It is important to ask the patient/family whether they wish to see a chaplain and to explain that chaplains will not be 'into hard sell religion' but can help people explore these issues.

1 Provide a secure, caring environment

- caring: need for a good positive relationship
- freedom: to explore safely
- symptom control
- care for role and appearance
- care for patients' family and friends

2 Listen

- to questions
- and join patients search for meaning
- to share emotional pain with sensitivity and compassion
- to enable expression of fear, anger, etc

3 Assess in terms of

- past: regrets, guilt, shame
- present: anger, grief for future loss of own life, lost sense of purpose
- future: hopes/fears of dying and death

4 Reassure

- about physical care in illness and dying
- with information - as desired and appropriate
- by personal affirmation and support
- with respect of patient's integrity, worth and values
- about concern for and provision for family/dependants

5 Prepare for Death

- help with unfinished business
- help with reviewing of life - in talking, looking at photographs
- help family to face patient's death and own feelings about it
- spiritual counselling - help to face mortality and reality of situation

Provide religious & sacramental care, according to faith

- make available suitable religious literature (if desired)
- provide opportunity for worship, prayer, communion, anointing or other religious ministry

Above all - be there

Further reading

The above summary of areas of spiritual pain commonly experienced has been adapted from:
Speck P 'Being There - Pastoral Care in Times of Illness' (SPCK)

CULTURE

Culture has an impact on the way an individual lives and dies.

In our society there are wide variations between people of different faiths, ethnic backgrounds and countries of origin. Within each ethnic/faith group, each person will express his/her cultural attitudes uniquely. This is influenced by upbringing, background, environment, beliefs and life experiences.

Areas where cultural influences play the greatest part include: attitudes towards food and diet; how symptoms are described; language and the use of colloquialisms; the role of the family, of individual family members and the family hierarchical structure; issues of autonomy and confidentiality; attitudes towards ill-health, western medicine and other therapies; attitudes towards death; rituals surrounding death.

Healthcare professionals may minimise conflicts over cultural issues by:

- ensuring that language is not a barrier by using appropriate interpretation services;
- demonstrating a willingness to listen and a wish to understand the culture;
- meeting the specific requirements (such as food, privacy, opportunity to practce religious observances, etc) wherever possible;
- maintaining a dialogue and checking out where there is uncertainty about cultural implications;
- being prepared to negotiate boundaries and details of care.

Note that it is not always possible to meet all cultural requirements - professionals must balance the needs of individuals with those of other patients. However, it is always possible to attempt careful negotiation.

Above all, understand that each person is unique, regardless of his/her cultural or ethnic background and professed faith

Do not make assumptions - ASK

Further reading

1 Neuberger J. Care for Dying People of Different Faiths. London: Lisa Sainsbury Foundation, 1987

2 Sheldon F. Psychosocial palliative care. Cheltenham: Stanley Thornes, 1997

BEREAVEMENT

Grief is a natural process experienced by anyone who has to adjust to a significant loss. To recognise when and what type of intervention is needed an appreciation of what is 'normal' is required. 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 affect 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 professional 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
- unpleasant death
- ambivalent relationship
- excessively dependent relationship
- child/adolescent (may be protected/excluded)
- social isolation
- excessive use of denial preventing anticipatory grieving
- unresolved anger
- previously unresolved losses
- previous psychiatric illness
- history of alcoholism/drug abuse
- other concurrent stressful life events

For many a trained volunteer who listens may be all that is needed in order fc the bereaved to recognise and express their feelings and fears, enabling them to make sense for themselves of the events which have occurred. Reassuranc 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 simiil 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 neeeded 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.

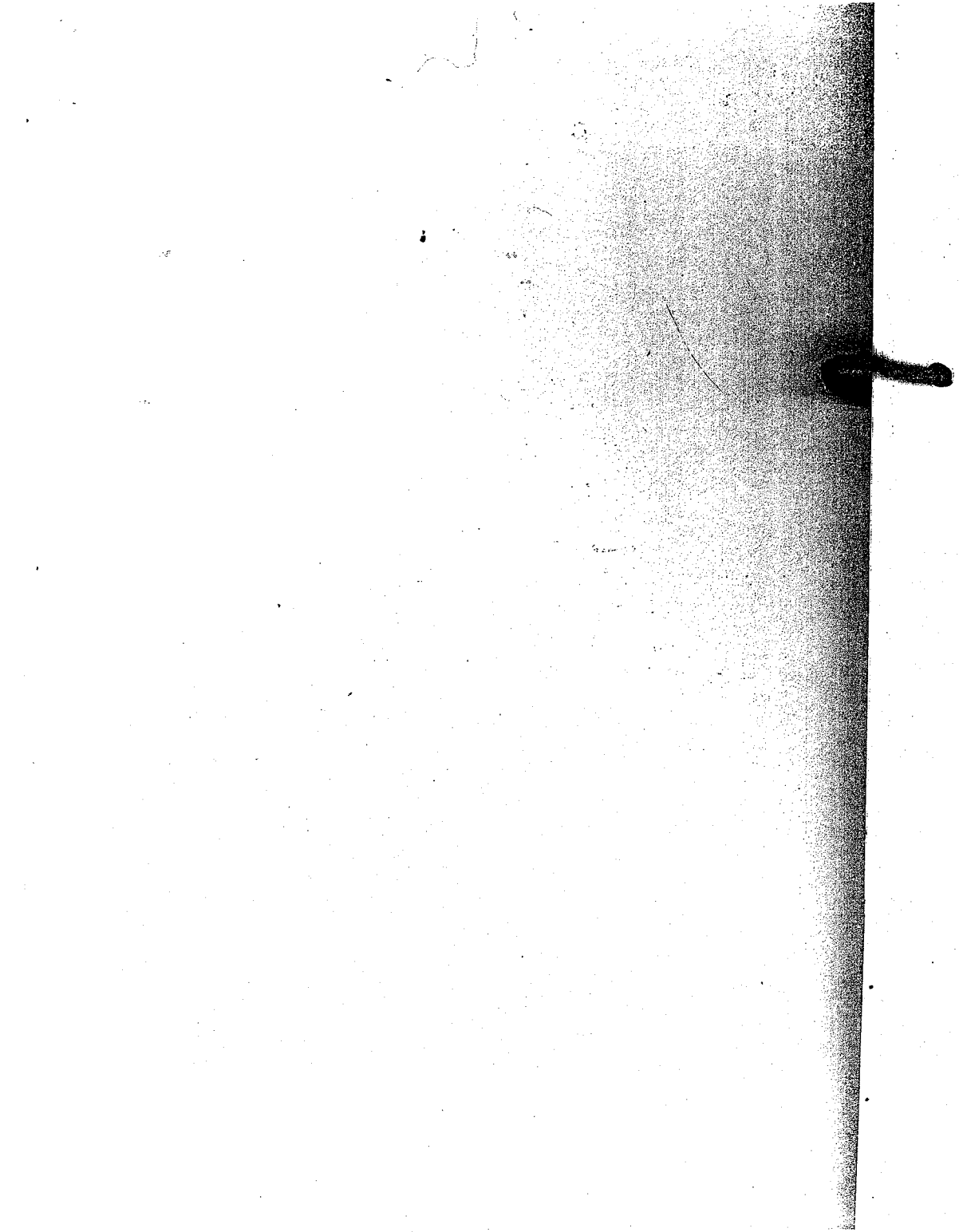
4 **Persistent hypochondriasis** can occur and may block grief. The bereaved may take on the symptoms of the deceased or develop symptoms related to anxiety or depression. Explaining to the patient what is happening may be all that is required. However, note that mortality and morbidity of widows and 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 (126 Sheen Road, Richmond, Surrey TW9 1UR): see health centres, hospitals or Citizens' Advice Bureaux for information, or contact The National Association of Bereavement Services, 10 Norton Folgate, London E1 6DB. Others require specialist help from psychotherapists or psychiatrists, and it is important for all professionals to realise their own skills and limitations.

FORMULARY

This list of drugs, dressings and other preparations recommended in this booklet 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 recommended 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.



ACKNOWLEDGEMENTS

These guidelines on clinical management are derived from the Bath District Health Authority clinical standards for palliative medicine and terminal care written by Dr Roderick MacLeod and Jane Vella-Brincat, Dorothy House Foundation, in 1993.

They were revised in 1995 by Dr Chris Higgs, Jane Vella-Brincat and Clare Spencer, Dorothy House Foundation/St Martin's Hospital Pharmacy, with additions from Dr Patricia Needham, Dorothy House Foundation and Dr Christine Wood, Salisbury Palliative Care Services.

This revision was undertaken in 1997/8 by the Wessex Palliative Physicians under the chairmanship of Dr Stephen Kirkham (Poole): Dr Carol Davis (Southampton), Dr David Harries (Andover), Dr Chris Higgs (Bath), Dr Richard Hillier (Southampton), Dr Ian Johnson (Isle of Wight), Dr Huw Jones (Portsmouth), Dr Patricia Needham (Bath), Dr Marion O'Reilly (Bath), Dr Lucinda Pritchard (Swindon), Dr Fiona Randall (Christchurch), Dr Joanna Shawcross (Southampton), Dr Richard Sloan (Dorchester), Dr David Spencer (Swindon), Dr Bee Wee (Southampton), Dr Bridget Wood (Lymington), and Dr Christine Wood (Salisbury). Additional invaluable assistance was provided by Rev Peter Speck, Sandra Brown, Liz McMillan and Denise Heals.

Disk translation by Robert Gray

Subediting and typesetting by Stephen Kirkham

Formulary compiled by Bee Wee and Richard Hillier

Most of the production costs of this handbook have been met by the individual specialist palliative care units in Wessex. Additional financial assistance from Andy Caldwell (Napp Laboratories) and Lesley-Ann Garrison (Janssen-Cilag) is gratefully acknowledged.

USEFUL TELEPHONE NUMBERS

The Rowans (Portsmouth Area Hospice)			
Inpatient unit and out of hours advice		01705 250001	ext 209
Portsmouth HealthCare NHS Trust			
at The Rowans (9 am - 5 pm)		01705 250001	ext 203
Consultant in Palliative Medicine			ext 203
Palliative Care Nurses (Community)		(Answerphone)	ext 326
Consultant Clinical Psychologist			ext 216
Charles Ward (Elderly Medicine)	QAH	01705 286059	
Portsmouth Hospitals NHS Trust			
Hospital Macmillan Nurses	SMH	01705 286000	ext 2408
			or bleep 419
	QAH	01705 286904	bleep 409
Macmillan Radiographer	SMH	01705 286000	ext 3425
			or bleep 288
Macmillan Centre	SMH	01705 788700	
Pain Clinic	QAH	01705 286312	
Pharmacy	QAH	01705 286117	
Drug Information	SMH	01705 866771	bleep 468
Countess Mountbatten House		01703 477414	
Macmillan Service, Midhurst		01730 812341	
St Wilfrid's Hospice, Chichester		01243 775302	
Haslar Oncology/Palliative Care Nurses		01705 584255	ext 2695