

Palliative and End of Life Care Guidance

Key Features of Common End of life Diseases

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Palliative Care Advice General Guidance

The following pages contain some general comments about some of the palliative care issues that may be encountered by people suffering from the end stages of some of the more common disease processes. All people are different and even people with the same diagnosis may experience different problems on their illness journey. The comments about each illness are not exhaustive, but are brief summaries of some of the clinical situations that may be encountered by any health or social care professionals working with these patients.

Flow diagrams **for the management of key symptoms** have been included at the end of the document to help guide health professionals. It is suggested that once you have read the key features of the end stage of that illness you turn to the flow diagram to see how you might start to manage the symptom. Thus if haemorrhage is seen as a potential problem you can look at the haemorrhage flow diagram at the end of the document to see suggested ways of managing the problem.

The summaries and flow diagrams are a guide only and definitive management of the more complex symptoms should only be undertaken after discussion with your local disease based specialists and local specialist palliative care services.

These notes and flow diagrams should be used in conjunction with the Lancashire and South Cumbria Cancer Network Palliative Care Prescribing Guidelines issued and revised in 2012 and the additional notes about how to safely provide advice and what to consider when giving advice. The flow diagrams have been adapted from those written and used by Bolton Hospice and St Catherine's Hospice, Preston (with their permission).

Useful websites for additional information:

www.endoflifecareforadults.nhs.uk

www.palliativesdrugs.com

www.macmillan.org.uk

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INDEX

Hints on how to ask for advice	5
North West End of Life care model, including advanced care planning, Care at the end of life and bereavement	7
North West End of Life Care Model	10

Key Features of common end of life cancers

Bladder Cancer	11
Brain Tumours (Primary and secondary)	13
Breast Cancer	15
Colo-rectal Cancer	17
Gynaecological Cancer	19
Head and Neck Cancer	21
Chronic Leukaemia and Myeloma	23
Lung Cancer	25
Mesothelioma	27
Prostate Cancer	29
Upper Gastro-intestinal Cancer (stomach and oesophagus)	31
Carcinomatosis of unknown primary	33

Key features of common end of life medical conditions

End Stage Congestive Cardiac Failure (CCF)	35
End Stage Respiratory Failure	37
End Stage Renal Failure	39
End Stage Cerebrovascular Disease	41
End Stage Dementia	43
End Stage Motor Neurone Disease	45
End Stage Multiple Sclerosis	47
End Stage Parkinson's Disease	49

Flow diagrams for the management of common symptoms

Bleeding / haemorrhage	51
Confusion	52
Constipation / bowel obstruction	53
Cord compression	55
Nausea and Vomiting	57
Pain	59
Hypercalcaemia	61
Superior Vena Cava Obstruction (SVCO)	62
Breathlessness	63
Fits	65
Acute distress	66
Implantable defibrillators at the end of life	67
Neutropenic sepsis	69

GENERAL PRINCIPLES AND RESPONSIBILITIES WHEN ASKING FOR ADVICE ABOUT PALLIATIVE CARE PATIENTS.

Asking for advice from a Specialist Palliative Care telephone helpline

Being prepared with as much information as possible will help both you and the person giving you advice to get the best out of the process. Before you pick up the phone think about the information you have and what additional information may be needed and where that might be found.

Remember the person giving advice is unlikely to know the patient and will be relying heavily on your clinical assessment. In most cases it is important that you see the patient and take a history from them in person before seeking advice. Ideally seek advice whilst with the patient as this means that questions can be clarified with them immediately. Where this is not possible ensure that you have up to date contact information on the patient and their carers so issues can be clarified quickly, if needed.

The person giving advice will only be able to offer a limited number of options, which will be aimed at holding a situation, until the patient can be reviewed by their own caring team or a member of the specialist palliative care team. The advice will only address the current acute issues not longer term issues.

Framework to help you ask for advice effectively

SETTING

Hello, I am	state name and role and where you work
I am calling about	state name of patient and their location
I am seeing this patient because	state in what capacity you are seeing the patient E.g. on call doctor asked to see the patient by family
I would like	state clearly what you want – advice, discussion, clarification, admission, urgent review etc

BACKGROUND / OBJECTIVE ASSESSMENT

Patient has	state diagnosis
Patient's condition	state what has changed – condition, new symptom and the time frame for this change
They have the following	state the key issue(s) you need help with – e.g. they are in severe pain despite having three doses of breakthrough pain medication state your clinical assessment – I am worried that they may have bone metastases what their observations are (if needed)

RELEVANT FACTORS

I am concerned because	state what patient's previous condition was reported to be e.g. pain free and alert list the reasons why you need help e.g. pain relief is not working, pain has suddenly got worse, family are really distressed and panicking etc
I have already done	state what measures you have already started e.g. I have given an anti-emetic Any other factors that you feel may play a part in any management plan.... e.g. the elderly wife feels exhausted

If you are not clear what is going on, and/or uncertain about potential causes say so clearly

I am not sure what the problem is

I am not sure why this is happening now

I am not sure what would be the appropriate thing to do

Also give a clear indication of how worried you are –

I am very worried,

I am concerned,

I just want to check that....

RECOMMENDATIONS

I wondered if or

State clearly if you want confirmation of your proposed management plan or if you want more detailed advice

I was planning to

e.g. Do you think it would be OK to give a fourth break through – the last one was two hours ago

e.g. do not think this family will cope – would it be appropriate to admit etc

e.g. what pain relief would you suggest

FOLLOW UP

What if advice does not work

as caller state clearly your plans

e.g. I will ring the patient back in an hour to see if things have improved

e.g. I am going off duty, how should the outcome of the advice be followed up

What will happen next day

SUMMARY

summarise what has been discussed and the plan highlighting what you are going to do and what you expect the person giving advice to do

(e.g. hand over the issue to the relevant person the next working day).

Double check drug names and doses if specific advice has been given around these. If you do not understand or lack confidence to follow advice say so.

Either the person giving the advice or the person receiving advice should ensure that a summary of the advice is read back as a double check that what has been proposed is understood by both parties.

Even at this stage do not be frightened to say if you are unclear about something or you are concerned about the effect of the advice.

If needed suggest that you phone back once you have checked out your concerns with a colleague etc

If you remain unsure say so and suggest what you would feel able to do.

Write clearly in the patients notes the outcome of the phone call and what should be done if the plan does not hold the situation. Sign, time and date the entry.

ALWAYS ENSURE THAT THE PATIENT IS REVIEWED TO CHECK THE IMPACT OF THE ADVICE GIVEN. IF THE PATIENT IS NOT SETTLED ASK FOR MORE ADVICE

North West End of life Care Model for the Last year of Life.

The model outlined on the following page gives a framework of how a patient in the last year of life can be managed effectively within any care setting.

Recognising when a patient may be eligible to be placed on a palliative care register.

This is not always easy and is fundamentally a clinical judgement that takes into account the following:

- Patient's diagnosis and/or co-morbidities that are potentially life limiting (including extreme old age and frailty)
- That the disease(s) the patient has are no longer responding to life pro-longing treatments and starting to cause a significant burden to the patient in terms of symptoms and/ or impact on their activities of daily living
- Patient appears to be in the final part of their expected illness journey – based on what is happening to them and what would be anticipated for that disease.
- Patient with capacity, having weighed the information given to them about their disease, express the view that they no longer want life prolonging treatment, and/ or no longer want to spend time in hospital or other health care institution

There are some general, non-specific changes that may also indicate advancing disease. These include

- Progressive physical weakness and fatigue despite limited physical activity
- Increase need for sleep and rest with tasks that require focus and concentration becoming more difficult such as reading a book, following a TV programme etc
- A reduced appetite
- Symptoms that indicate that a system is starting to fail e.g. breathlessness due to impaired cardiac and/or lung function, persistent nausea and fatigue due to progressive renal impairment

It can be hard to be specific about time frames and there are relatively few objective measures that on their own indicate a relative prognosis, however there are a few which may help:

- Significant decrease in functional ability over a few months
- Repeated admissions to hospital for similar symptoms, which if they respond to acute management, recur quickly once the patient is discharged
- Falling serum albumin
- Worsening liver or renal function

Sometimes asking the **surprise question** is helpful – “would I be surprised if this patient was to die in the next twelve months?” If you would not be surprised then the patient should be considered for the palliative care register.

It can be hard to be honest with patients about what is happening, and acknowledging with them that approaches that may have helped in the past are no longer being effective. Many patients assume that when they are “labelled as palliative,” all active management” will stop and they will receive less treatment as a result. They may need reassurance when placed on a palliative care register it is the focus of care rather than the amount of care that changes.

Recognising that a patient is no longer responding to life-prolonging and/or disease modifying drugs, and communicating this to the patient, allows that individual to actively engage in advanced care planning and to share those plans with significant others if they choose to. This may include making a will, discussing funerals, disposal of the body after death as well as other practical wishes. Being open about the reality of what is happening also allows a patient and their family to

make more informed choices about their care, including what medication they may want to try and stop as well as what medication they may be more willing to try.

Advanced Care Planning

Whilst it is often hard for patients and families to discuss issues around worsening disease and approaching death, many appreciate the opportunity to share their views on issues such as where they would prefer to be cared for and who they want involved in decision making with them. It may also help people to think about their legacy, such as leaving memory boxes for loved ones.

Some may decide to make an **advance decision to refuse treatment**. This must be written by a person over 18, clearly and unambiguously specify what intervention is to be refused and under what circumstances. The statement must not have been made under pressure from other people and the statement signed to that effect. Others may complete **Preferred Priorities of Care (PPC) document**. This allows a patient to express their preferences about their care as they become less well. Whilst the document is not a guarantee that the patient will achieve all their wishes, and is not legally binding, it is a useful guide for all involved in the individual's care. The process of having an advanced care planning conversation may be straightforward, but on occasions may become complex, in which case involving specialist palliative care professionals may help.

For vulnerable adults who are unable to make specific welfare decisions or who, it is anticipated may be in such a position in the future, can give someone they trust legal authority to look after their personal welfare (and finances) through a **Lasting Power of Attorney (LPA)**. This is a legal document and must be registered with the Public Guardian. They only come into force when the individual loses capacity. The nominee must act in the individual's best interests. If there are concerns that this is not the case the office of the public guardian should be alerted and asked to investigate.

Health and social care professionals must be able to justify their decision, if they decide to act contrary to a patient's wishes as expressed in their PPC or advance decision to refuse treatment.

Diagnosis of Dying

This is complex and requires careful assessment of each individual. The diagnosis of dying is inherently uncertain. Some patients will live for longer than expected and others will die more quickly. This is the reason why the diagnosis should be constantly reviewed.

- Does it make clinical sense that this patient is dying now?
- Are there any potential reversible causes for the current deterioration? In particular consider the possibility of neutropenic sepsis in a cancer patient having palliative chemotherapy (in last 10-14 days) or an overwhelming infection.
- If there are other potential reversible causes is it appropriate for them to be treated?
- If treated, will the burdens of that treatment outweigh the potential or actual benefits of such treatment
- What are the expressed wishes of the patient and / or their carers about their end of life care?
- Does the multi-professional team agree that the current deterioration indicates the start of the dying phase?

Many patients have been ill for a prolonged period of time and may have responded to treatment a number of times in the past. Careful negotiation may be required to ensure that an individual is not put through burdensome and potentially futile management, or refuses an approach that may improve their quality of life. Considerable skill may be needed to ensure that the diagnosis of dying is communicated clearly as well as empathically to patient and their family. Without a shared understanding of the focus of care, it can become increasingly difficult to manage symptoms and provide quality care.

End of life Pathway

This is a document that may be used in the last few days of life to mark the transition from palliative care to end of life care. It summarises the 5 key priorities around end of life care. Each locality will have their own version, with prompts aimed at ensuring excellent symptom control irrespective of a patient's diagnosis. This should include the prescription of appropriate drugs in advance, to control key symptoms, (**anticipatory prescribing**). Each locality will have at least 4 core drugs that should be available and prescribed so they can be administered by an appropriately qualified nurse, before a medical assessment has been completed. The core symptoms that should be prescribed for include: Pain, nausea and/or vomiting, respiratory tract secretions, terminal restlessness, breathlessness

End of life care must **never** be started without careful and empathic discussion with the patient (if well enough) and with key members of the patient's family. It is essential that there is **honest and open communication** by the professionals about what is happening. If the patient's condition appears to improve, or other information comes to light, that raises doubt about the diagnosis of dying then management reviewed by an experienced doctor.

Staff should proactively involve families and check on their well being as often as they can. They should ensure that the family know what is likely to happen and also what is available to support them as needed at this time. Investing time with the family at this stage can help with the bereavement process after the person's death.

Bereavement

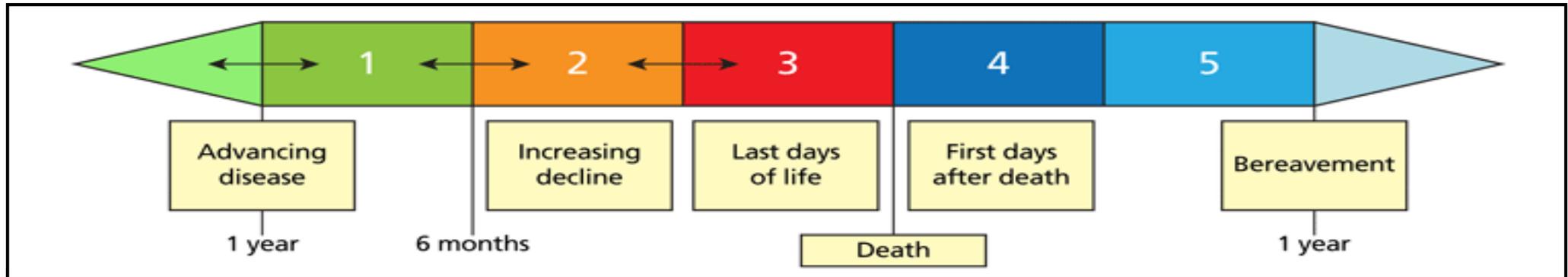
This is a very personal issue which affects people in different ways. Grieving is a natural adjustment process which takes time and is physically as well as emotionally exhausting. However there are some individuals who are at risk of prolonged and abnormal grief which may significantly impact on their ability to function:

- Multiple bereavements in the last 12 months
- Sudden, or perceived unexpected death
- Traumatic or unpleasant death such as after a major haemorrhage
- History of significant depression or anxiety state
- Poor social or family support network
- Death of a child of any age
- Where there are perceived or actual issues around the quality of care given to the deceased

Every locality should have a local bereavement service for adults. Some will also provide support for children. Your local specialist palliative care team should have details of local provision. There are also a number of national organisations that provide support either in a group setting or on a one to one basis.

The older bereaved are at high risk of depression and have increased mortality after the death of a spouse or partner.

NORTH WEST END OF LIFE CARE MODEL Adapted for the Fylde Coast Health Economy



Advancing disease (<1 year)	Increasing decline (<6 months)	Increasing decline (last weeks of life)	Last days of life	First days after death	Bereavement
Holistic patient assessment (inc. physical, psychological, social & spiritual domains)	Review care plan (including social care needs)	Review care plan (including ACP and PPC)	Initiate Individualised plan of Care for people approaching the last days & hours of life	Verification of death Certification of death	Bereavement support Counselling support Psychological support
Carer needs assessment	Initiate ACP discussion, consider using PPC document	If in hospital: Consider AMBER Consider Fast Track Discharge to Preferred Place of Care	Confirm Preferred Place of Death	Bereavement information booklet given to relatives	
Consider Advance Care Planning (ACP) discussion, using Preferred Priorities for Care (PPC) document	Optimise medications	Rationalise medications	If in hospital: Consider 4 Hour Discharge to Preferred Place of Death	If at home: GP to notify hospital/hospice teams If in hospital: Team to notify GP and DN	
Inclusion on Supportive & Palliative Care Register (Gold Standards Framework, GSF)	Check benefits (DLA/AA/DS1500)	Arrange equipment for end of life care at home, including comfort box, bed, other equipment, etc	Discuss, prescribe and supply 'Just in Case 4 Core Drugs', if not already in situ	Notify FCMS & NWAS	
Refer to community services: DN / Matron / Social Worker	Consider Continuing Health Care (CHC) funding	Arrange support for end of life care at home	Complete DNACPR, if not already completed	Discuss After Death Significant Event Analysis (SEA), where appropriate	
Check benefits (DLA/AA)	Consider DNACPR	Consider DNACPR, if not already completed	Update FCMS & NWAS: PPD, Care Co-ordination Plan & DNACPR	Refer 'at risk' bereavement	
Update FCMS & Ambulance Service (NWAS): ACP & Care Co-ordination Plan	Update FCMS & NWAS: ACP, Care Co-ordination Plan & DNACPR	Update FCMS & NWAS: ACP, Care Co-ordination Plan & DNACPR	Identify 'at risk' bereavement		

Consider referral to:
Specialist Palliative Care Services
District Nurse / Community Matron / Site Specific Nurse / Social Worker / Chaplaincy
Voluntary Services / Carer support

Consider training in:
End of life care competencies training
Communication skills training
Psychological support training
Spiritual assessment training

Useful Online Resources
Trinity Hospice Information for Healthcare Professionals
<http://www.trinityhospice.co.uk/infoforprofessionals.html>
Lancs & S Cumbria Palliative Care Prescribing Guidelines
 Available to download from Trinity Hospice website:
<http://www.trinityhospice.co.uk/infoforprofessionals.html>

Palliative Care of Bladder Cancer Patients

General Comments

Many patients will have had extensive investigations and treatment for polyps, over a number of years before a malignant tumour occurs. **Surgical intervention** such as local treatment via cystoscopy, cystectomy and urinary diversion may be appropriate. In addition **radical radiotherapy** and **intra-vesical chemotherapy** may be indicated. The cancer journey is often long with many difficult symptoms that can lead to exhaustion and an increased risk of **depression** in both patient and carers.

Specific pain complexes

- **Bladder spasm** can be frequent and troublesome leading to severe and disabling episodic pain which can be difficult to control. **Anti-cholinergic drugs** as well as **neuropathic pain** agents may help, but often specialist advice is needed.
- **Pelvic pain** is common in advanced disease due to tumour progression. This is often complex and only partially responds to opioids. Usually there is a neuropathic element that will require adjuvant analgesics in the form of **antidepressant and/or anti-convulsant medication**. Specialist advice is frequently needed to maintain symptom control.

Other Complications

Recurrent haematuria is common and may be sufficient to cause **anaemia**. Clot retention may result in acute retention that may be difficult to manage. Discussion is needed about the appropriateness of repeated transfusion if the haematuria is persistent. Intra-vesical prothrombotic agents may be of use in some cases.

Urinary incontinence may occur, causing fatigue of patients and carers through disturbed sleep as well as social isolation because of the associated stigma. Many patients have long term indwelling catheters, which increases the risk of **cystitis** and **urinary tract infections**. These aggravate bladder spasm but may be difficult to treat.

Lymphoedema of the lower limbs and genital area, due to disease infiltration of the pelvic lymph nodes of tumour bulk, may occur and requires specialist management to prevent complications. This should include excellent skin care.

Fistulae between the bladder, rectum or vagina may occur. Some may be amenable to surgery. If surgery is not possible they can cause skin break down and be malodorous and be very difficult to manage. Diverting the flow of urine via the judicious use of catheters may help. Excellent skin care including the use of stoma bags to collect the leaking urine and the use of barrier creams may help.

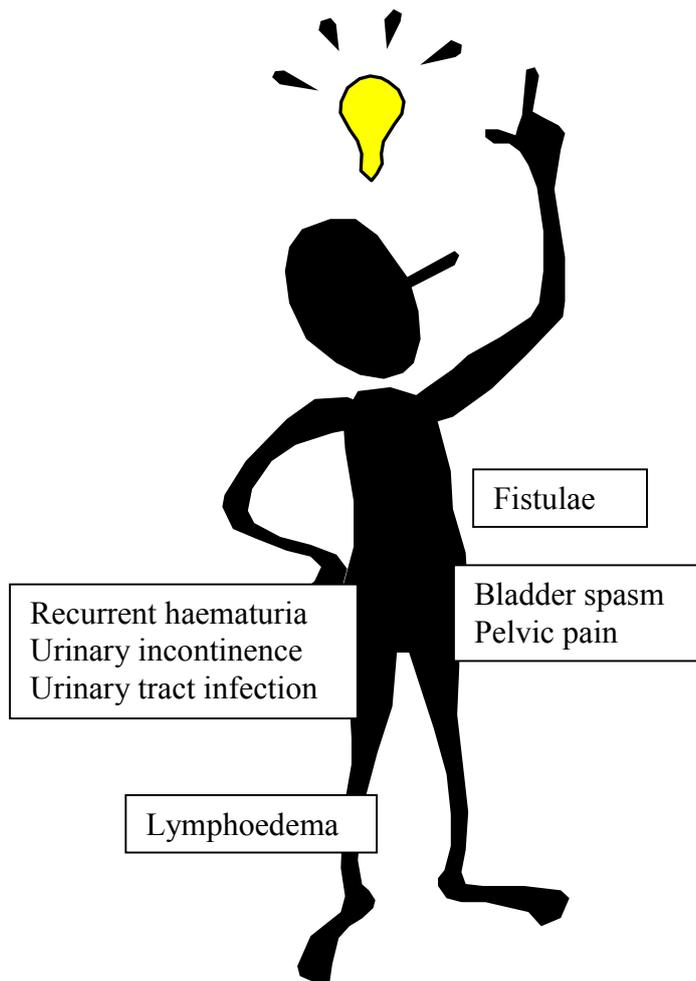
Renal failure may occur. Stenting the renal tract may be possible but is often inappropriate. Dialysis is rarely indicated. Specialist advice may be needed about maintaining symptom control in a patient with established renal failure because of the increased toxicity of many commonly used drugs including opioids and NSAIDs.

Altered body image and problems with sexual function may arise. **Depression** is common because of the protracted time frame of the illness, social isolation and the sense of loss of dignity and control. **Chronic fatigue** is common often caused by nocturia in patients who are not catheterised, chronic anaemia and broken sleep because of spasmodic pain.

Key Points in Palliative Care of Bladder Cancer Patients

General Comments

- Altered Body Image
- Sexual Problems
- Depression
- Fatigue
- Renal Failure



Palliative Care of Patients with Primary and Secondary Brain Tumours

General Comments

Benign tumours and some malignant ones are curable if they can be completely removed surgically.

Primary malignant brain tumours are treated with **surgery** where possible, but **radiotherapy** and **chemotherapy** may also be needed. The disease course may be protracted months or years. Primary brain tumours do not metastasise outside the brain and spinal cord and hence the terminal stage may be prolonged.

Surgical resection of tumours carries significant risk of morbidity, which includes aphasia, dysphasia, paralysis, blindness, and change of personality or memory problems. There is also a risk of persistent coma or death.

Secondary brain tumours are more common. **Surgical resection** of some isolated secondaries may be appropriate in breast, kidney and colon cancers. Otherwise **palliative radiotherapy** for those who are fit enough may help depending on the sensitivity of the tumour, the site of the metastases and the general fitness of the patient.

Specific pain complexes

- **Headaches** due to raised intra-cranial pressure are usually controlled with **high dose oral steroids** and **strong opioids** in the majority of patients. The side effects of steroids often limit the doses and length of time that they can be used. If there is evidence of hydrocephalus, neuro-surgical referral for a shunt should be considered.
- **Meningeal irritation** occurs in advanced disease and this may produce photophobia as well as neck stiffness. This may respond to **NSAIDs and/or oral steroids**.

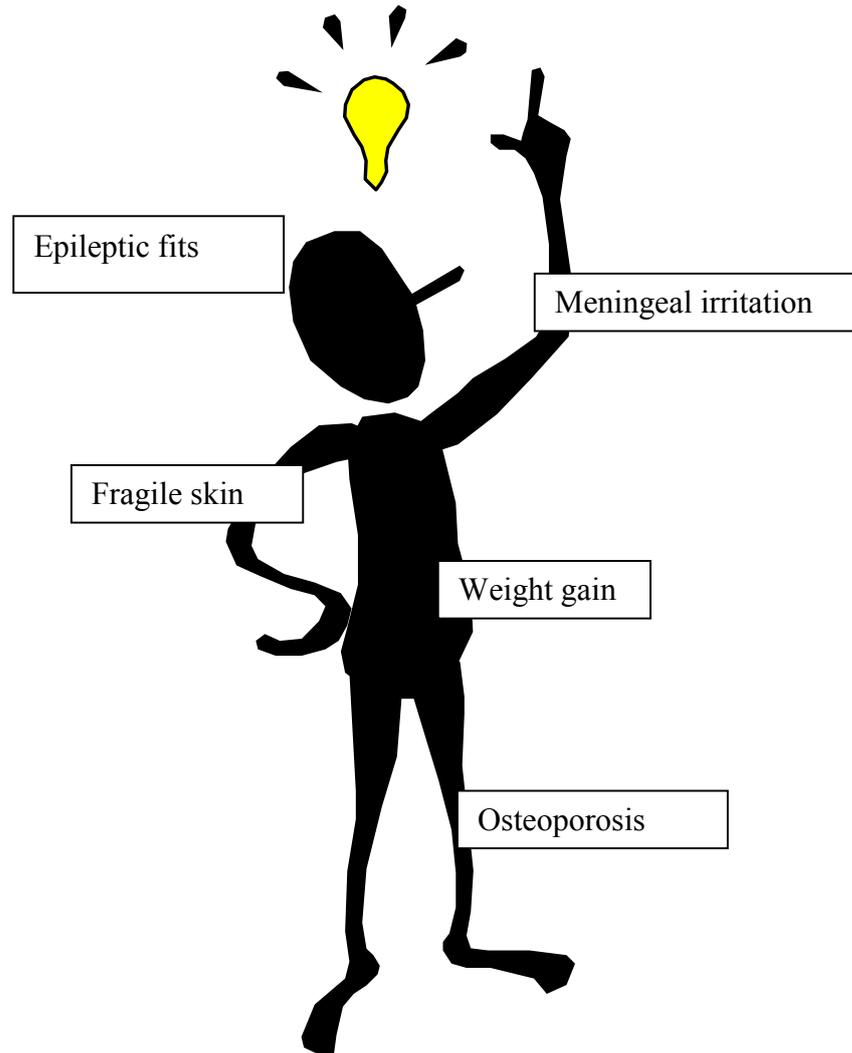
Other complications

- **Altered body shape**, osteoporosis, skin fragility, steroid induced diabetes and mental effects of steroids commonly occur if patients are on high dose steroids for a long time.
- **Epileptic fits** are not universal but are relatively common. They may be difficult to diagnose as they may be atypical. They may also be difficult to control and advice from neurologists may be needed to ensure adequate control using **anti-convulsant medication**.
- **Disability** as a result of impaired mobility, incontinence and personality changes mean that patients and their families often need intensive **multi-disciplinary support and rehabilitation**.
- **Social and psychological issues** are common. Many patients with primary brain tumours are young and may be the **main wage earner** in a family leading to complex financial issues. They may also have young children who need support during their parents illness and also need to have provision for their care after the patient has died. **Children** often need specialist support before and after the patient's death, particularly if the patient has undergone personality and behaviour changes.

Key Points in Palliative Care of Patients with Primary and Secondary Brain Tumours

General Comments

- Multiple needs/disabilities
- Complex social issues
- Risk of bereavement problems
- Altered Body Image



Palliative Care of Breast Cancer Patients

General comments

Metastatic recurrence is possible even after a number of years of disease free survival. If a patient develops symptoms such as pain, persistent nausea or breathlessness it is essential that investigations be carried out to make a firm diagnosis of their cause. This should include chest X-ray and liver ultrasound. If bone pain is a significant issue, plain X rays of the affected area and/or a bone scan may be helpful. Disease specific measures including hormone manipulation, radiotherapy and chemotherapy may achieve good palliation and should be considered in all patients, even those with advanced disease. Genetic counselling should be considered for those families with a strong family history of breast and /or ovarian cancer.

Specific pain complexes

Widespread **bone metastases** are common. Patients are at risk of:

- **Pathological fracture** that may occur without obvious trauma. These may need **orthopaedic intervention** (pinning or joint replacement) and/or **radiotherapy**. Prophylactic pinning of long bones such as humerus or femur should be considered if there are large metastatic deposits at risk of fracture.
- **Spinal cord compression** that requires prompt diagnosis, high dose oral steroids in a single daily dose and **urgent, same day, discussion with an oncologist**. The steroids should be continued at a high dose until a definitive plan has been made. They may then be titrated down in accordance with the patient's condition and symptoms.
- **Neuropathic pain**. Local recurrence of tumour or axillary lymph node spread may directly affect the brachial plexus. This may produce neuropathic pain affecting the arm and anterior chest wall. Metastatic spread to the spine may cause nerve root compression and subsequent neuropathic pain. Such pain is partially opioid sensitive but adjuvant analgesics in the form of **anti-depressant and/or anti-convulsant medication** are usually required to supplement the effect of the opioid. Specialist advice is frequently needed to maintain good symptom control.
- **Liver metastases** often occur and may cause pain. This usually responds well to **Non-steroidal anti-inflammatory drugs (NSAIDs)** or **steroids**. Liver metastases may also lead to hepatomegaly that may cause squashed stomach syndrome with delayed gastric emptying, persistent nausea, occasional vomiting, loss of appetite and a feeling of fullness. This may respond to a prokinetic agent such as **metoclopramide**.

Other complications

Hypercalcaemia may occur. In most cases treatment should be considered with **IV hydration and IV bisphosphonates**.

Lymphoedema usually affects the arm involved in the original surgery. It can develop at any time after diagnosis. It needs to be actively managed if complications are to be avoided. Management includes good skin care, avoiding additional trauma to the affected arm (including taking of blood tests and BP measurement) and appropriately fitting compression garments.

Lung and pleural disease are common and may cause breathlessness and cough. Consider draining a pleural effusion if present. This may only afford temporary relief as the fluid may recur. Active management of the underlying disease using chemotherapy or hormone manipulation may reduce the rate of accumulation of the fluid. **Surgical pleurodesis** may be appropriate.

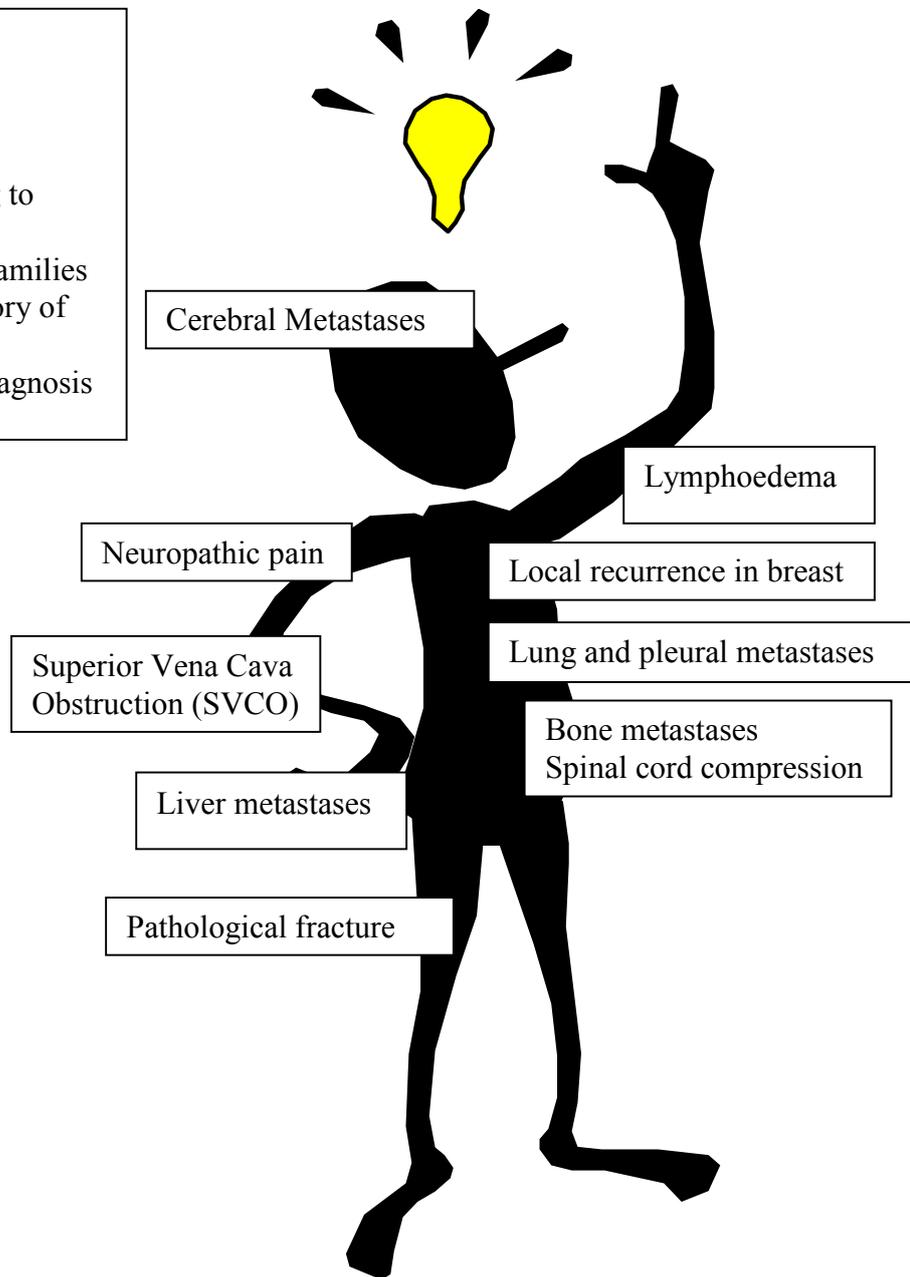
Cerebral metastases are less common. Decisions about investigation and management may be complex and need to be made on an individual basis, (see notes on secondary brain tumours). Associated headaches usually respond well to steroids and opioids. There is a risk of epileptic fits and **prophylactic anti-convulsant medication** may be appropriate, if there is evidence of seizure activity, or the patient is felt to be at high risk of a seizure..

Superior vena cava obstruction (SVCO) can occur in patients with an indwelling venous catheter and less commonly in those patients who have extensive pulmonary disease. Management includes removal of the line (in consultation with the patient's oncologist), **vascular stenting, radiotherapy and high dose steroids**. Long-term anti-coagulation may be considered.

Altered body image and problems with intimate relationships may arise as a consequence of the disease itself, (fungating breast tumours), surgery and subsequent treatment. **Depression and anxiety** are common because of the often extensive burden of disease, protracted time frame of the illness and the burden of treatment.

Key Points in Palliative Care of Breast Cancer Patients

- General Comments**
- Hypercalcaemia
 - Altered Body Image
 - Depression and anxiety
 - Protracted course leading to patient and carer fatigue
 - Genetic counselling for families with a strong family history of breast cancer
 - Long interval between diagnosis and metastases



Palliative Care of Colorectal Cancer Patients

General Comments

Prognosis is closely linked to histological staging (Duke's classification). Adjuvant chemotherapy may be helpful in prolonging disease free survival. Patients may present with bowel obstruction (see below). **Genetic counselling** should be considered for those with a family history of colonic cancer or who have polyposis coli.

Specific pain complexes

- **Liver metastases** often occur and may cause pain. This usually responds well to **Non-steroidal anti-inflammatory drugs (NSAIDs)** or **steroids**. Liver metastases may also lead to hepatomegaly that may cause squashed stomach syndrome with delayed gastric emptying, persistent nausea, occasional vomiting, a loss of appetite and a feeling of fullness. This may respond to a prokinetic agent such as **metoclopramide**.
- **Perineal and pelvic pain** may be caused by advancing disease or by surgical intervention. There is nearly always a neuropathic element to the pain that will only be partially opioid sensitive. Adjuvant analgesics such as **as antidepressant and/or anticonvulsant medication** may be needed as well as more specialist interventions such as nerve blocks.
- **Tenesmus** is a unique type of neuropathic pain. It requires specialist assessment, but may respond to drugs that have an effect on smooth muscle including **nifedipine, nitrates and baclofen**.
- **Bone metastases**. These are becoming increasingly common as adjuvant chemotherapy prolongs the disease course. Response to NSAIDs and radiotherapy is variable. Management of subsequent pain may be difficult and specialist advice should be sought.

Other complications

Bowel obstruction unless it can be palliated surgically should be managed medically using a syringe driver containing a mixture of **analgesics, anti-emetics and anti-spasmodics**. Nasogastric tubes are rarely needed, and adequate hydration can usually be maintained orally if the nausea and vomiting are adequately controlled.

Fistulae between the bowel and the skin, bladder or vagina may occur. These can be very difficult to manage and require a multidisciplinary approach with specialist input. Some may be amenable to surgery. If surgery is not possible they can cause skin break down and be malodorous and be very difficult to manage. Excellent skin care including the use of stoma bags to collect the leaking gut contents and the use of barrier creams may help.

Anorexia and altered taste are very common with advanced disease and difficult to manage, particularly for the family. **Small, frequent and appetising meals** may help as may supplement drinks. **Low dose steroids** may temporarily boost the appetite.

Rectal discharge and bleeding are unpleasant and difficult symptoms to manage. They may respond to **palliative radiotherapy**. Seek specialist advice.

Hypoproteinaemia is common due to poor oral intake and poor absorption from the bowel and may lead to lower limb oedema. This may be complicated by pelvic disease causing to lower limb **lymphoedema**. Early assessment by the specialist lymphoedema service is essential to maintain patient's comfort and prevent complications.

Anaemia may occur due to chronic bleeding from the tumour especially rectal lesions. Control of bleeding from rectal tumour may be achieved through radiotherapy in some cases. A trial of

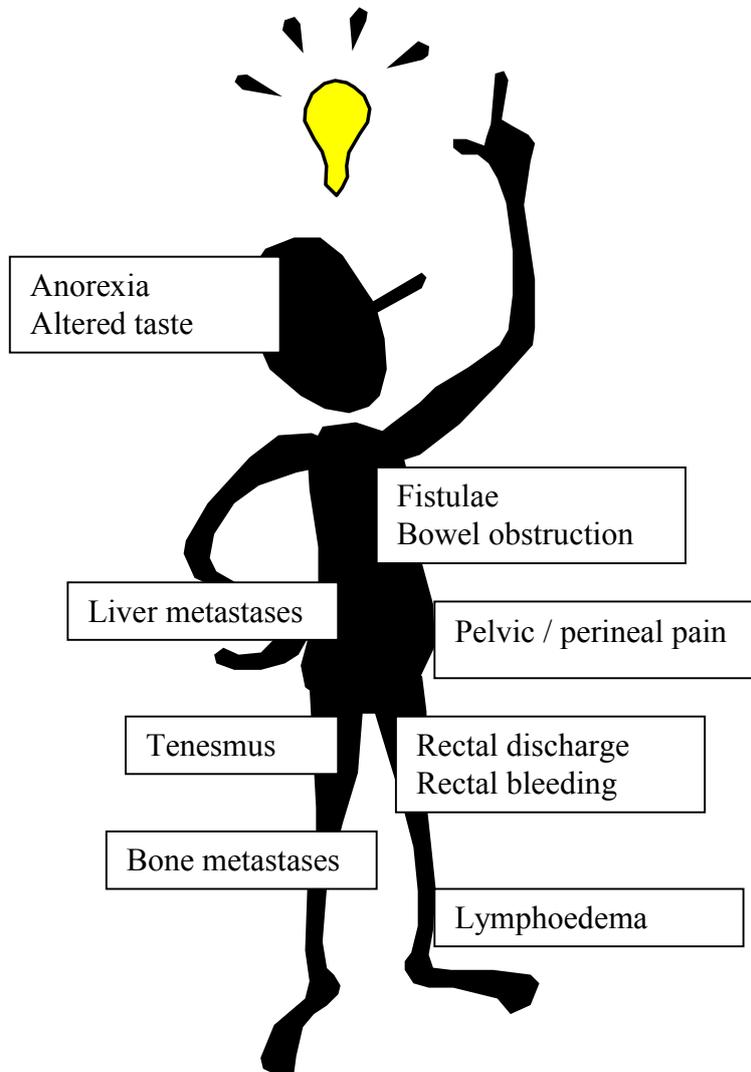
pro-thrombotic agents such as tranxemic acid should be considered. Anaemia may warrant regular blood transfusion in some cases. Discussion is needed about the appropriateness of repeating transfusion if the anaemia is persistent.

Cerebral metastases are less common, but more likely in patients with a rectal carcinoma. Decisions about investigation and management may be complex and need to be made on an individual basis, (see notes on secondary brain tumours). There is a risk of epileptic fits and **prophylactic anti-convulsant medication** may be appropriate if there are signs of seizure activity or the patient is at high risk of a seizure.

Key Points in Palliative Care of Colo-rectal Cancer Patients

General Comments

- Hypoproteinaemia
- Body Image
- Genetic counselling for those with a strong family history



Palliative Care of Gynaecological Cancer Patients

General comments

Primary treatment may have affected **body image, sexual function and fertility** and this will impact on coping strategies. Ovarian and vulval cancers often present late and so it may be appropriate for specialist palliative care input from the point of diagnosis. **Genetic counselling** should be considered for close female relatives of patients with ovarian cancer particularly if there is also a strong family history of breast cancer.

Specific pain complexes

- **Perineal and pelvic pain** is common in all three of the common malignancies; cervical, ovarian and vulval carcinomas. There is nearly always a neuropathic element to the pain that will only be partially opioid sensitive. Adjuvant analgesics such as **antidepressant and/or anticonvulsant medication** may be needed as well as more specialist interventions such as **nerve blocks**.

Other Complications:

Lymphoedema affecting one or both lower limbs may develop with uncontrolled pelvic disease. It can develop at any time following diagnosis. It needs to be actively managed if complications are to be avoided. Management includes good skin care, avoiding additional trauma to the affected leg(s) and appropriately fitting compression garments.

Ascites is particularly common with ovarian cancer and can be difficult to manage. **Oral diuretics**, particularly spironolactone in combination with a loop diuretic such as furosemide may help a little. Repeated paracentesis is often needed. Consideration of a **peritovenous (Leveen) shunt** may be appropriate in some cases where prognosis is thought to be longer than three months.

Complete or subacute bowel obstruction can occur in advanced disease and is often not amenable to surgical intervention and should be managed medically using a **syringe driver containing a mixture of analgesics, anti-emetics and anti-spasmodics**. Naso-gastric tubes are rarely needed, and hydration can often be maintained orally if the nausea and vomiting are adequately controlled.

Renal impairment can develop in any patient with advanced pelvic disease. It may be a pre-terminal event. Ureteric stenting may be appropriate depending on the patient's perceived prognosis, the patient's wishes and future treatment options. Specialist advice around maintaining symptom control may be needed because of the increased potential of toxicity from commonly used drugs such as opioids and NSAIDs.

Vaginal or vulval bleeding may respond to antifibrinolytic agents such as **tranexamic acid, radiotherapy and/or surgery**. Anaemia may warrant regular blood transfusion in some cases. Discussion is needed about the appropriateness of repeating transfusion if the anaemia is persistent.

Offensive vaginal or vulval discharge can cause considerable distress to patient and carers. **Topical or systemic metronidazole** may help, as can barrier creams. **Deodorising** machines may also help if the patient is confined to one room.

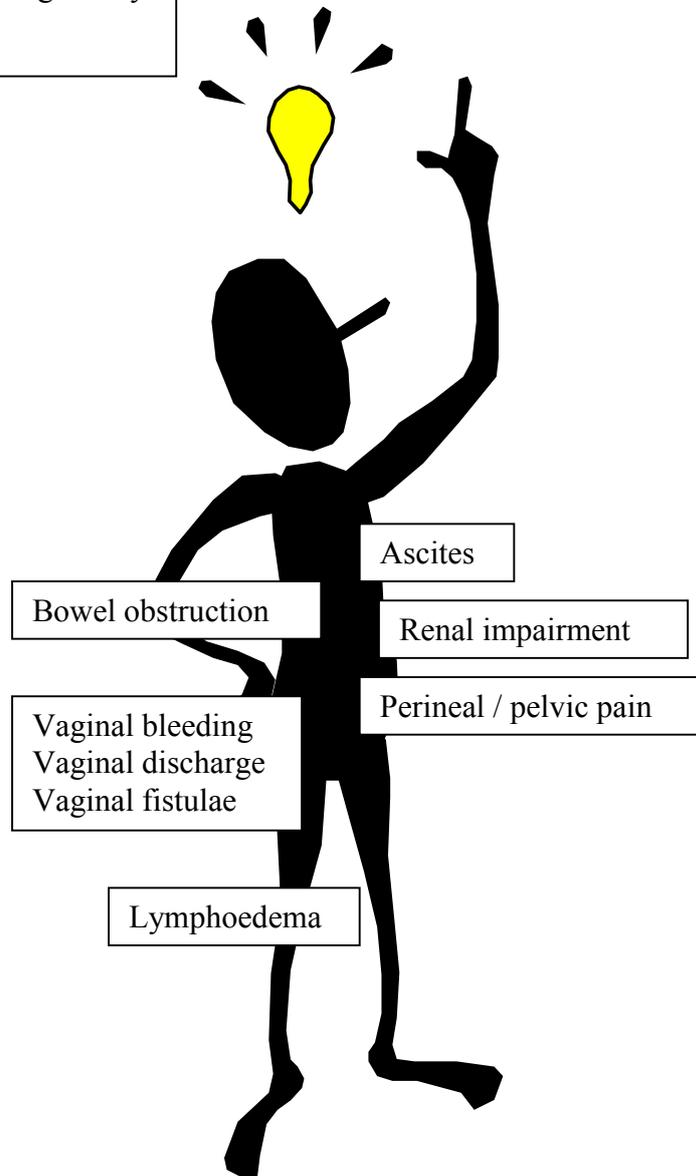
Vesico-colic and recto-vaginal fistulae need a surgical assessment. These can be very difficult to manage and require a multidisciplinary approach with specialist input.

- **Social and psychological issues** are common because of altered body image, issues around fertility and sexual function. Many patients with cervical primaries are young and may be the **main wage earner** in a family leading to complex financial issues. They may also have young children who need support during their parents illness and also need to have provision made for their care after the patient has died.

Key Points in Palliative Care of Gynaecology Cancer Patients

General Comments

- Body Image
- Fertility
- Sexual function
- Social issues
- Genetic counselling for those with a strong family history



Palliative Care of Head and Neck Cancer Patients

General Comments

There are a wide variety of cancers affecting the head and neck including the oral cavity, oropharynx, larynx, hypopharynx, nasopharynx, nasal cavity sinuses and salivary glands. They have two aetiological factors in common, namely cigarette smoking and heavy alcohol consumption. Many of the patients with these cancers have lifestyles that mean they find it hard to use the health service effectively. Frequently the patients present late when **curative surgery and radiotherapy**, which are the mainstays of treatment, cannot be undertaken.

Specific pain complexes

- **Neuropathic pain** affecting the head and neck and radiating to the upper arm is not uncommon. This can be the result of direct compression of nerves by the tumour or a result of treatment. There may be associated hypersensitivity of the skin and oral mucosa that may be so severe that the patient is unable to tolerate a light breeze or chewing food. The pain syndromes are often complex and only partially respond to opioids. An adjuvant analgesic in the form of anti-depressants and/or anti-convulsant medication is usually needed. Specialist advice is frequently needed to maintain symptom control especially as compliance with medication may be a problem.
- **Dysphagia** due to direct compression by a tumour mass or lymphadenopathy causes both difficulty and pain on swallowing. Feeding gastrostomies may be needed to maintain nutrition and aid with the administration of medication as the oral route may not be unreliable or unavailable. There may be ethical dilemmas towards the end of life particularly with regard to the administration of feeds in the last days of life.

Other complications

The tumour or the surgery performed often adversely affects a patient's **body image** in a site that is hard to hide from public view. Patients often become **socially isolated** as they feel disfigured may have problems speaking and so become reluctant to go out. **Depression** is a common feature. Relationship problems are not uncommon.

Oral problems are common. **Dry mouth** as a consequence of treatment or as a side-effect of medication may cause problems with speaking, altered taste and chewing food. **Dental caries** may be accelerated by a dry mouth so patients need excellent and regular mouth care. Poor saliva production may be helped by chewing sugar free gum or the regular use artificial saliva. Oral thrush should be treated with antifungal mouth wash in the first instance. Dentures should also be soaked in antifungal solution.

Anorexia and altered taste are very common with advanced disease and difficult to manage, particularly for the family. **Small, frequent and appetising meals** may help as may supplement drinks. **Low dose steroids** may temporarily boost the appetite.

Difficulties with articulation and speech production are common. In some cases after laryngectomy speech will not be possible and the patient has to learn to communicate in other ways. For others the quality of the voice may change significantly making the patient self-conscious. Recurrent laryngeal nerve palsy results in a hoarse voice. This may be improved to some extent by Teflon injections into the vocal cord. All these problems may need input of specialist **speech and language therapists**. **Communication aids** may be needed after major surgery to enable a patient to express their needs and preferences.

Difficulty breathing and stridor may develop in some patients. In some cases a tracheostomy is formed to prevent choking. This needs regular specialist care. Home suction to manage secretions may be needed.

Fungating and malodorous tumours can cause considerable distress. **Radiotherapy** may help in some cases especially where there is bleeding. Topical antibiotics may help along with regular dressings sensitively applied to maintain dignity, but cover the most disfiguring parts of the tumour. The use of **deodorisers** in the patient's room may help.

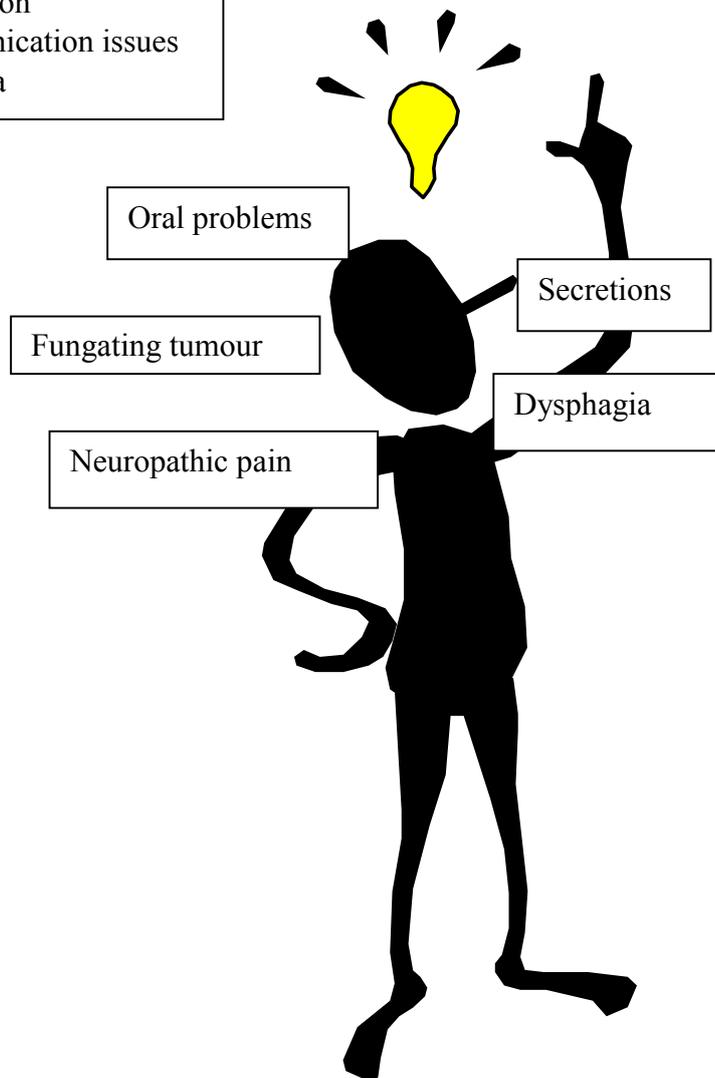
Many patients with advanced disease have problems have a poor cough reflex that makes expectoration of oral **secretions** that may be very thick difficult. Treating infections with antibiotics can reduce the viscosity of secretions and so relieve distress. **Nebulised normal saline** can moisten airways, making it easier for patients to expectorate secretions. **Oral mucolytics** can sometimes help.

Major haemorrhage. Patients with progressive tumours near the large blood vessels of the neck are at risk of a sudden massive bleed. This is rare, but difficult to manage and the early involvement of specialists should be considered.

Key Points in Palliative Care of Head and Neck Cancer Patients

General Comments

- Body image
- Social Isolation
- Relationship problems
- Depression
- Communication issues
- Anorexia



Palliative Care of Patients with Chronic Leukaemia, Lymphomas and Myeloma

General Comments

The clinical course tends to be very variable, but is characterised by a **protracted cycle of relapses and remissions**. This can cause considerable distress as the patients and their carers have to live with considerable uncertainty about the future. Both patient and the professionals involved with their care may find it hard to recognise and then accept a patient is entering the terminal phase.

Infection is a frequent and unpredictable complication of both the disease process and its treatment. It can be fatal and this makes the prognosis even more uncertain.

Chemotherapy may continue in advanced illness because of the possibility of a further remission and/or useful palliation.

Specific pain complexes

- **Bone pain** due to infiltration of the bones and joints is very common. The pain is often worse on movement or weight-bearing, which makes titration of analgesics very difficult. The pain often **responds to radiotherapy and/or oral steroids**. **Non-steroidal anti-inflammatory drugs** (NSAIDs) may help but must be used with caution because they may interfere with platelet and renal function.
- **Pathological fractures** are particularly common in myeloma due to the lytic bone lesions. These often require **orthopaedic intervention** and subsequent **radiotherapy**. Prophylactic pinning of long bones and/or radiotherapy should be considered to prevent fracture and reduce the likelihood of complex pain syndromes developing.
- **Spinal cord compression** requires prompt diagnosis, high dose oral steroids in a single daily dose and **urgent, same day, discussion with a clinical oncologist**. The steroids should be continued at a high dose until a definitive plan has been made. They may then be titrated down in accordance with the patient's condition and symptoms.
- **Wedge and crush fractures of the spinal column** can lead to severe back pain which is often associated with nerve compression and neuropathic pain. Such pain is partially opioid sensitive but adjuvant analgesics in the form of **anti-depressants and/or anti-convulsant medication** are usually required to supplement the effect of the opioid. Specialist advice is frequently needed to maintain symptom control.

Other complications

Bone marrow failure is usual. **Recurrent infections** and **bleeding episodes** can leave the patients and carers exhausted. Dependence on frequent blood and platelet transfusions may mean that difficult decisions about stopping transfusions must be faced at some stage.

Night sweats and fever are common, imposing a heavy demand on carers, particularly as it may mean several changes of night and bed clothes. Specialist advice may help in relieving the symptom, as there are a number of drugs that appear to be effective although not licensed.

Hypercalcaemia may occur, especially in myeloma. It should be considered in any patient with persistent nausea, altered mood or confusion, even if this is intermittent, worsening pain and/or constipation. Treatment with **IV hydration and IV bisphosphonates** should be considered for a first episode. Resistant hypercalcaemia may be a pre-terminal event when aggressive management would be inappropriate.

Oral problems are common. **Dry mouth** as a consequence of treatment or as a side-effect of medication may cause problems with speaking, altered taste and chewing food. **Dental**

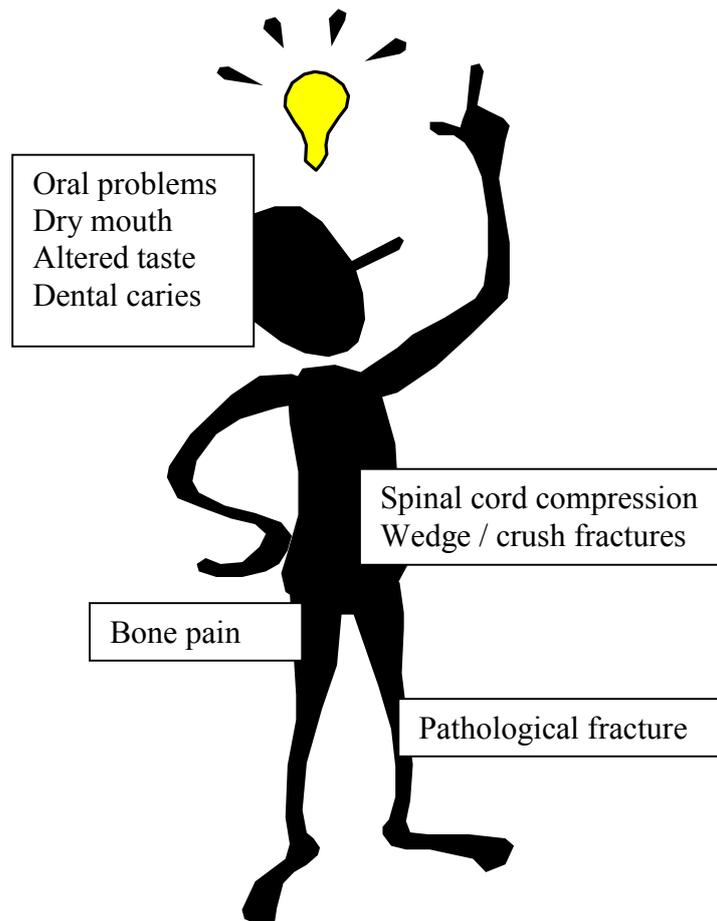
caries may be accelerated by a dry mouth so patients need excellent and regular mouth care. Poor saliva production may be helped by chewing sugar free gum or the regular use artificial saliva. Oral thrush is common and should be treated aggressively with nystatin mouth wash in the first instance. Dentures should also be soaked in nystatin.

Anorexia and altered taste are very common with advanced disease and difficult to manage, particularly for the family. **Small, frequent and appetising meals** may help as may supplement drinks. **Low dose steroids** may temporarily boost the appetite, although these may already be in use as part of the disease modifying regime.

Key Points in Palliative Care of Patients with Chronic leukaemia, Lymphoma and Myeloma

General Comments

- Difficult to predict terminal stage
- Infection
- Night sweats
- Hypercalcaemia
- Bone marrow failure



Palliative Care of Lung Cancer Patients

General Comments

This is one of the commonest cancers. There is a direct link between squamous cell carcinoma and smoking, (both active and passive). This causal link may be the cause of emotional distress in the patient and their carers. Lung cancers often occur on a background of pre-existing lung disease which may alter the patient's perception of the intensity of breathlessness and of the burden of a persistent cough. On the whole the prognosis for lung cancers not amenable to surgery is poor, with 90% of patients dying within a year of diagnosis.

Specific pain complexes

- **Pleuritic pain** may be associated with the tumour itself, metastases in the rib, or local infection. This type of pain responds well to **non-steroidal anti-inflammatory drugs** (NSAIDs). It may also be helped by local nerve blockade
- **Pancoast tumour** (tumour in the apex of an upper lobe) can produce severe neuropathic pain affecting shoulder and arm which will only be partially opioid responsive and will need adjuvant analgesics such as **antidepressant and/or anticonvulsant medication**. Early referral for specialist help should be considered.
- **Bone metastases** may occur putting the patient at risk of **pathological fractures** and **spinal cord compression**. Management of subsequent pain may be difficult and specialist advice should be sought.

Other complications:

Breathlessness is common and can be very distressing for carers. Treat reversible causes such as anaemia and pleural effusion where appropriate. Give clear explanations of what is happening. Ensure that practical measures such as sitting the patient up, opening windows and using fans have been discussed with the family. Regular doses of **short acting oral morphine** (2.5 – 5 mg) every 2 - 4 hours may decrease the sensation of breathlessness. Other more specialist interventions such as **palliative radiotherapy, endobronchial laser therapy** and **stenting** may help some patients. Panic and anxiety are frequently associated with breathlessness and may be helped by **simple relaxation techniques**. A low dose of an **anxiolytic** such as diazepam may be helpful. **Oxygen** should be used with caution and rarely has any benefit beyond the other measures outlined, unless the patient is measurably hypoxic.

Haemoptysis is a frightening symptom. **Palliative radiotherapy** may be effective if the patient is fit enough. Oral antifibrinolytics such as **tranexamic acid** may help. Occasionally frequent small episodes herald a catastrophic haemoptysis. This is a rare, but distressing situation to manage and early involvement of specialists should be considered.

Cough can exacerbate breathlessness and pain; can affect sleep and a patient's ability to eat. Its management will depend on the cause but it is often appropriate to try and suppress the cough pharmacologically using **codeine or morphine linctus**. If not responding to simple measures refer for specialist assessment.

Dysphagia may occur because of tumour compression, from para-tracheal lymphadenopathy or from pressure of a large pleural effusion. Small meals given often and a soft diet may help. In addition **antacids** and **proton pump inhibitors** may ease symptoms from reflux.

Hypercalcaemia may occur, even in the absence of bone metastases. It should be considered in any patient with persistent nausea, altered mood or confusion, even if this is intermittent, worsening pain and or constipation. It may be a pre-terminal event when treatment with **IV hydration and IV bisphosphonates** would be inappropriate.

Cerebral and cerebellar metastases are common. Decisions about investigation and management may be complex and need to be made on an individual basis. Altered behaviour and personality as well as problems of comprehension and communication can be very distressing for relatives. **Persistent headache**, worse in the mornings and **unexplained**

vomiting may be early signs of this diagnosis. There is a risk of epileptic fits and **prophylactic anti-convulsant medication** may be appropriate if there is evidence of seizure activity or the patient is felt to be at risk of a seizure.

Hyponatraemia and other biochemical imbalances are particularly common in small cell lung cancer. Management can be complex and needs specialist input.

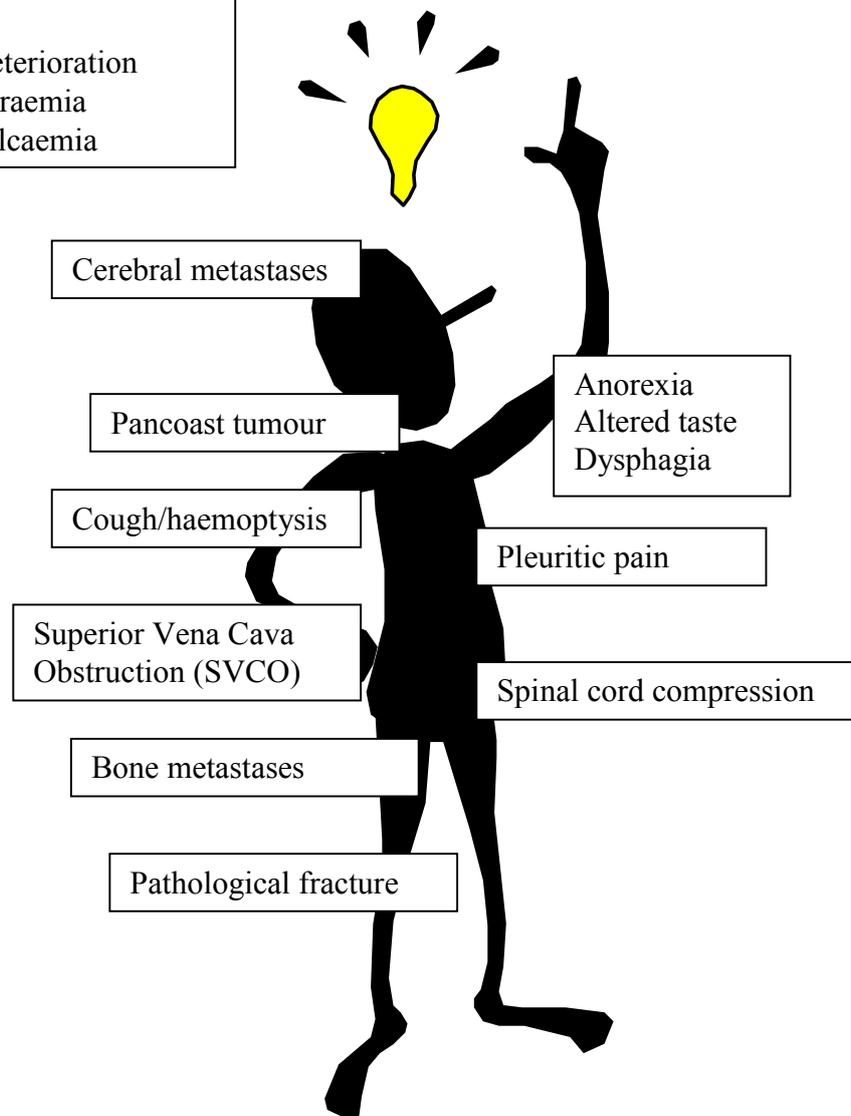
Altered taste and anorexia are common. **Good oral hygiene**, effective treatment of oral candidiasis may help. Carers may find it helpful to talk through different ways of encouraging the patient to eat, such as freezing supplement drinks to make lollipops, making small meals frequently etc.

Superior vena caval obstruction (SVCO) can occur in patients who have extensive pulmonary disease, particularly small cell lung cancer. Management includes consideration of **vascular stenting, radiotherapy and high dose oral steroids** in a single daily dose.

Key Points in Palliative Care of Lung Cancer Patients

General Comments

- Usually related to smoking
- Rapid deterioration
- Hyponatraemia
- Hypercalcaemia



Palliative Care of Patients with Mesothelioma

General Comments

This usually affects the lung but can affect other parts of the body particularly the peritoneum. It is associated with exposure to asbestos and there are clusters of cases around certain industrial sites. It is a relentlessly progressive tumour.

It is important that the patient is aware that they or members of their family (spouse) may be entitled to **compensation** and should consult a specialist lawyer about this.

All patients must have a **coroner's post mortem** regardless of any compensation claims or litigation. The family should be made aware of this at an appropriate time to try and minimise distress at the time of death. It is useful to find out before a death what the local coroner's office will do in terms of who, if any one will visit and how quickly the post mortem may be carried out.

Specific pain complexes

- Mesotheliomas can produce **severe neuropathic pain** which will only be partially opioid responsive and will need adjuvant analgesics such as **antidepressant and/or anticonvulsant medication**. Early referral for specialist help should be considered. **Local nerve blockades** can help in some cases.

Other complications

Pleural effusions are common, frequently blood stained and become increasingly difficult to aspirate as the disease progresses. **Surgical intervention** to prevent re-accumulation of fluid may be helpful if carried out early enough.

The tumour may grow along the track of a biopsy or drainage needle to produce a cutaneous lesion. These areas can become painful, ulcerated and can be difficult to manage. **Palliative radiotherapy** has a limited role to play in preventing the complication at the time of biopsy and also in managing established cutaneous spread.

Breathlessness can be severe due to pleural disease limiting the capacity of the lung as well as the occurrence of pleural effusions. Give clear explanations of what is happening. Ensure that practical measures such as sitting the patient up, opening windows and using fans have been discussed with the family. **Regular doses of short acting oral morphine** (2.5 – 5 mg) every 2 – 4 hours may decrease the sensation of breathlessness. Panic and anxiety are frequently associated with breathlessness and may be helped by **simple relaxation techniques**. A low dose of an **anxiolytic** such as diazepam may be helpful. Other treatment options are limited.

Cough can exacerbate breathlessness and pain; can affect sleep and a patient's ability to eat. Its management will depend on the cause but it is often appropriate to try and suppress the cough pharmacologically using **codeine or morphine linctus**. If not responding to simple measures refer for specialist assessment.

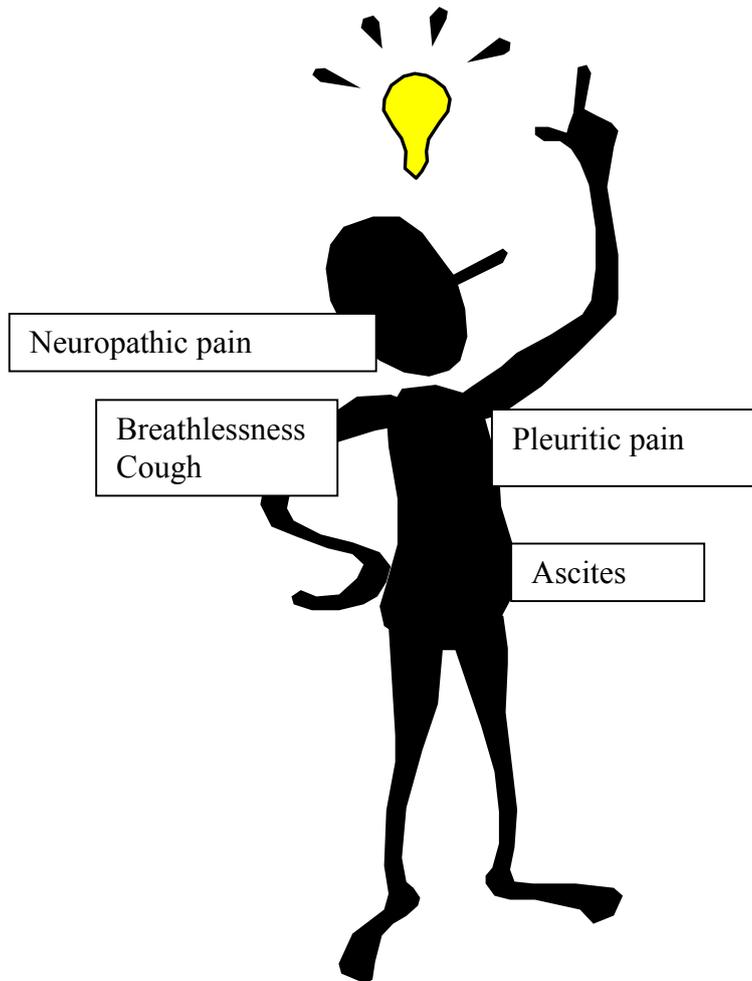
Altered taste and anorexia are common. **Good oral hygiene**, effective treatment of oral candidiasis may help. Carers may find it helpful to talk through different ways of encouraging the patient to eat, such as freezing supplement drinks to make lollipops, making small meals frequently etc.

Ascites occurs with peritoneal mesothelioma. The ascitic fluid is frequently blood stained and becomes increasingly difficult to aspirate as the disease progresses.

Key Points in Palliative Care for Patients with Mesothelioma

General Comments

- Industrial compensation
- Compulsory coroner's post mortem
- Relentlessly progressive tumour



Palliative Care of Prostate Cancer Patients

General Comments

This is a common cancer that most often affects elderly men. The time course can be very variable ranging from years with relatively few symptoms, to an illness that lasts months with many symptoms. The mainstay of treatment is **hormonal manipulation** with **palliative radiotherapy**. A few patients present early enough for potentially curative treatment to be attempted using surgery and/or radiotherapy.

Specific pain complexes

Widespread **bone metastases** are common and are often present at diagnosis. Patients are at risk of

- **Pathological fracture** that may occur without obvious trauma. These may need **orthopaedic intervention** (pinning or joint replacement) and/or radiotherapy.
- **Spinal cord compression** that requires prompt diagnosis, oral high dose steroids in a single daily dose and **urgent, same day, discussion with a clinical oncologist**. The steroids should be continued at a high dose until a definitive plan has been made. They may then be titrated down in accordance with the patient's condition and symptoms.
- **Neuropathic pain**. Local recurrence of tumour, pelvic spread or a collapsed vertebra may cause neuropathic pain. Such pain is partially opioid sensitive but adjuvant analgesics in the form of **anti-depressant and/or anti-convulsant medication** are usually required to supplement the effect of the opioid. Specialist advice is frequently needed to maintain symptom control.
- **Bone pain**. If the tumour is hormone sensitive then bone pain often responds to a change in hormone therapy. Skilled pain management is often needed and specialist advice should be sought about the appropriate use of **radiotherapy and radioactive strontium** as well as **nerve blockade**. A trial of a **bisphosphonate paraenterally** should also be considered. Patients need to be made aware of the risk of osteonecrosis of the jaw and should have a dental examination before the infusion is commenced.

Other complications

Bone marrow failure may occur in patients with advanced disease. Typically the patient has symptomatic anaemia and thrombocytopenia. Support with **palliative blood transfusions** may be appropriate initially, but their appropriateness should be discussed with the patient and their family when there is no longer symptomatic benefit gained from them.

Urinary incontinence may occur, causing fatigue of patients and carers through disturbed sleep as well as social isolation because of the associated stigma. Many patients have long term indwelling catheters, which increases the risk of **cystitis** and **urinary tract infections**. These may cause bladder spasm which may be difficult to treat.

Retention of urine caused by problems with micturition and haematuria may lead to retention of urine. This may be acute and painful, or chronic and painless. If the patient is unfit for transurethral resection of the prostate (TURP) then consider a permanent **indwelling urinary catheter**. Chronic urinary retention with outflow obstruction causes back pressure on the kidney and can lead to renal failure.

Lymphoedema of the lower limbs and occasionally the genital area is usually due to advanced pelvic disease. It can develop at any time in a patient's cancer journey. It needs to be actively managed if complications are to be avoided. Management includes good skin care and using appropriately fitting compression garments.

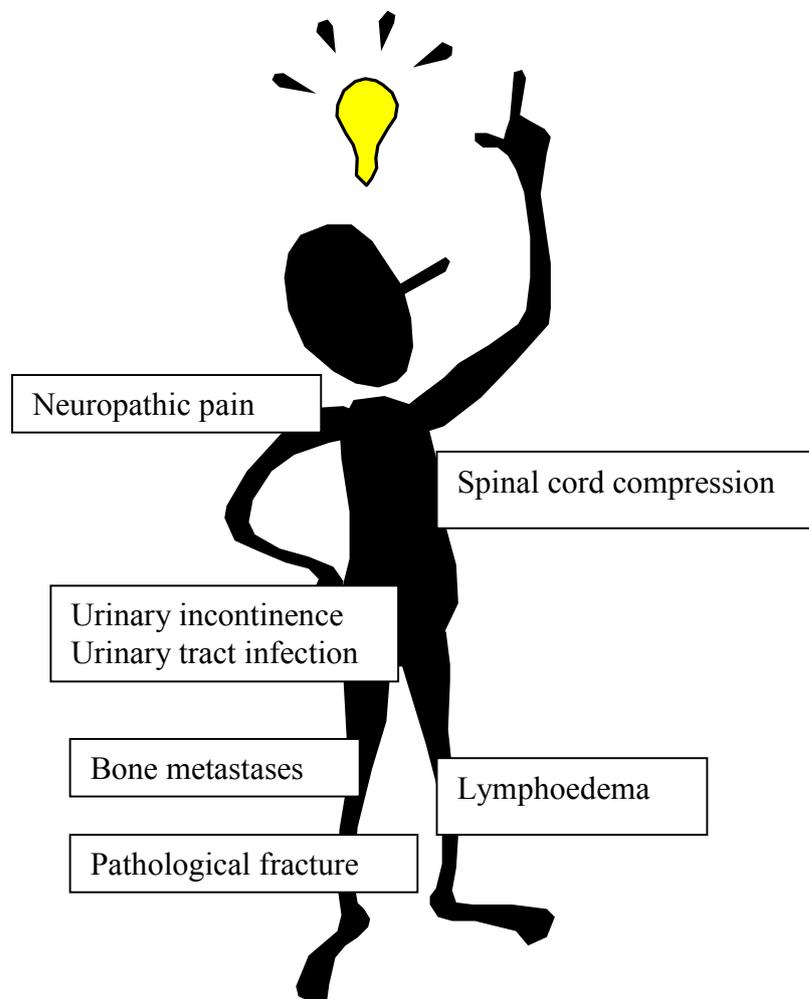
Altered body image and sexual dysfunction can result from any of the treatment modalities, hormone manipulation, radiotherapy, or surgery. This may be exacerbated by apathy and

clinical depression that are particularly common in patients with prostate cancer. Specialist mental and psychological health strategies may be required.

Key Points in Palliative Care of Prostate Cancer Patients

General Comments

- Variable course
- Depression
- Sexual dysfunction
- Bone marrow failure
- Social isolation



Palliative Care of Upper Gastrointestinal Cancer Patients – Stomach and oesophageal

General Comments

Mild and non-specific symptoms often precede the onset of **dysphagia** for many months in oesophageal carcinoma. Stomach cancer often presents late and is frequently advanced at presentation.

Specific pain complexes

- **Liver metastases** often occur and may cause pain. This usually responds well to **Non-steroidal anti-inflammatory drugs (NSAIDs)** or **steroids**. Liver metastases may also lead to hepatomegaly that may cause squashed stomach syndrome with delayed gastric emptying, persistent nausea, occasional vomiting, a loss of appetite and a feeling of fullness. This may respond to a prokinetic agent such as **metoclopramide**.
- **Oesophageal spasm** may occur and can be difficult to manage. Specialist advice should be sought. It may be caused by **oesophageal candidiasis** that needs systemic treatment with **oral imidazole antifungals** such as fluconazole, or itraconazole.
- Involvement of the **coeliac plexus** causes a difficult pain syndrome with non-specific abdominal pain and mid back pain. Blockade of the plexus using **anaesthetic techniques** can be very effective.

Other complications

Dysphagia. Can occur in both oesophageal and stomach cancer. It may be helped by stenting, although the stent itself may cause discomfort. **Oncological treatment** of the tumour may provide temporary relief. Advice about appropriate diet and consistency of the food taken may also help. **Feeding gastrostomies** can improve nutrition and quality of life but can cause ethical dilemmas towards the end of life with regard to continuing nutrition including the volume of feed, its calorie content and the rate of infusion.

Regurgitation of food may occur due to motility problems. Is rarely associated with nausea and can be differentiated from vomiting by the fact it happens passively without retching. Sitting the patient up and using thickened fluids may help. Prokinetics such as **metoclopramide** may help with some patients.

Anorexia is frequent and often profound. There may be a fear of eating because of pain. Rapid satiation is also a problem because of tumour bulk or previous surgery reducing the capacity of the upper GI tract to cope with food. This may bring the patient and their carer into conflict about food and the 'need to eat'. Open and honest explanation can help to relieve anxiety and provide practical approaches to dealing with the situation. This includes discussing using a soft diet, freezing supplement drinks to make lollipop and eating and drinking often.

Altered taste is also common. **Good oral hygiene**, effective treatment of oral candidiasis may help.

Weight loss and altered body image. Can be extreme with these cancers and can cause real problems for the patient and their family.

Nausea and vomiting can be persistent and difficult to control. Specialist advice is often needed and drugs may need to be given subcutaneously. **Small frequent meals** may improve the pattern of vomiting.

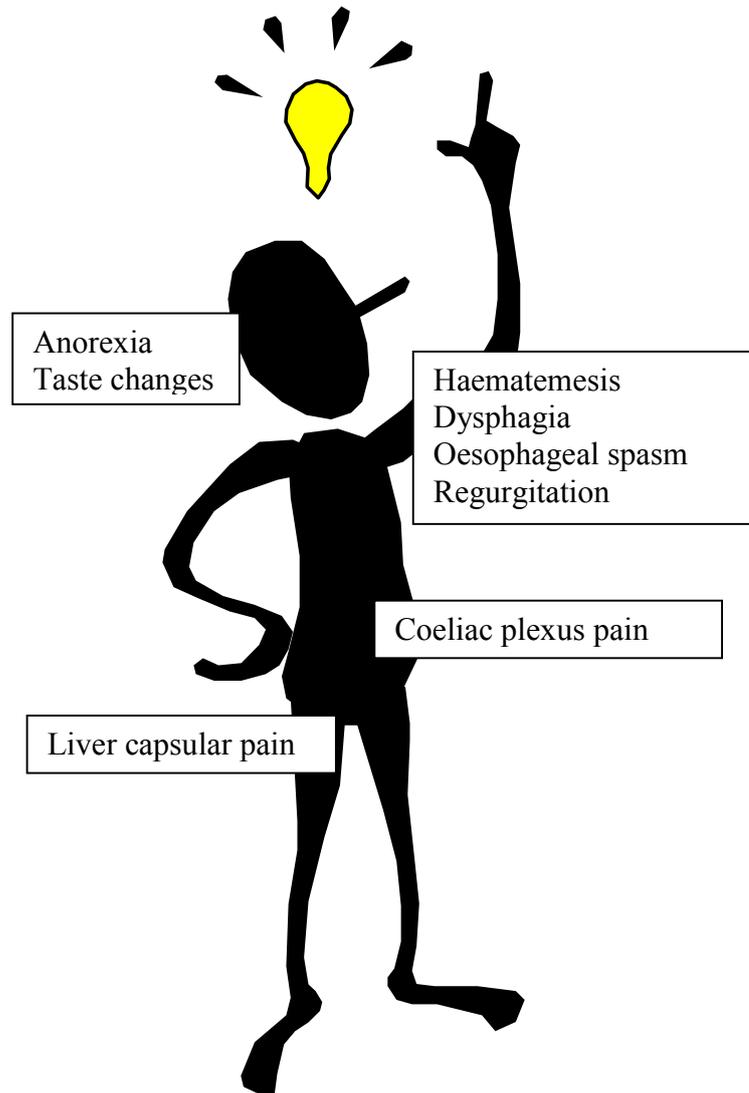
Haematemesis may be one of the presenting symptoms but can also occur as the tumour progresses. Where appropriate, identifying and controlling the bleeding points, either endoscopically or surgically may help. Localised **Brachytherapy** or **laser therapy** to the tumour,

where available, can reduce the incidence. There is risk of a major bleed. This is a difficult situation to manage and early involvement of specialists should be considered.

Key Points in Palliative Care of Upper Gastro-intestinal Cancer Patients

General Comments

- Nausea and vomiting
- Nutrition issues
- Late presentation



Palliative Care of Patients with Carcinomatosis of unknown primary

General comments

In 5% of patients presenting with metastatic cancer the site of origin is never established. Prognosis is generally poor. It is often difficult to anticipate, and advise on, the rate of disease progression and therefore to advise patients and their carers about symptoms and mode of deterioration that might occur.

It can be difficult to know how aggressively to pursue the primary cancer site. Cancers that respond to oncological intervention such as breast, thyroid, lymphoma, ovary and testicular should be considered.

Anxiety is common in this group of patients. Not knowing the site of the primary tumour causes considerable distress. Extensive investigations may raise false expectations and may exhaust the patient. Equally, patients and carers may feel cheated of the chance to have effective treatment if the primary is not looked for.

Carers may find coming to terms with the patient's death difficult and are at greater risk of an adverse bereavement reaction.

All the symptoms of the common cancers should be expected. The site where the cancer was first identified (usually liver, bone or lung) may produce symptoms in line with other cancers.

Key Points

- Anxiety
- Anger
- Risk of over investigation
- Adverse bereavement reaction

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Palliative Care of Patients with End Stage Cardiac Failure

General Comments

The clinical course tends to be very variable, but the end stage is usually characterised by an increasing frequency of **exacerbations of cardiac failure over time with worsening breathlessness and persistent peripheral oedema**. This uncertainty and the profound fatigue experienced in end stage cardiac failure cause considerable distress to patients and their carers. There may be emotional distress in patients and carers because of the link between heart disease and smoking. Patients and health professionals may find it hard to recognise and accept that the terminal phase is approaching, as the patient may have already survived a number of life threatening episodes. Sudden death is not uncommon.

Specific pain complexes

- **Liver capsular pain** due to liver congestion from fluid overload. This is only partially opioid responsive. The pain responds well to **non-steroidal anti-inflammatory drugs** (NSAIDs) **or oral steroids**, but these may worsen cardiac function and so be poorly tolerated.
- **Generalised aches, particularly of limbs** due to impaired circulation. These may vary in location and intensity, are often worse at night, on exertion and when a limb is elevated. They may respond to simple analgesics such as **paracetamol**, but may need **opioid medication**. Follow the analgesic ladder.
- **Ischaemic pain, both cardiac and peripheral** due to impaired circulation. This may respond to regular opioids. For lower limb pain, lumbar sympathectomy may help in some cases.

Other Complications

Breathlessness is common and can be very distressing for patients and carers. Give clear explanations of what is happening. Ensure that practical measures such as sitting the patient up, opening windows and using fans have been considered. Treat reversible causes where possible and appropriate. Consider maximising diuretic and cardiac therapy and treating arrhythmias and underlying chest infections where present. Regular doses of **short acting oral morphine** (2.5 - 5 mg) every 2 - 4 hours may decrease the sensation of breathlessness and can temporarily improve cardiac function. Panic and anxiety are frequently associated with breathlessness and may be helped by **simple relaxation techniques**. A low dose of an **anxiolytic** such as diazepam may be helpful.

Anorexia and altered taste are common. **Good oral hygiene** and effective treatment of oral candidiasis may help. Carers may find it helpful to talk through different ways of encouraging the patient to eat, such as freezing supplement drinks to make lollipops, making small meals frequently etc. **Hepatomegaly** may cause **squashed stomach syndrome** with delayed gastric emptying and a feeling of fullness. This may respond to a prokinetic agent such as **metoclopramide**.

Oedema of the lower limbs and ascites frequently develop. It needs to be actively managed if complications are to be avoided. Management includes good skin care, avoiding additional trauma to the affected leg(s), elevation of the affected limbs, aggressive treatment of superficial infections, and maximising cardiac function.

Renal impairment due to poor perfusion may lead to anorexia, profound fatigue and significant alteration in the handling of renally excreted drugs, particularly opioids.

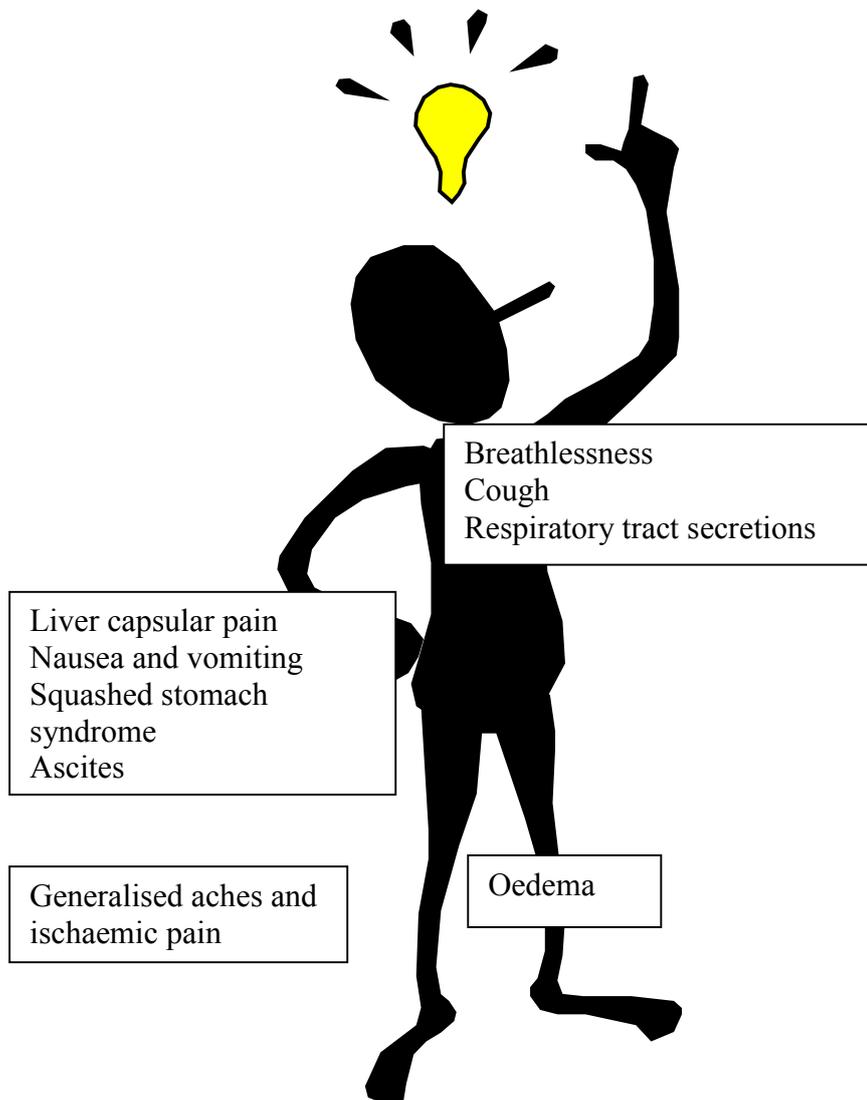
Cough can exacerbate breathlessness and pain; can affect sleep and a patient's ability to eat. Its management will depend on the cause but it is often appropriate to try and suppress the cough pharmacologically using **codeine linctus or morphine**. If not responding to simple measures, refer for specialist assessment.

Nausea and vomiting due to uraemia, hepatic congestion and/or oedema of the bowel may be profound. Specialist advice is often needed and drugs may need to be given subcutaneously. **Small frequent meals** may improve the frequency of vomiting.

Key Points in Palliative Care of End Stage Cardiac Patients

General Comments

- Variable course
- Anorexia/altered taste
- Fatigue
- Anxiety/depression
- Sudden death



Palliative Care of Patients with End Stage Respiratory Disease

General Comments

The clinical course tends to be very variable depending on the underlying cause of the chest disease, but the end stage is usually characterised by an increasing frequency of exacerbations in breathlessness, with or without infection. As the chest disease worsens there is often concurrent heart failure. Uncertainty of prognosis, the profound physical limitation and fatigue experienced by the patient can cause considerable distress to both patient and their carers, which may lead to depression. There may also be emotional distress because of the link with smoking and exposure to some industrial processes. Patients and the professionals involved in their care may find it hard to recognise and accept that the terminal phase is approaching, as the patient may have survived a number of severe exacerbations in the past.

Specific pain complexes

- **Generalised aches** particularly of the chest wall and limbs due to impaired oxygenation and the physical effort of breathing. These may be exacerbated by concurrent medical problems and steroid induced osteoporosis. They may respond to simple analgesics such as **paracetamol**, but may need stronger analgesics, so follow the analgesic ladder.
- **Rib pain** due to rib fracture subsequent to frequent violent coughing episodes. The pain responds well to **non-steroidal anti-inflammatory drugs** (NSAIDs) or **oral steroids**, but these may worsen respiratory function and so be poorly tolerated.
- **Pleuritic pain** may be associated with local infection. This type of pain responds well to **non-steroidal anti-inflammatory drugs** (NSAIDs). It may also be helped by local nerve blockade

Other complications:

Breathlessness is common and can be very distressing for patients and carers. Give clear explanations of what is happening. Ensure that practical measures such as sitting the patient up, opening windows and using fans have been considered. Treat reversible causes such as infection, anaemia and pleural effusion where appropriate. Oxygen therapy should be used with care and under the guidance of a respiratory physician or other specialist. Regular doses of **short acting oral morphine** (2.5 – 5 mg) every 2 - 4 hours may decrease the sensation of breathlessness. Panic and anxiety are frequently associated with breathlessness and may be helped by **simple relaxation techniques**. A low dose of an **anxiolytic** such as diazepam may be helpful.

Cough can exacerbate breathlessness and pain; can affect sleep and a patient's ability to eat. Its management will depend on the cause but it is often appropriate to try and suppress the cough pharmacologically using **codeine linctus or morphine**. If not responding to simple measures refer for specialist assessment.

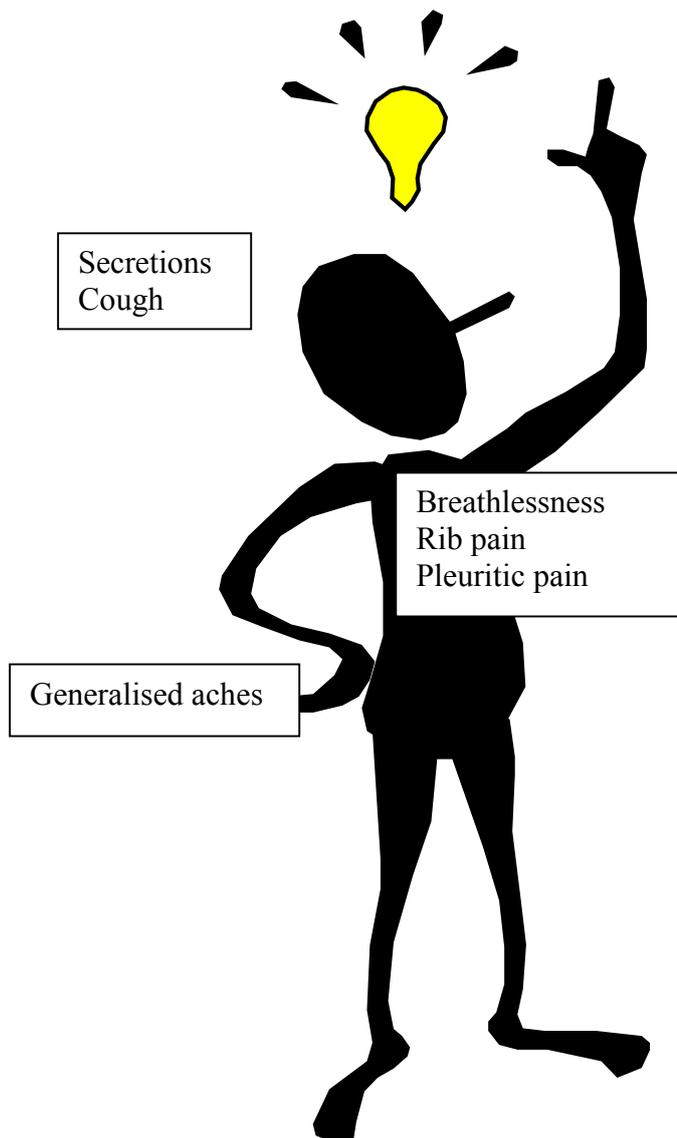
Altered taste and anorexia are common. Severe breathlessness may affect a patient's ability to eat. **Good oral hygiene**, effective treatment of oral candidiasis and management of dry mouth may help. Carers may find it helpful to talk through different ways of encouraging the patient to eat, such as freezing supplement drinks to make lollipops, making small meals frequently etc.

Respiratory tract secretions can be troublesome, particularly as the patient deteriorates. Treating infections with antibiotics can reduce the viscosity of secretions and so relieve distress. **Nebulised normal saline** can moisten airways, making it easier for patients to expectorate sputum/secretions. **Oral mucolytics** can sometimes help.

Key points in Palliative Care of End Stage Respiratory Patients

General Comments

- Variable course
- Anorexia
- Fatigue
- Anxiety/depression



Palliative Care of Patients with end stage renal disease

General Comments

The general course can be very variable depending on the underlying pathology of the renal disease. Issues around renal transplantation and effectiveness of continued dialysis may complicate the approach to palliation of end stage renal disease. The frequency of hospital visits and dependency on the healthcare system, as well as the profound fatigue and anorexia most patients experience, may lead to significant clinical depression. As many drugs are excreted by the kidney, problems with drug toxicity are complex, and the risk/benefit ratio may be hard to determine in some cases. The patient and their carers are often well known to the healthcare team, which can add to the distress and difficulties for the team in recognising the terminal phase. It is easy for patients and carers to feel abandoned if active management of their renal failure is suddenly stopped. Sudden death is not uncommon due to electrolyte imbalances inducing cardiac arrhythmias.

Specific pain syndromes

- **Joint and bone pain** is common and can be difficult to manage. The pain may respond to NSAIDs but these may adversely affect renal function, thus exacerbating other symptoms. The pain may also respond to step 2 and/or step 3 analgesics, but these drugs are often renally excreted, making the risk of adverse side effects and toxicity higher.

Other Complications:

Profound fatigue as renal function deteriorates can markedly affect quality of life. Advice about adaptations in the house, and other approaches to saving energy, such as having a bed downstairs and the use of commodes can be helpful.

Oedema of limbs and ascites may develop. This needs to be actively managed if complications are to be avoided. Management includes good skin care, avoiding additional trauma to the affected leg(s), elevation of the affected limbs, aggressive treatment of superficial infections, and maximising cardiac function.

Weight loss and altered body image. Can be profound and can cause real problems for the patient and their family, particularly as anorexia may make meal times a real battle between patient and carers. The strict renal diet most patients follow when having dialysis can also cause conflict in the terminal phase. There is a fine balance between maintaining electrolyte balance and being able to enjoy food and have a reasonable quality of life.

Altered taste and anorexia are common. **Good oral hygiene** and management of dry mouth may help. Carers may find it helpful to talk through different ways of encouraging the patient to eat, such as freezing supplement drinks to make lollipops, making small meals frequently etc

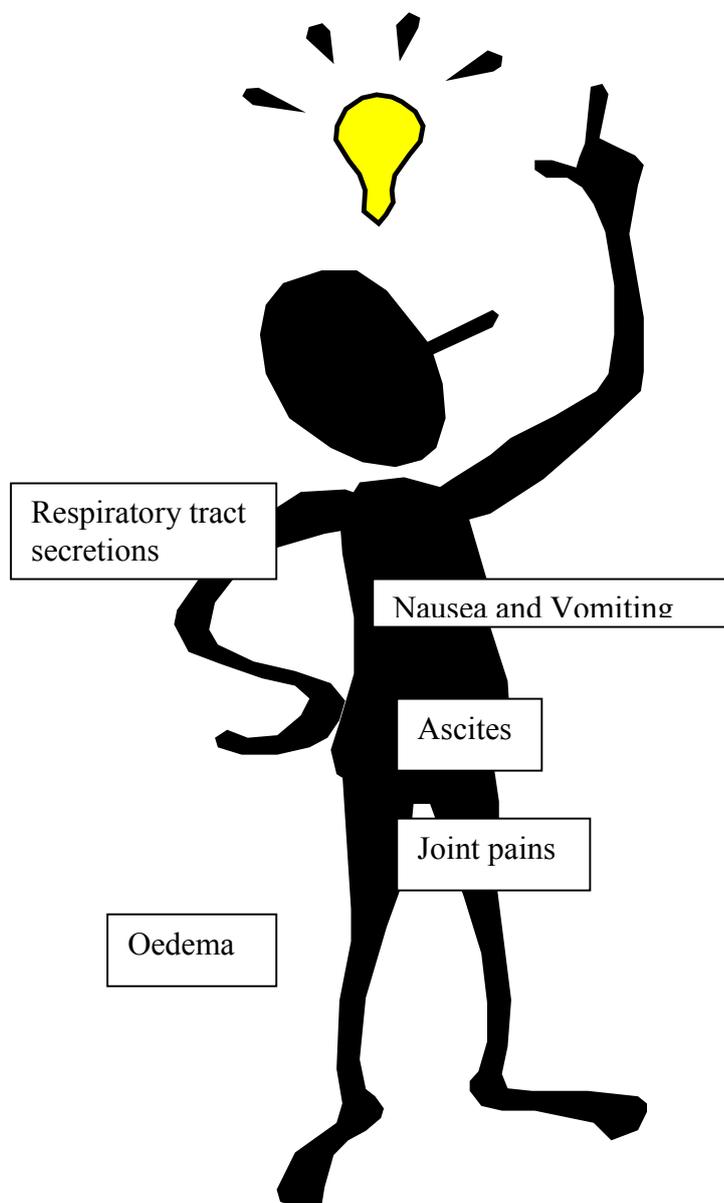
Nausea and vomiting can be persistent and difficult to control. Specialist advice is often needed and drugs may need to be given subcutaneously. **Small frequent meals** may improve the pattern of vomiting.

Respiratory tract secretions can be troublesome, particularly as the patient deteriorates. Treating infections with antibiotics can reduce the viscosity of secretions and so relieve distress. **Nebulised normal saline** can moisten airways, making it easier for patients to expectorate sputum/secretions. **Oral mucolytics** can sometimes help.

Key points in Palliative Care of End Stage Renal Disease

General Comments

- Variable course
- Ethical Dilemmas
- Fatigue
- Anorexia
- Altered body image



Palliative Care of Patients with End Stage Cerebro-vascular Disease

General Comments

The clinical course tends to be very variable, but the end stage is usually characterised by increasing drowsiness, deteriorating physical and mental function and further strokes. The time frame can be highly variable. This uncertainty and the profound fatigue experienced by both patients and their carers' causes considerable distress. Patients, their families and the professionals involved in their care may find it hard to recognise and accept that a patient is entering the terminal phase, as the patient may have survived a number of life threatening cerebral episodes previously. Sudden death is common.

Specific pain complexes

- **Generalised aches, particularly of limbs** due to impaired circulation and immobility. These may vary in location and intensity, are often worse at night, on exertion and when a limb is moved. They may respond to simple analgesics such as **paracetamol**, but may need **opioids** in some cases. Follow the analgesic ladder.
- **Headaches** are often multifactorial and can be difficult to control. Follow the analgesic ladder. If there is evidence of hydrocephalus, neuro-surgical referral for a shunt may be appropriate.
- **Ischaemic pain, both cardiac and peripheral** due to impaired circulation. This may respond to regular opioids. For lower limb pain, lumbar sympathectomy may help in some cases.
- **Meningeal irritation** can occur after multiple strokes and this may produce photophobia as well as neck stiffness. This may respond to **NSAIDs and/or oral steroids**.

Other complications

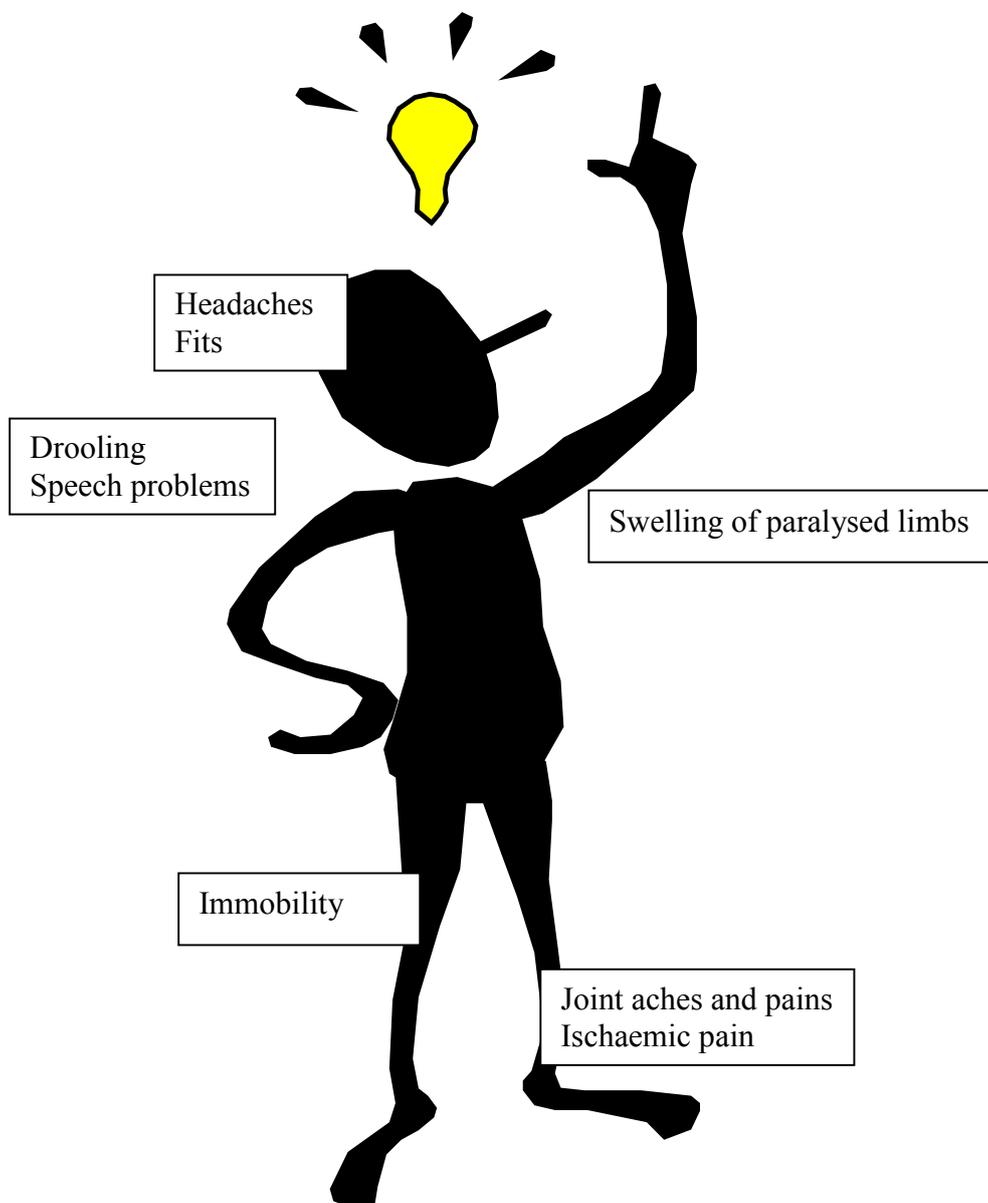
- **Dysphagia** due to damage in the neural mechanisms that control swallowing often means that feeding gastrostomies are needed to maintain nutrition and aid with the administration of medication as the oral route may not be available. There may be ethical dilemmas towards the end of life particularly with regard to the administration of feeds in the last days of life.
- **Difficulties with articulation and speech production** are common. The quality of the voice may change significantly and make the patient self-conscious. Difficulty swallowing saliva may make **drooling** a problem. All these problems need the regular input of specialist **speech and language therapists**. **Communication aids** may be needed to enable a patient to express their needs and preferences.
- **Disability** with impaired mobility, incontinence and personality changes mean that patients often need intensive **multi-disciplinary support** and **rehabilitation for a period of time**
- **Constipation** is not uncommon due to immobility and poor diet. This can lead to overflow diarrhoea in some individuals. Regular oral laxatives and in some cases regular rectal laxatives may be needed.
- **Altered body shape**, due to paralysis and subsequent immobility can lead to troublesome weight gain.
- **Epileptic fits** are common, but not universal. They may be difficult to manage and advice from neurologists may be needed to ensure adequate control using **anti-convulsant medication**.
- **Social and psychological issues** are common. Many patients undergo personality and behaviour changes after their strokes which can cause considerable stress to carers, especially if the patient becomes aggressive or dis-inhibited.

- **Depression** is a common feature. Relationship problems are not uncommon. Patients often become **socially isolated** as they feel different and become reluctant to go out.
- **Swelling** of paralysed limbs. Management includes good skin care, avoiding additional trauma to the affected limb(s), elevation of the affected limbs, aggressive treatment of superficial infections, and maximising function where possible.

Key points in Palliative Care of End Stage Cerebro-vascular Disease

General Comments

- Variable course
- Ethical Dilemmas
- Fatigue
- Altered body image
- Depression



Palliative Care of Patients with End Stage Dementia

General Comments

The clinical course can be very variable as dementia is a clinical syndrome rather than a specific disease. It can be difficult to recognise the end stage of the process, but it is usually characterised by an increasing reluctance to eat or drink, growing fatigue, increased susceptibility to infection, worsening cognitive function and deterioration in physical capabilities. The severe cognitive impairment suffered by patients makes assessment difficult, which may result in the under-treatment of symptoms such as pain. Careful assessment, using specific tools designed to be used with cognitively impaired patients, is key to effective symptomatic control such as the Abbey pain scale. Issues around hydration and nutrition may complicate the approach to palliation in end stage dementia. Families and carers are frequently exhausted by the long course of deterioration and may find it hard to recognise when to stop seeking active treatment for their loved one. Discussions around avoiding inappropriate and distressing hospital admissions need to be handled with sensitivity.

Mental Capacity Act (2005) is underpinned by 5 key principles: a presumption of capacity, support for individuals to make decisions for themselves when they can, the right to make decisions that may seem eccentric or unwise to others, patients rights and freedoms must be restricted as little as possible and that all acts done or decisions made on behalf of a person must be in their best interests. Some people with dementia may retain some capacity and it is not acceptable that a person lacks capacity based on their diagnosis, age or behaviour alone. Many patients with dementia will lack capacity because they cannot understand, retain, use and weigh information sufficiently to make a decision about their care. It is essential to ensure that a person has been enabled to communicate their wishes by any appropriate means available.

When a person is deemed as lacking capacity then carers must act in the person's best interests, taking into account past wishes, relevant written statements, the person's beliefs and values. All decisions about care should be taken in a multi professional setting, with the family and carers fully engaged at every point. Ultimately the care team must act in the best interests of the patient, balancing the risk/benefit of any decision made. If there is conflict with the family about what is in the patient's best interests legal advice may be needed. (For further information see guidance on Mental Capacity Act)

Specific pain issues

- **Limb contractures or muscle spasm** may occur, particularly if there is loss of muscle tone which requires that the patient be nursed in bed. Such pain is evident on movement, and can be treated with a mixture of **analgesics (following the analgesic ladder) and anti-spasmodics**. If oral medication cannot be tolerated or maintained, medication can be given rectally, transdermally or subcutaneously.
- **Generalised aches** due to lack of movement and general debility. These may vary in intensity and are often worse on waking. They may respond to simple analgesics such as **paracetamol**, but may need weak **opioids** in some cases. Follow the analgesic ladder.

Other Complications

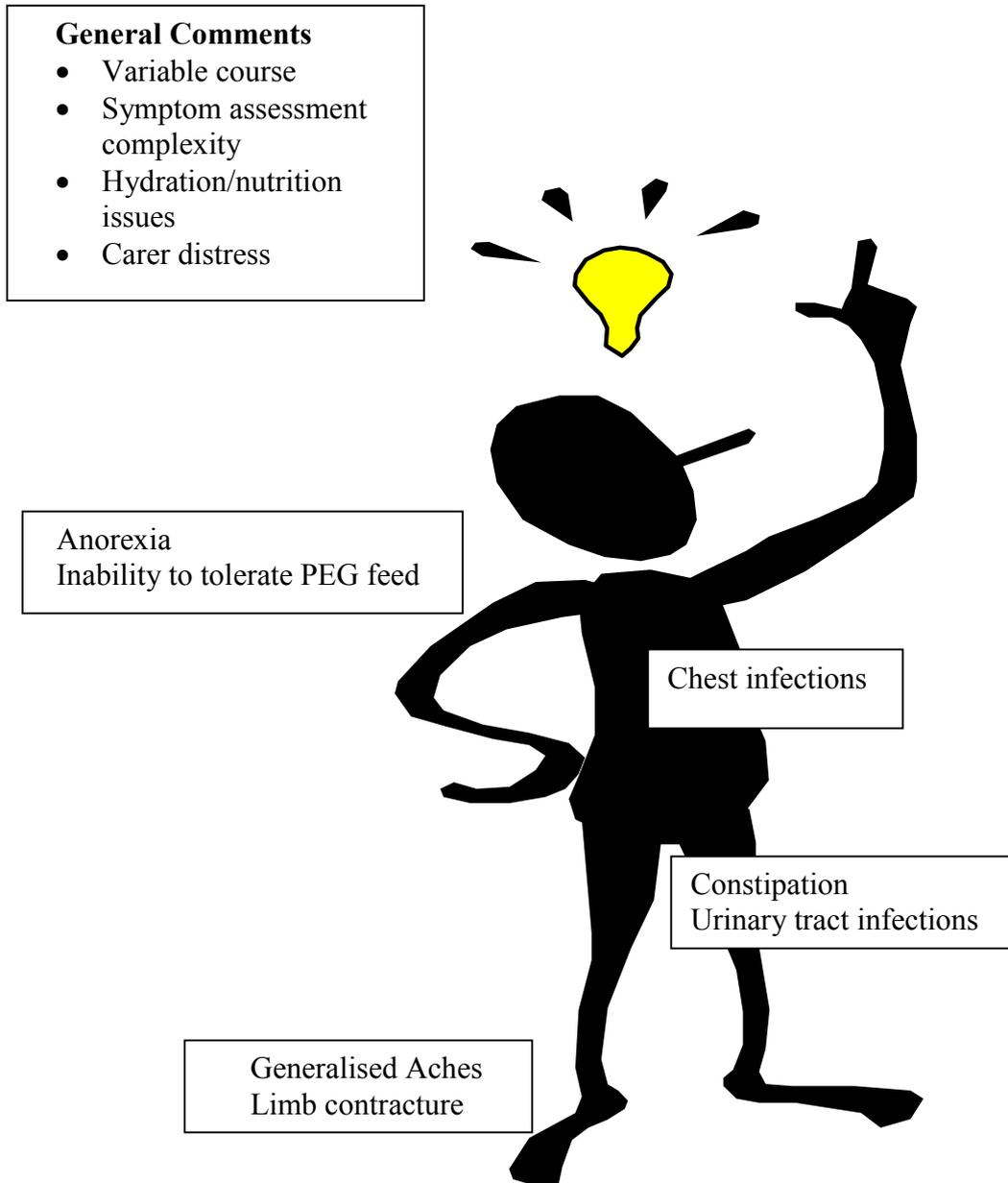
Anorexia and dehydration occur as the patient increasingly declines oral input. **Good oral hygiene** can help and patients will often tolerate crushed ice, especially if it is flavoured with a preferred taste. Relatives and carers can be encouraged to offer small amounts of easily ingested foods such as chocolate mousse. Many dementia patients have a preference for sweet foods.

Increased agitation may be symptomatic of pain or discomfort. Careful assessment of physical status should be undertaken to exclude a treatable cause. Agitation can be treated with an **anti-psychotic** such as **haloperidol**. Should the problem persist seek specialist advice.

Pressure sores can occur due to incontinence, lack of voluntary movement, and increased frailty, poor diet and incontinence. Muscle spasm and a patient's inability to comply with change of position can further compound the problem. Referral to the **specialist tissue viability** services is advised.

Constipation due to poor nutrition and hydration, and lack of movement is common. If constipation is a recurrent problem **laxatives** containing both a **stool softener** and **bowel stimulant** should be available for regular usage.

Key Points in Palliative Care of End Stage Dementia Patients



Palliative Care of Patients with End Stage Motor Neurone Disease.

General Comments

Motor neurone disease is a relatively uncommon neurological condition which can affect adults from their early 20s to the 70s. In the majority of cases it is relentlessly progressive with a prognosis of two years or less from the point of diagnosis. Diagnosis can be difficult as the initial presentation can be subtle. Patient and carers may feel that there has been a delay in diagnosis which may add to their emotional distress. There is no effective treatment available although Riluzole may slow its progression. There are two main forms of presentation. One type presents with mainly bulbar motor problems such as dysphagia, aspiration and/or poor speech articulation. The second type presents with motor problems in the distal limbs either arms or legs. The initial problem may be a foot drop, loss of grip strength, change in handwriting or difficulty the leg giving way. In both cases the presenting problems progress with other muscle groups becoming involved. Visible muscle fasciculation usually develops late. The end stages are characterised by increasing fatigue, profound muscle weakness including the respiratory muscles, profound cachexia, loss of appetite and increasing drowsiness.

From the point of diagnosis it is essential to ensure access to appropriate equipment to help the patient can remain as independent as possible for as long as possible. Timing the introduction of equipment can be difficult as patients may not wish to be reminded that they will inevitably deteriorate at some point, but using equipment early is important because time is short and it may help to maintain function for longer.

There are a number of **ethical dilemmas** that arise at the end of life. These include the use of **feeding tubes** as the ability to swallow fails, (or swallow safely), and the role of **non invasive ventilation** when respiratory muscles start to fail.

Specific pain complexes

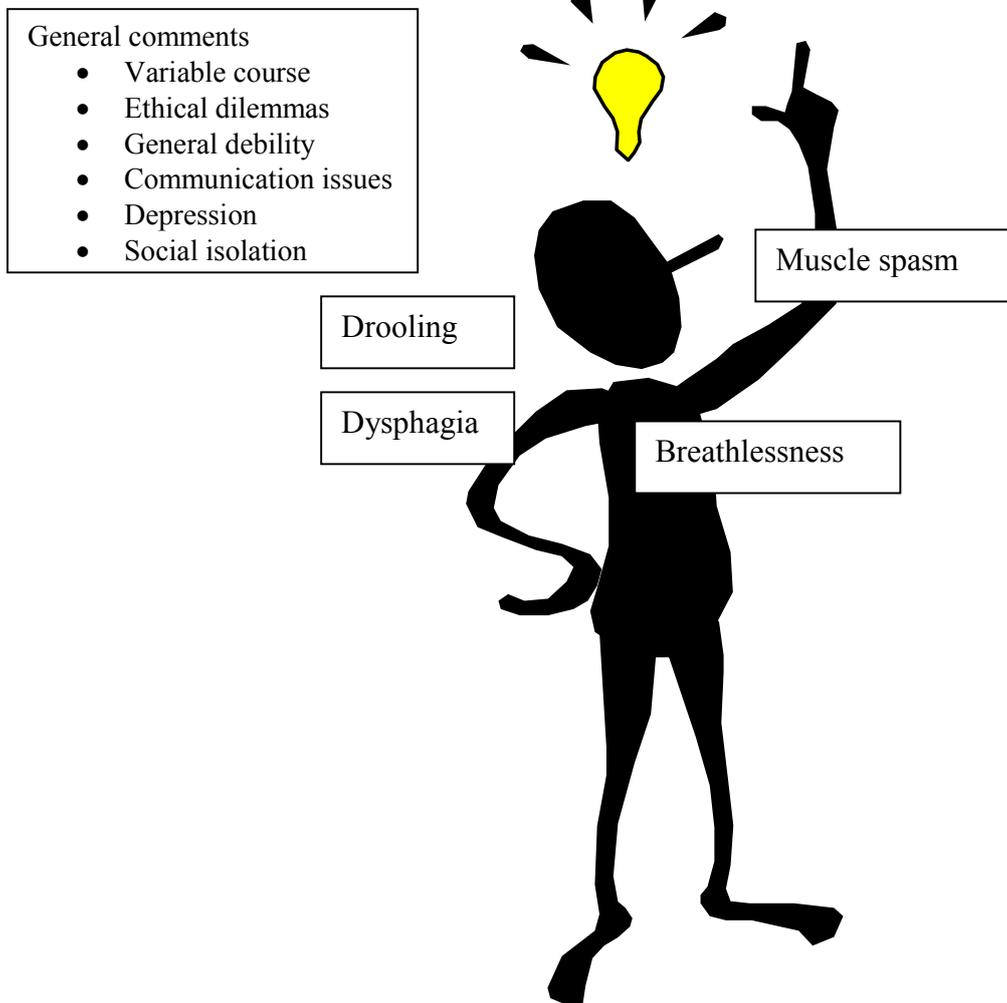
- **Muscle spasm** may occur. Such pain may be worse on movement and may be difficult to treat. It can be treated with a mixture of **analgesics (following the analgesic ladder) and anti-spasmodics**. If oral medication cannot be tolerated or maintained, medication can be given rectally, transdermally or subcutaneously.
- **Generalised aches** due to lack of movement and general debility. These may vary in intensity and are often worse on waking. They may respond to simple analgesics such as **paracetamol**, but may need weak **opioids** in some cases. Follow the analgesic ladder.

Other Complications

- **Breathlessness** is common due to respiratory muscle weakness and can be very distressing for patients and carers. Give clear explanations of what is happening. There is often a fear that the person may choke to death or literally be unable to take their next breath. Ensure that practical measures such as sitting the patient up, opening windows and using fans have been considered. Treat reversible causes such as infection where appropriate. Oxygen therapy should be used with care and under the guidance of a respiratory physician or other specialist. Regular doses of **short acting oral morphine** (2.5 – 5 mg) every 2 - 4 hours may decrease the sensation of breathlessness. Panic and anxiety are frequently associated with breathlessness and may be helped by **simple relaxation techniques**. A low dose of an **anxiolytic** such as diazepam may be helpful. In some cases, especially if respiratory muscles fail early in the disease course **non-invasive ventilation** (NIPPV) may be appropriate.
- **General debility** due to progressive muscle weakness is severe. Patients often have major problems with sitting posture. A particular problem occurs with the neck, with patients losing the ability to hold up their heads. Often they are unable to wear a neck support making feeding and communication even more difficult.

- **Dysphagia** due to muscle weakness and inco-ordination of the swallow reflex means that patients may struggle to maintain an adequate nutritional intake. In addition there is a high risk of **aspiration** in some patients. **Feeding gastrostomies** may be needed to maintain nutrition especially as these patients have a high metabolic rate and so lose weight quickly exacerbating the muscle wasting. They may also aid with the administration of medication. There may be ethical dilemmas towards the end of life particularly with regard to the administration of feeds in the last days of life.
- **Difficulties with articulation and speech production** are common. The quality of the voice may change significantly and make the patient self-conscious. Difficulty swallowing saliva may make **drooling** a problem. Specialist advice may be needed. For some local **botox injections** into the salivary glands may be helpful. All these problems need the regular input of specialist **speech and language therapists**. **Communication aids** may be needed to enable a patient to express their needs and preferences.
- **Depression** is a common feature as inevitable progression of muscle weakness robs the patient of their ability to function whilst their mental capabilities remain unaffected. Relationship problems are not uncommon. Patients often become **socially isolated**.

Key Points in Palliative Care of End Stage Motor Neurone Disease



Palliative Care of Patients with end stage Multiple Sclerosis

General Comments

Multiple sclerosis is a relatively common neurological condition which has a highly variable relapsing and remitting course over many years. The diagnosis can be hard to make as the presentation is variable and often subtle. Common presenting symptoms include persistent numbness and tingling in the distribution of a nerve, temporary loss of vision, intermittent weakness of a limb often in the early thirties. For many patients the course is fairly slow with function being well maintained over many years. For others the course is more aggressive with rapid loss of function in a matter of a few years. It often affects younger adults who may have young families creating complex social problems.

Recognising the end stages of MS is very difficult. Patients can survive for many years even when bed bound and quadriplegic, but it is usually characterised by increased susceptibility to infection, worsening cognitive function and deterioration in any remaining physical capabilities. The severe cognitive impairment suffered by most patients makes assessment difficult, which may result in the under-treatment of symptoms such as pain. Careful assessment, using specific tools designed to be used with cognitively impaired patients, is key to effective symptomatic control. Final illness may some form of infection such as a chest infection or urinary tract infection.

Issues around appropriate treatment of infections, hydration and nutrition may complicate the approach to palliation in end stage. Families and carers are frequently exhausted by the long course of deterioration and may find it hard to recognise when to stop seeking active treatment for their loved one. Discussions around avoiding inappropriate and distressing hospital admissions need to be handled with sensitivity.

Specific pain complexes

- **Muscle spasm** may occur. Such pain may be worse on movement and may be difficult to treat. It can be treated with a mixture of **analgesics (following the analgesic ladder) and anti-spasmodics**. If oral medication cannot be tolerated or maintained, medication can be given rectally, transdermally or subcutaneously.
- **Generalised aches** due to lack of movement and general debility. These may vary in intensity and are often worse on waking. They may respond to simple analgesics such as **paracetamol**, but may need weak **opioids** in some cases. Follow the analgesic ladder.
- **Neuropathic pain** may occur especially in the limbs. They may require regular **neuropathic pain agents**.

Other Complications

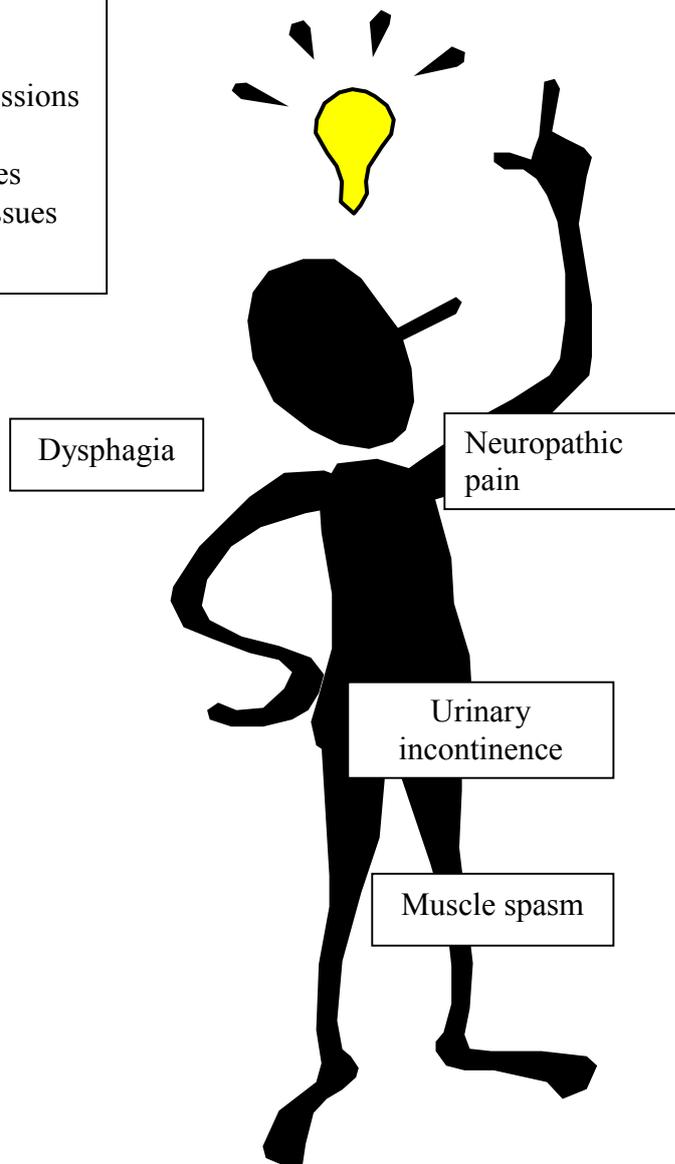
- **Dysphagia** due to damage in the neural mechanisms that control swallowing often means that feeding gastrostomies are needed to maintain nutrition and aid with the administration of medication as the oral route may not be available. There may be ethical dilemmas towards the end of life particularly with regard to the administration of feeds in the last days of life.
- **Difficulties with articulation and speech** are common. **Communication aids** may be needed to enable a patient to express their needs and preferences.
- **Urinary incontinence** is common as are problems with long-term indwelling catheters.
- **Constipation** is not uncommon due to immobility and poor diet. This can lead to overflow diarrhoea in some individuals. Regular oral laxatives and in some cases regular rectal laxatives may be needed.

- **Severe disability** and urinary incontinence make patients at high risk of pressure sores. Muscle spasm and a patient's inability to comply with change of position can further compound the problem. Referral to the **specialist tissue viability** services is advised.
- **Personality changes** and **cognitive impairment** mean that patients may be unable to take part in decision making. It is important therefore that the patient's known wishes via an **advanced statement to refuse treatment** should be taken into account if available. All decisions about care should be taken in a multi professional setting, with the family and carers fully engaged at every point. Ultimately the care team must act in the best interests of the patient, balancing the risk/benefit of any decision made. If there is conflict with the family about what is in the patient's best interests legal advice may be needed.

Key Points in Palliative Care of End Stage Multiple Sclerosis

General Comments

- Variable course
- Relapses and remissions
- Severe disability
- Personality changes
- Communication issues
- Feeding issues



Palliative Care of Patients with End Stage Parkinson's Disease

General Comments

Parkinson's disease is a slowly progressive, degenerative disease of the basal ganglia, producing an akinetic-rigid syndrome, usually with a resting tremor and accompanied by many other motor disturbances including a flexed posture, a shuffling gait and defective balance. It tends to be a disease of old age. It is relatively easy to diagnose in most patients, usually presenting with tremor, mask like face, rigidity, small spidery handwriting and shuffling gait. Treatment with levodopa relieves symptoms and prolongs life. Over time resistance to levodopa increases leading to the need for escalating doses. Recognising the end stage of the disease can be difficult, but is usually associated with a lack of response to drugs, increasing fatigue, increasing problems with balance and prolonged episodes of freezing. Final illness may some form of infection such as a chest infection or urinary tract infection.

Specific pain complexes

- **Muscle spasm** may occur. Such pain may be worse on movement and may be difficult to treat. It can be treated with a mixture of **analgesics (following the analgesic ladder) and anti-spasmodics**. If oral medication cannot be tolerated or maintained, medication can be given rectally, transdermally or subcutaneously.
- **Generalised aches** due to lack of movement and general debility. These may vary in intensity and are often worse on waking. They may respond to simple analgesics such as **paracetamol**, but may need weak **opioids** in some cases. Follow the analgesic ladder.

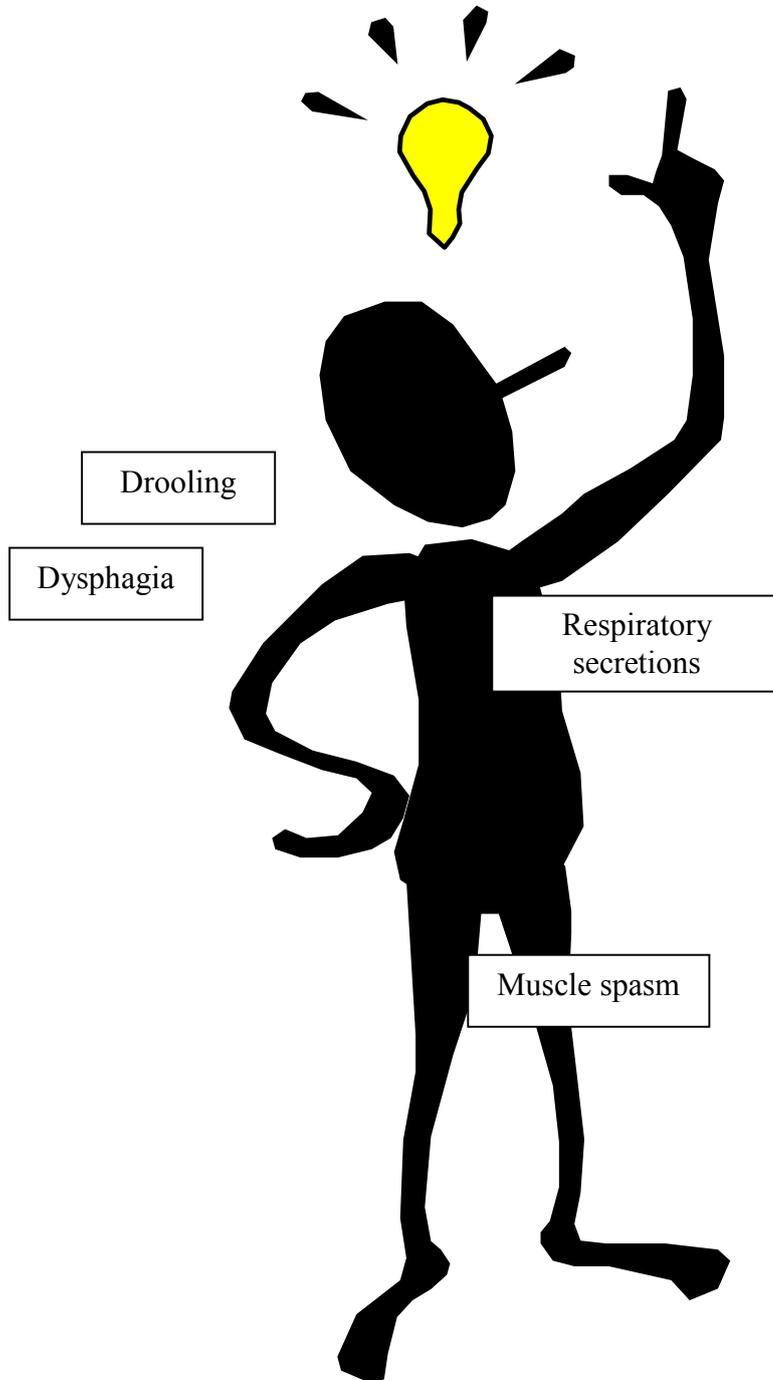
Other complications

- **Dysphagia** due to muscle weakness and inco-ordination of the swallow reflex means that patients may struggle to maintain an adequate nutritional intake. In addition there is a high risk of **aspiration** in some patients. **Feeding gastrostomies** may be needed to maintain nutrition especially as these patients have a high metabolic rate and so lose weight quickly exacerbating the muscle wasting. They may also aid with the administration of medication. There may be ethical dilemmas towards the end of life particularly with regard to the administration of feeds in the last days of life.
- **Difficulties with articulation and speech production** are common. The quality of the voice may change significantly and make the patient self-conscious. Difficulty swallowing saliva may make **drooling** a problem. Specialist advice may be needed. For some local **botox injections** into the salivary glands may be helpful. All these problems need the regular input of specialist **speech and language therapists**. **Communication aids** may be needed to enable a patient to express their needs and preferences.
- **Depression** is a common feature as inevitable progression of muscle weakness robs the patient of their ability to function whilst their mental capabilities remain unaffected.
- **Postural hypotension and poor righting mechanism** can lead to recurrent falls, leading to an increase risk of fractures and further debility.
- **Respiratory tract secretions** can be troublesome particularly as the patient deteriorates. Treating infections with antibiotics can reduce the viscosity of secretions and so relieve distress. **Nebulised normal saline** can moisten airways, making it easier for patients to expectorate sputum/secretions. **Oral mucolytics** can sometimes help.
- **Profound fatigue and freezing episodes** can make caring for patients very difficult and distressing. Specialist advice may be needed to help with moving and handling.

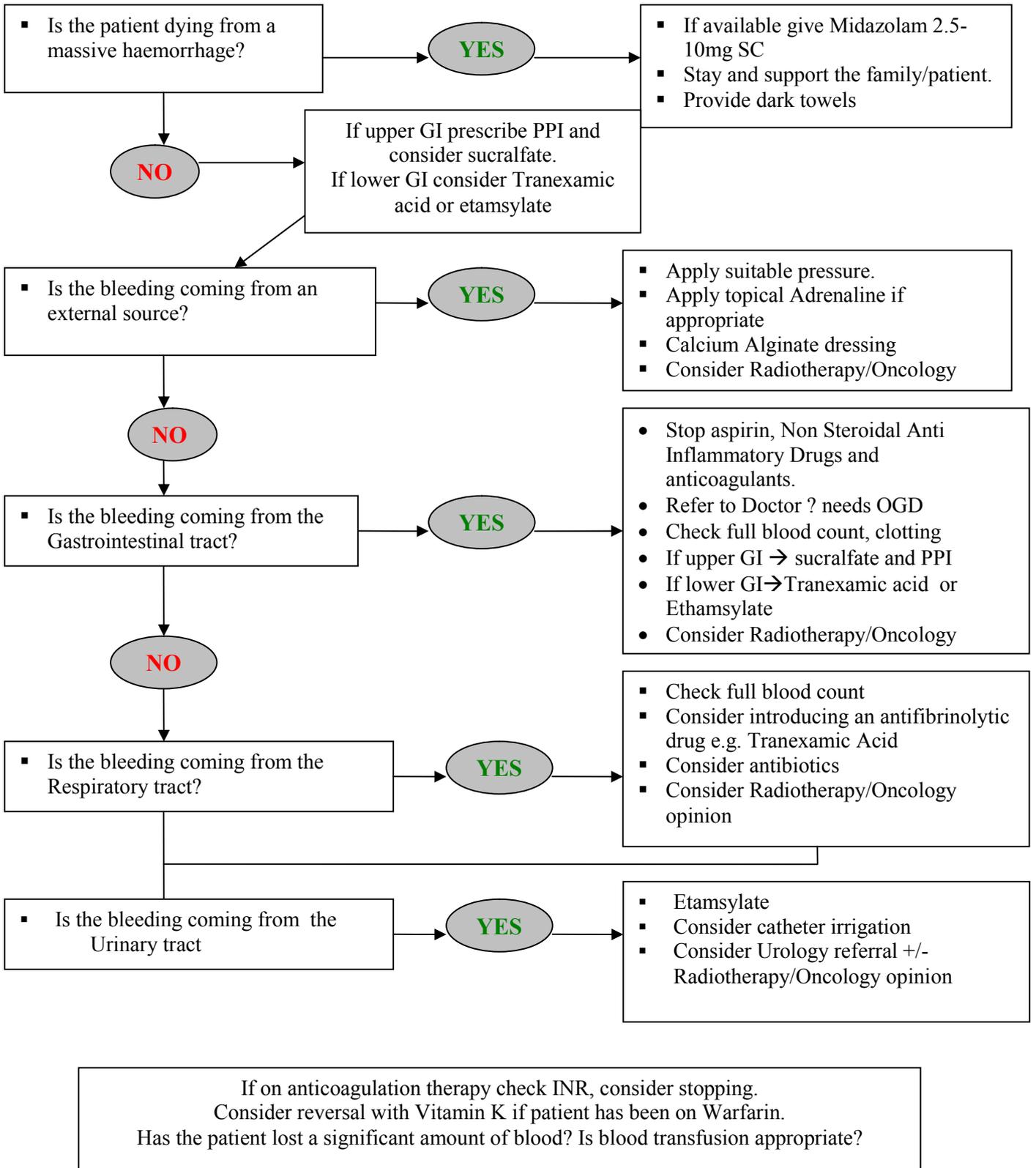
Key Points in Palliative Care of End Stage of Parkinson's Disease

General Comments

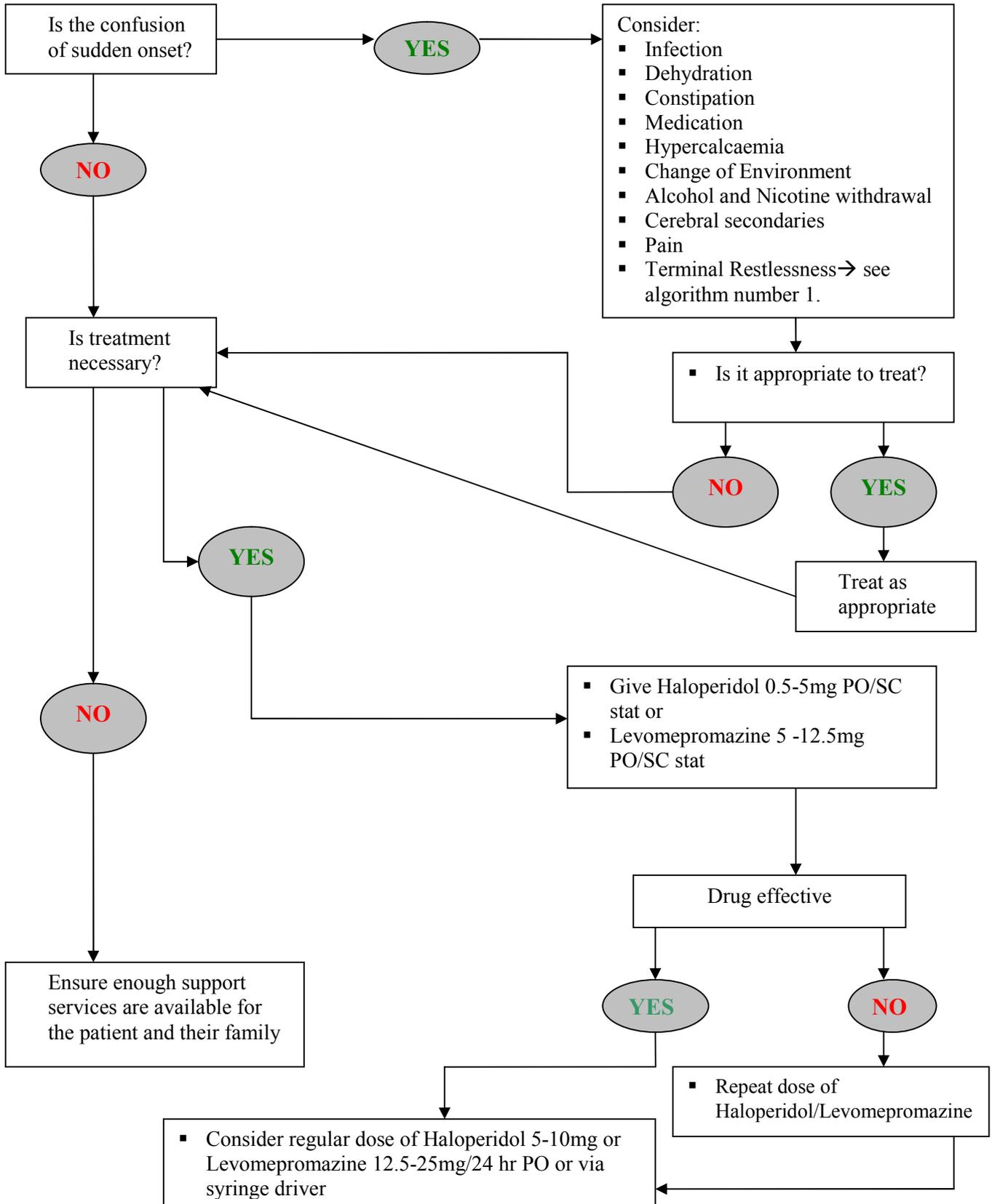
- Variable course
- Fatigue
- Communication difficulties
- Depression
- Postural hypotension



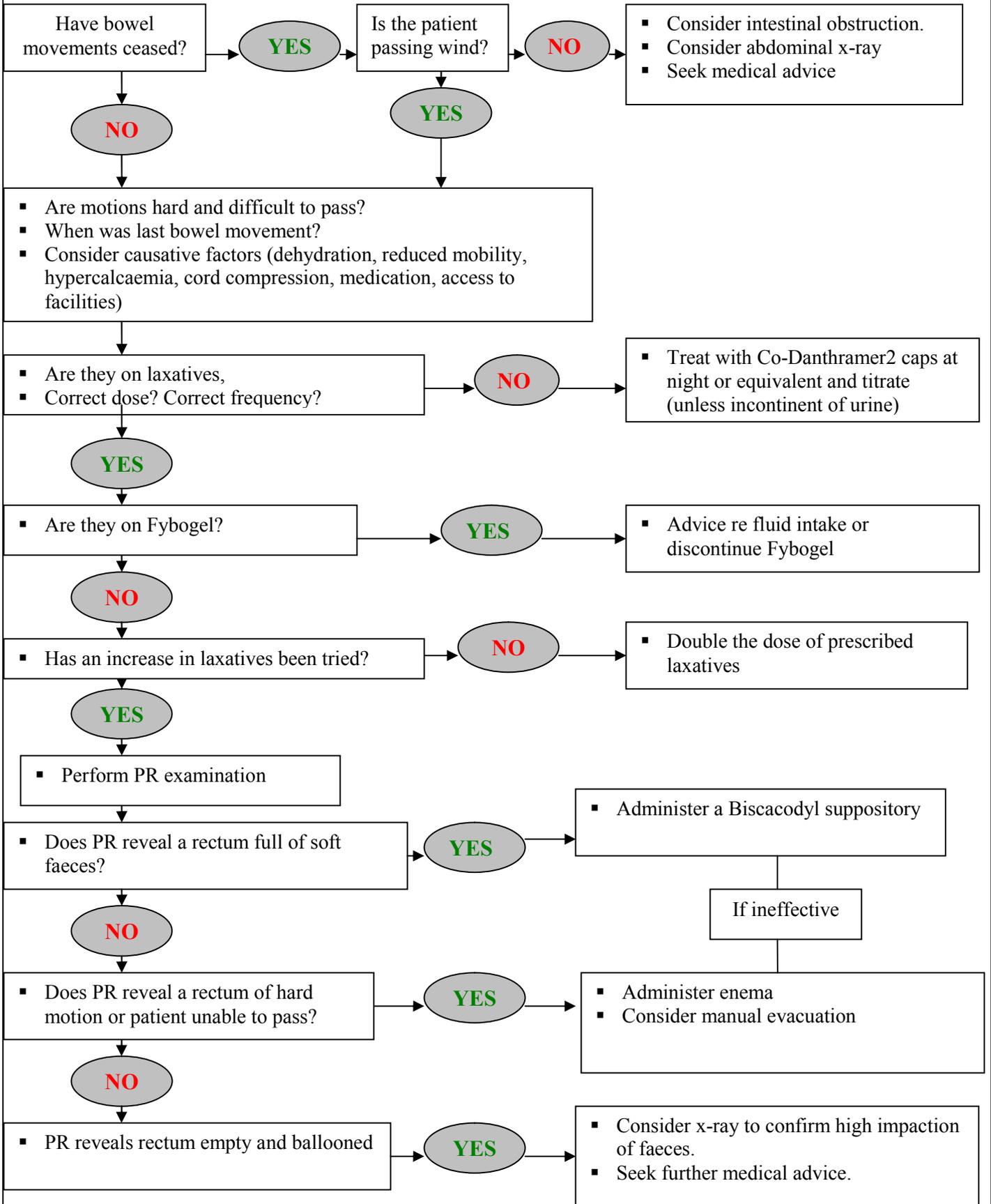
BLEEDING/HAEMORRHAGE



CONFUSION



CONSTIPATION AND BOWEL OBSTRUCTION



CONSTIPATION : ADDITIONAL CONSIDERATIONS

What is normal for the patient?

Severity of symptoms:

- Altered sensation – consider spinal cord compression
- Nausea and vomiting – consider gastrointestinal obstruction
- Presence of blood and/or mucus in faeces – may require medical review

Is there a reversible underlying cause?

- Has **hypercalcaemia** been excluded?
- Consider whether switching to an alternative opioid analgesic may help
- Treat reversible causes if possible

Which laxatives have already been tried?

- Has the patient been taking them regularly?
- Did they help?
- Were there any adverse effects?

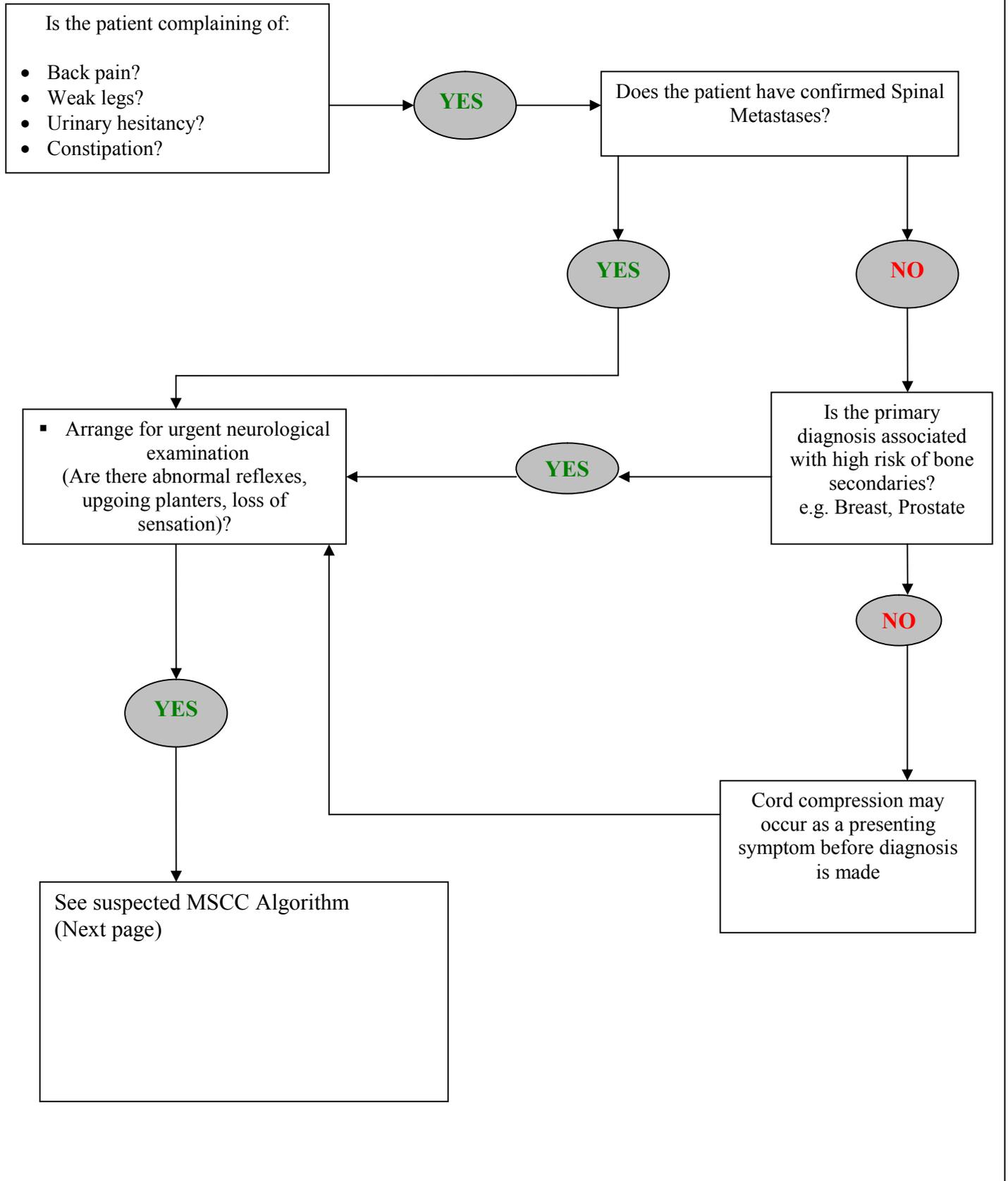
Does the patient have any suitable laxatives available to them?

Remember non-drug measures:

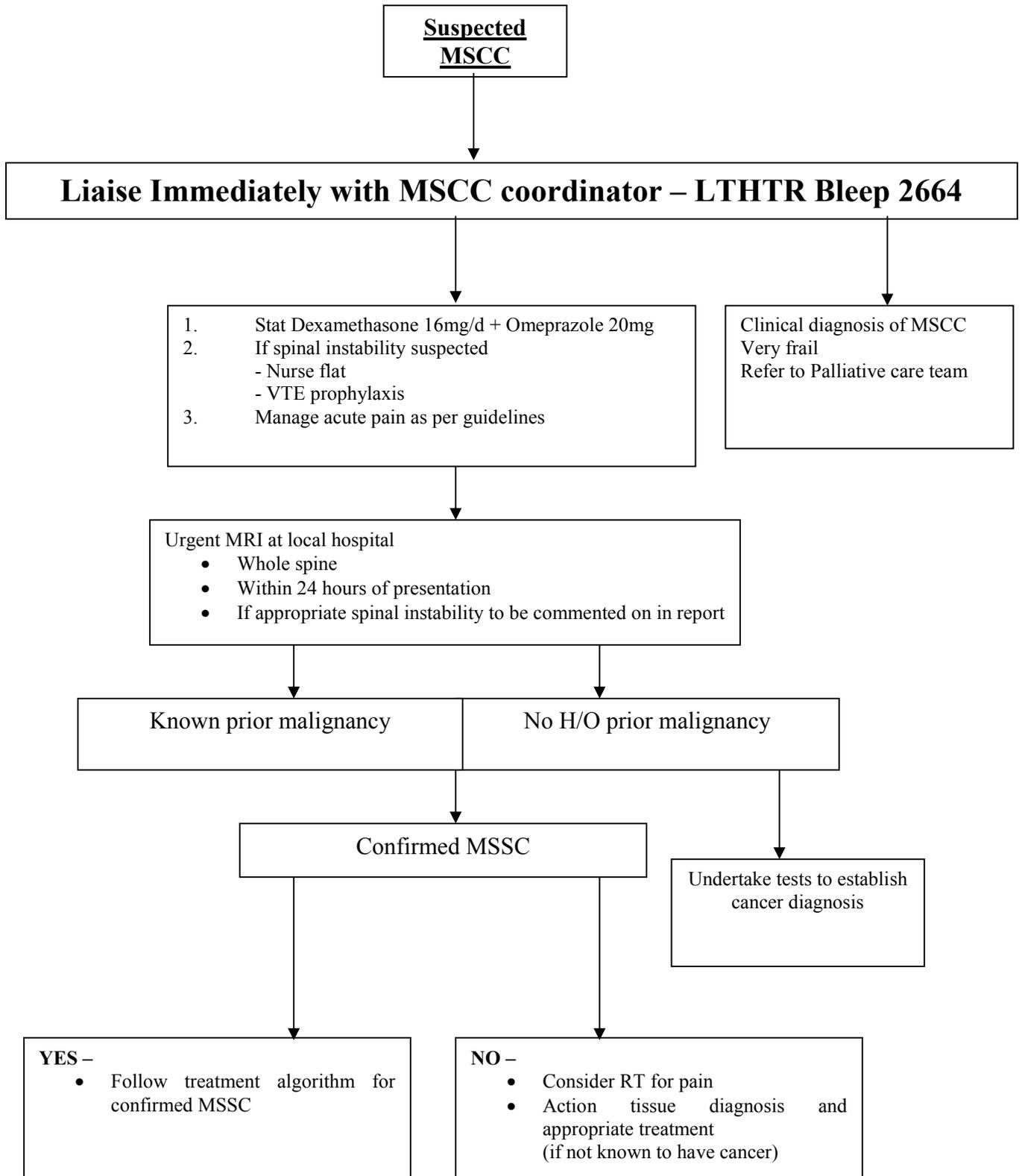
- Drink plenty
- Increase mobility
- Eat plenty of fibre (as long as fluid intake is good)

Aim for regular, easy bowel action, minimum every 3 days.

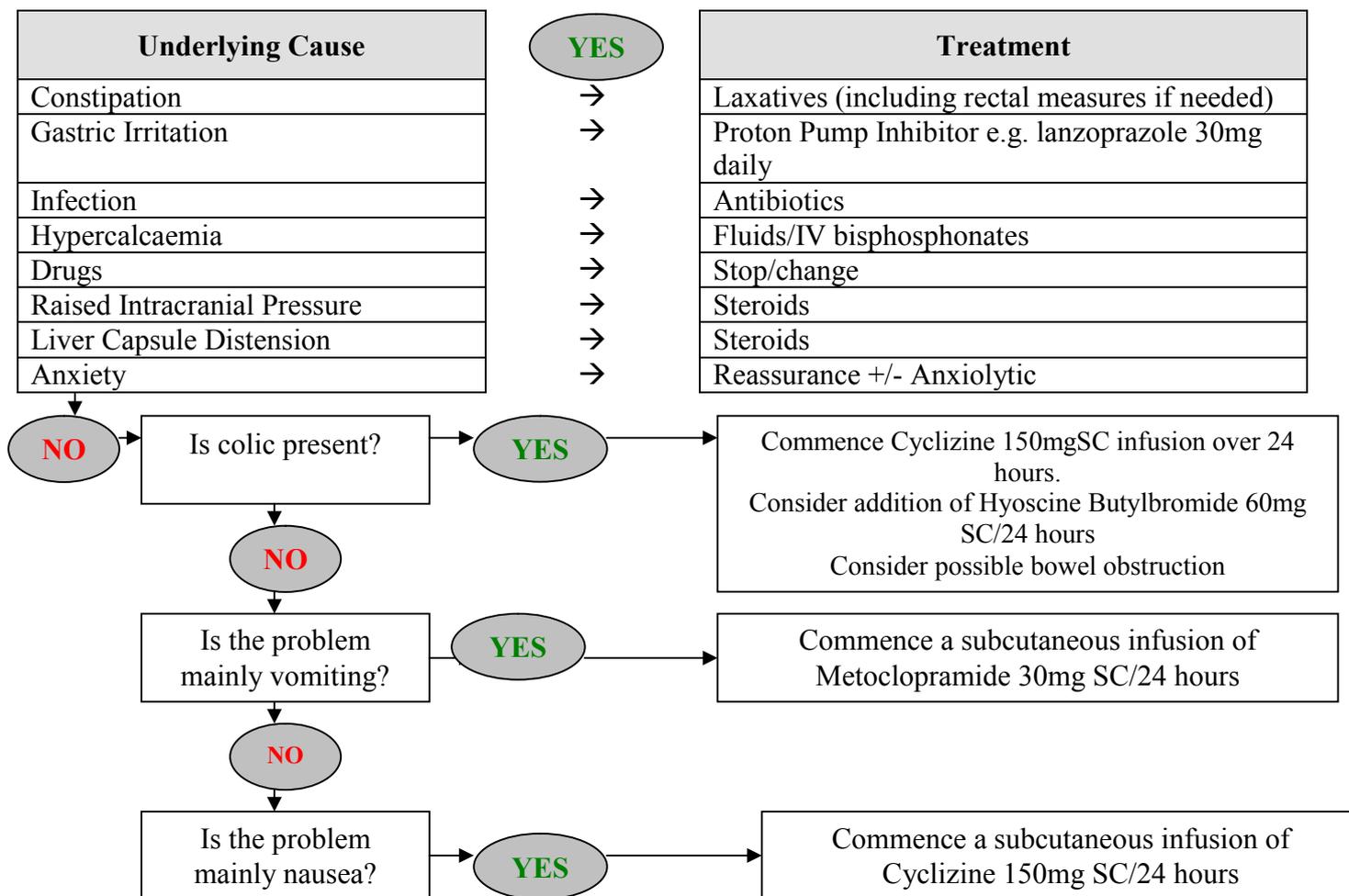
SUSPICIOUS SYMPTOM ALGORITHM FOR METASTATIC SPINAL CORD COMPRESSION



DIAGNOSTIC ALGORITHM FOR SUSPECTED MSCC



NAUSEA AND VOMITING



Drug	Suggested Regular Dose/Route	Suggest PRN Dose/Route	Indications/Comments
Metoclopramide	10mg tds PO 30mg/24hrs SC	10mg 8 hourly PO/SC	Delayed gastric emptying, e.g. hepatomegaly, ascites, tumour mass AVOID IN COMPLETE BOWEL OBSTRUCTION
Cyclizine	50mg tds PO/SC 75-150mg/24hrs SC	25-50mg 8 hourly PO/SC	Raised intracranial pressure Cranial radiotherapy Liver capsule distension Intestinal obstruction Pharyngeal stimulation Motion
Haloperidol	1.5-3mg nocte PO or 2.5-5mg/24hrs SC	1.5mg 8 hourly PO or 2.5mg 8 hourly SC	Drug induced nausea, e.g. opioids Biochemical causes of nausea, e.g. hypercalcaemia, uraemia, tumour toxins
Levomepromazine	3-6mg od-bd PO 5-12.5mg/24hrs SC	6mg 4 hourly PO 5-6.25mg 4 hrly SC	Broad spectrum antiemetic SEDATIVE AT HIGHER DOSES
Ondansetron	8mg bd PO	Not recommended	First 3 days post chemotherapy or radiotherapy ONLY .

NAUSEA AND VOMITING : ADDITIONAL CONSIDERATIONS

What is most troublesome – nausea, vomiting or retching?

Severity of symptoms:

- If not passing wind, **consider gastrointestinal obstruction**. See constipation protocol.
- Is the patient **vomiting blood**?
- If **unable to tolerate fluids/food**, consider advising medical review or 999 call.

Is there a reversible underlying cause?

- Has **hypercalcaemia** been excluded?
- Consider whether switching to an alternative opioid analgesic may help
- Treat reversible causes if possible (and if appropriate).
- Cover with most specific antiemetic whilst awaiting response.
- If not reversible, look for most likely causes and target with a specific antiemetic.

Which antiemetics have already been tried, and by which dose and route?

- Has the patient been taking them regularly?
- Did they help?
- Were there any adverse effects?

Does the patient have any suitable antiemetics available at home?

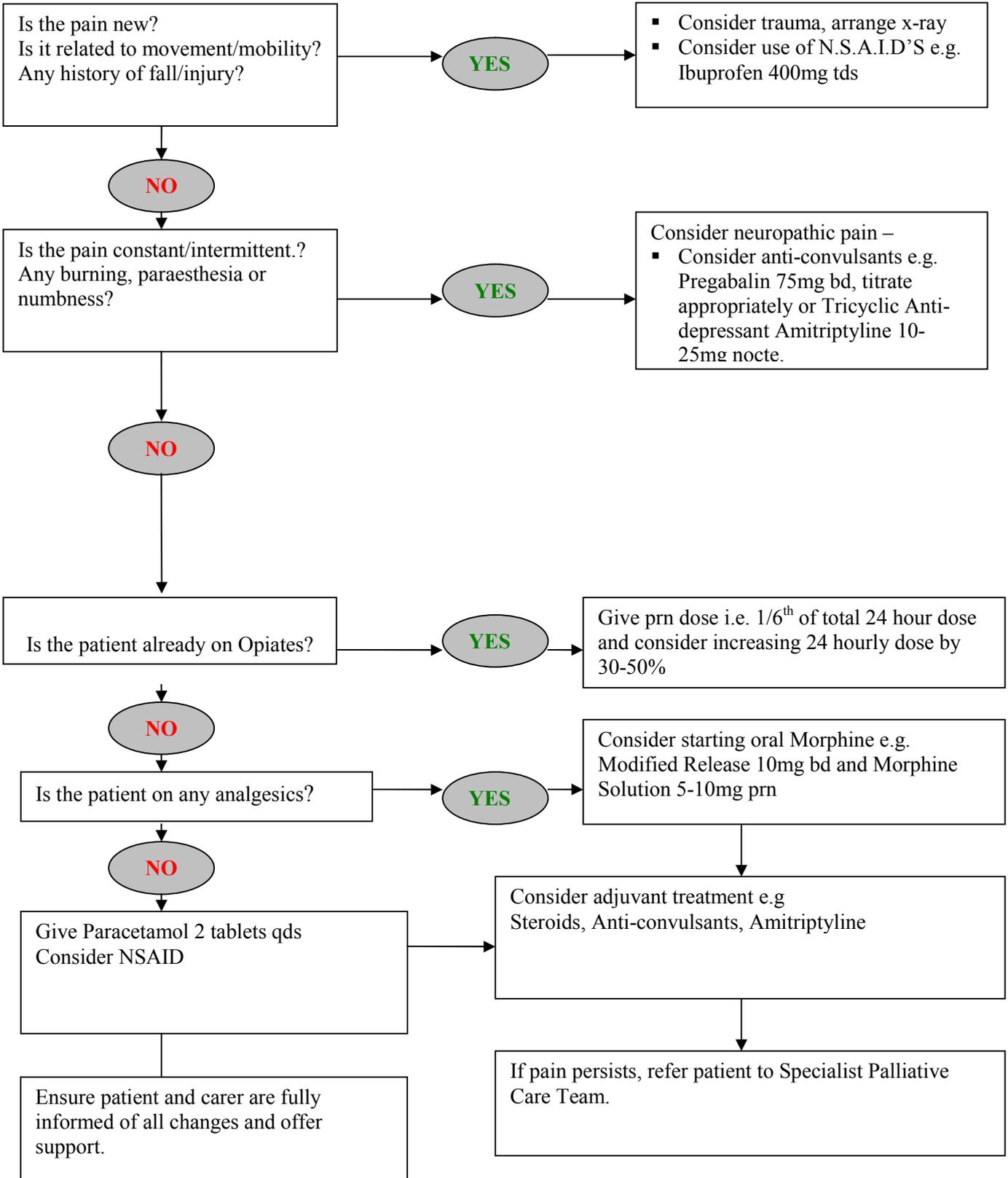
What drugs are available in the house? When was the last dose taken, and what is the maximum dose frequency/24 hour dose of the drug?

- The oral route is only suitable for mild nausea or prophylaxis.
- In established nausea, gastric stasis interferes with oral absorption, so suppositories are useful.
- Consider a syringe driver if vomiting for more than one day, or moderate/severe nausea unresponsive for more than 48 hours.
- Give antiemetics regularly, and ensure SC prn antiemetic is also prescribed.
- After 72hrs of good control with the subcutaneous route, consider converting to oral. If the patient is anxious when switching back to oral, phase out the subcutaneous drugs one at a time and replace with oral.

Remember non-drug measures:

- Eat and drink little and often
- Sit upright to eat and drink
- Light diet
- Avoid strong smells
- Acupuncture

PAIN



PAIN : ADDITIONAL CONSIDERATIONS

Common types of pain and their management:

Pain	Examples	Character	Initial Management	Adjuvants	Consider
Deep somatic	Bone metastases	Gnawing, aching. Worse on moving or weight bearing	WHO ladder	NSAID's	Radiotherapy Surgery Bisphosphonate
Visceral	Liver, lung bowel	Sharp ache or deep throbbing Worse on bending or breathing	WHO ladder	Corticosteroid NSAID's	Nerve block Surgery
Neuropathic	Nerve compression, Nerve damage	Burning, shooting Sensory disturbance in affected area	WHO ladder	Tricyclic antidepressant Anticonvulsant Corticosteroid	Radiotherapy TENS Nerve block
Smooth muscle spasm	Bowel obstruction, Bladder spasm	Deep, twisting, colicky, in waves	May be sensitive to opioid - variable	Anticholinergic e.g. hyoscine butylbromide	Surgical relief of obstruction

Consider:

Site of pain

- **Chest pain:** Could there be a cardiac cause? Could it be pulmonary embolism? If possible, advise urgent medical review or 999 call.
- **Back pain:** Rapidly escalating and/or bilateral nerve root pain, loss of continence and/or power. Suggestive of cord/cauda equina compression. Recommend urgent medical assessment with a view to MRI scan +/- radiotherapy/surgery.

Severity of pain

- If severe consider advising medical review or 999 call.

What has been tried in the past? Did it help? Were there any adverse effects?

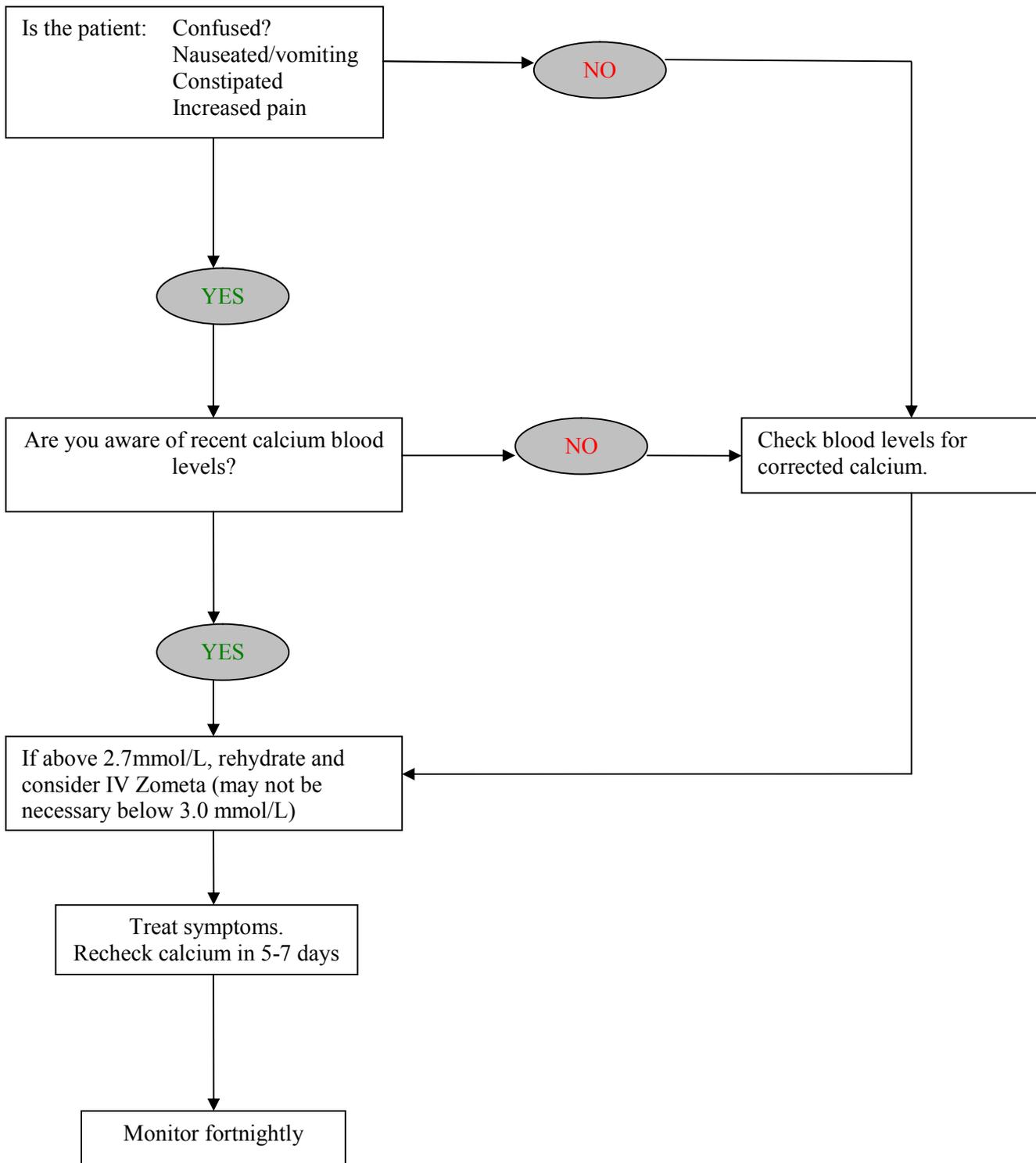
What drugs are available in the house? When was the last dose taken, and what is the maximum dose frequency/24 hour dose of the drug?

Route of drug administration

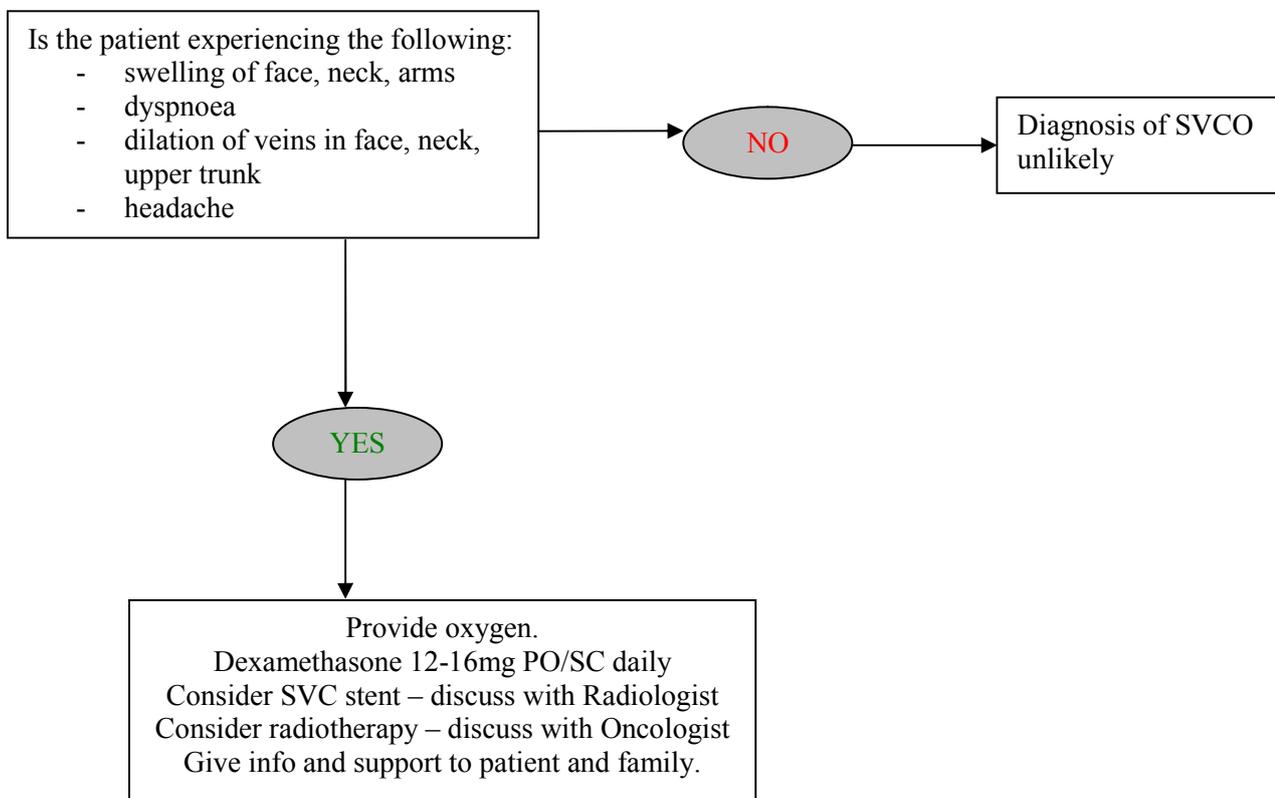
Remember non-drug measures:

- Positioning
- Rest/immobilisation
- Heat/ice packs
- TENS

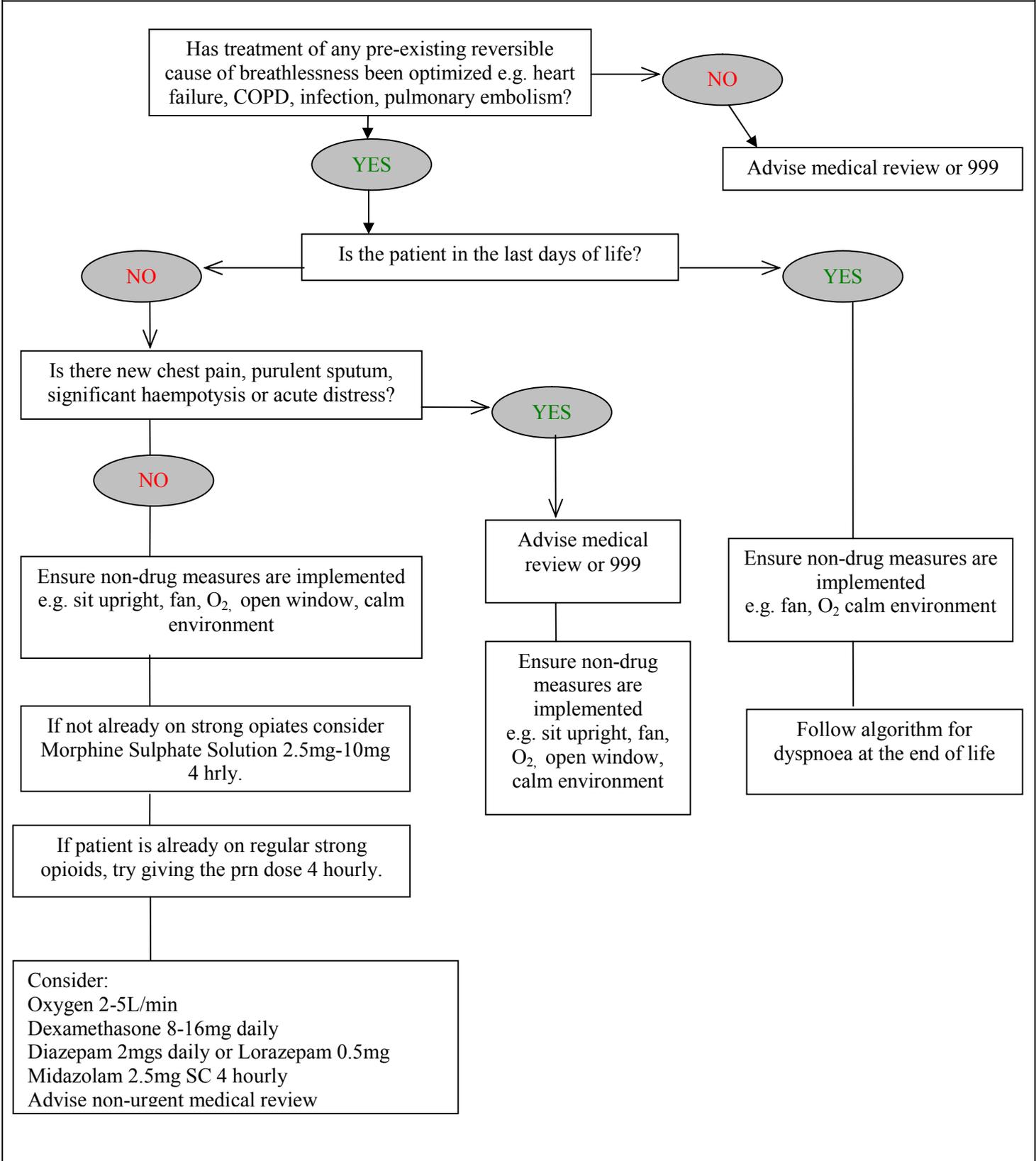
HYPERCALCAEMIA



SUPERIOR VENA CAVA OBSTRUCTION (SVCO)



BREATHLESSNESS



BREATHLESSNESS : ADDITIONAL CONSIDERATIONS

Causes of breathlessness

Cause	Specific intervention
Chest infection	Antibiotics - Is treatment appropriate, particularly if admission for IV antibiotics is being considered? - Is the patient neutropenic? If so, advise urgent admission to hospital
Cardiac ischaemia	Advise 999 if unable to exclude acute MI Rest GTN spray/tablet Morphine May need medical review
Pulmonary embolism	Advise 999 if unable to exclude pulmonary embolism Anticoagulation
COPD/asthma	Bronchodilators Steroids
Pleural effusion	Consider chest drain
Progressive lung disease	Consider steroids Chemotherapy/radiotherapy may be an option
Lymphangitis	Steroids
Anaemia	Consider blood transfusion

Consider:

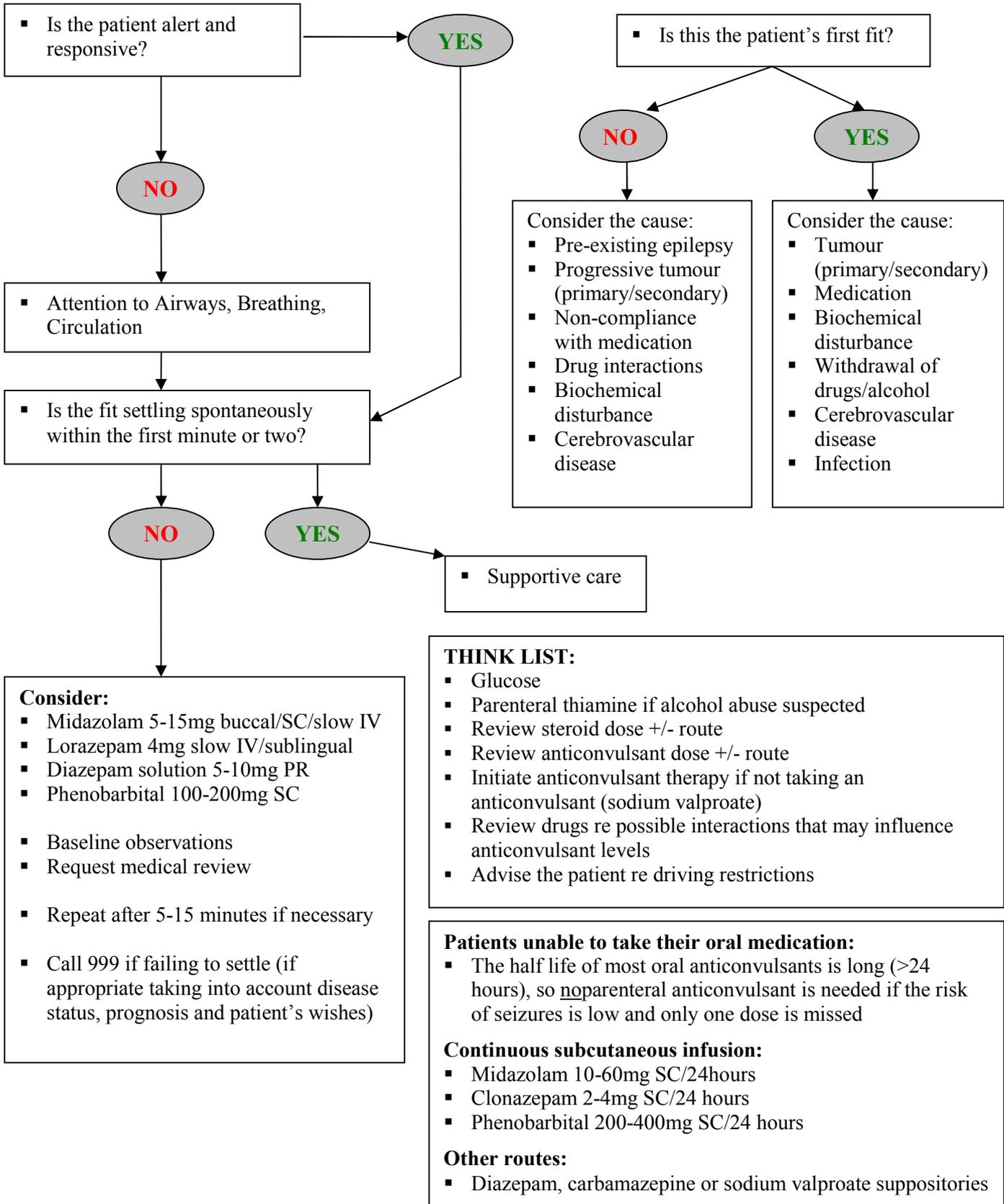
What has been tried for symptoms in the past? Did it help? Were there any adverse effects?

What drugs are available in the house? When was the last dose taken, and what is the maximum dose frequency/24 hour dose of the drug?

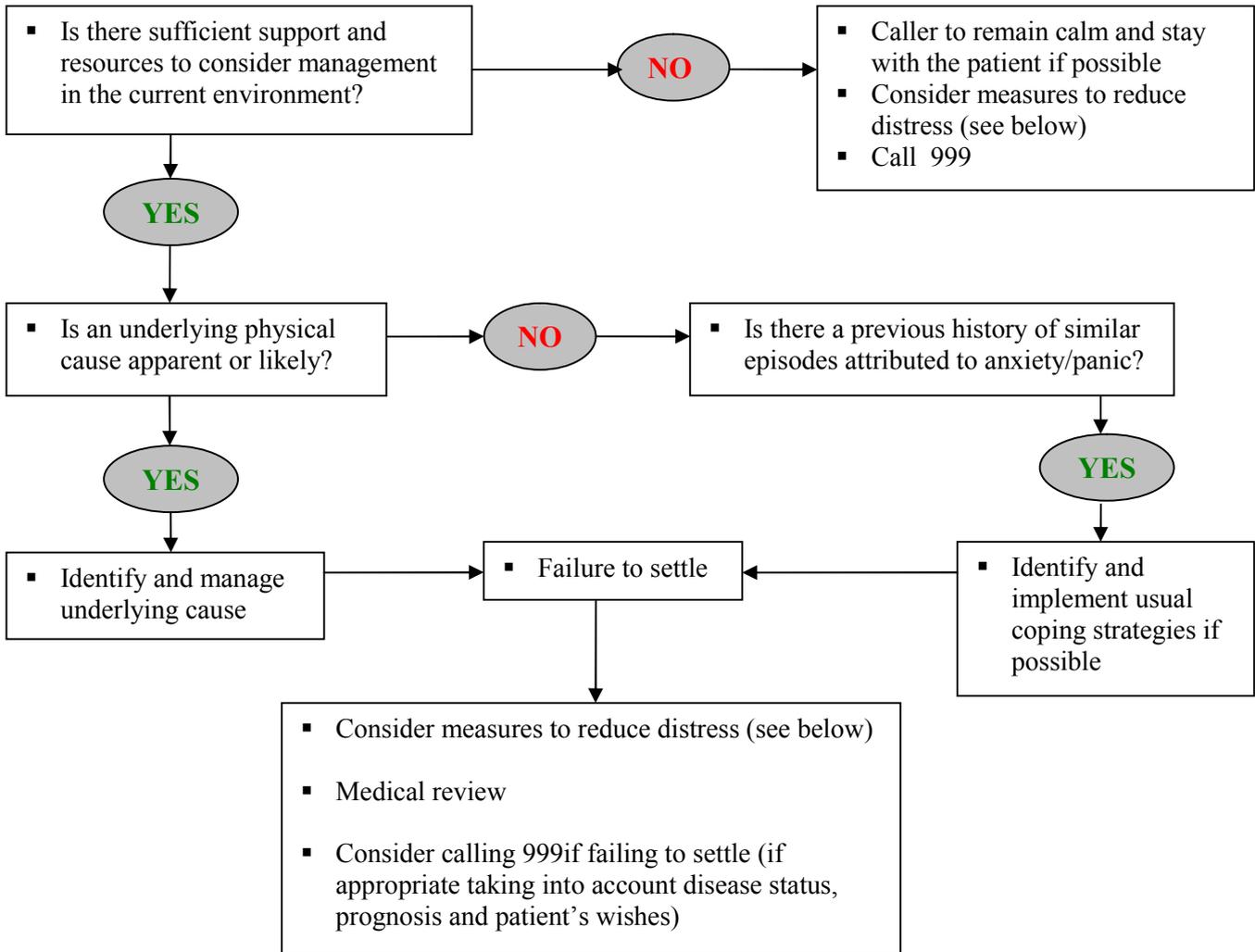
Remember non-drug measures:

- Positioning
- Open window
- Fan
- Calm environment
- Relaxation/breathing techniques

EPILEPTIC FITS



ACUTE DISTRESS



Consider:

Non-medical interventions to reduce distress.

- Distraction
- Relaxation
- Visualisation
- Breathing techniques/rebreathing
- Reassure appropriately; avoid false reassurance

Medical interventions to reduce distress

- Diazepam 2-5mg orally 4 hourly prn
- Lorazepam 0.5-1mg sublingual 4 hourly prn
- Promazine 25-50mg orally qds prn
- Midazolam 2.5-5mg SC 4 hourly prn

THREAT OF SUICIDE:

- Does the patient have a plan? How detailed is it?
- Does the patient have the means?
- Are there any factors stopping the patient acting on their thoughts?
- Is there anybody with them or who can be contacted?
- Gain the patient's permission to seek additional help and support
- Consider giving information about the Samaritans (Contact tel: 08457909090)
- ***If active, immediate risk to life, consent is NOT required. Contact GP, duty psychiatrist, duty social worker, police as necessary***

Consider debrief with the team following the call.

INFORMATION re: IMPLANTABLE DEFIBRILLATORS at the END OF LIFE

Background to use of implantable cardiac devices (ICDs)

Most forms of heart disease will require lifelong medication and various interventions. An ICD is one form of intervention. It is used for:

- patients who have a life-threatening ventricular arrhythmia
- those who have been identified as being at risk of developing a life-threatening ventricular arrhythmia.

The purpose of an ICD is to monitor the heart rhythm and respond to arrhythmias and has several key functions:

- automatic administration of defibrillation shocks to terminate ventricular fibrillation (VF) or fast ventricular tachycardia (VT)
- anti-bradycardia pacing, often used after a defibrillation shock as the heart returns to normal sinus rhythm
- anti-tachycardia pacing to terminate slower rate VT, and
- cardioversion of VT.

Patients subjected to a defibrillation shock from their ICD tend to describe the experience as a startling, jolt-like discomfort that has been rated 6 on a 0-10 pain scale. The shock may follow a period of light headedness or faintness related to the primary arrhythmia. The experience of having the shock is very distressing and often induces anxiety and fear. Such symptoms would certainly be intrusive in dying patients. Anti-tachycardia pacing activity may be sensed as palpitation.

In accordance with current treatment guidelines, ICDs are increasingly offered to people with congestive heart failure due to left ventricular systolic dysfunction that is essentially a chronic progressive syndrome. The typical trajectory of heart failure is of gradual functional decline, punctuated by crises due to episodic decompensation or arrhythmia. Heart failure is usually a disease of the older adult who may have several medical problems. So dilemmas may also arise when an unrelated terminal illness such as cancer occurs in a patient who has already had an ICD implanted. Patients about to die with end-stage heart failure or another illness frequently exhibit metabolic or biochemical derangement and are at risk of developing complex arrhythmias that might trigger firing of the ICD.

In general, maintaining an ICD in active defibrillation mode is inconsistent with an active DNR order and is rarely justified. However, it is possible that a competent patient may decline a full resuscitation attempt because of the loss of dignity inherent in this, but may decide that keeping their ICD active is an acceptable option. While this approach might seem to be at odds with conventional clinical practice, the patient's request should be respected. While an ICD is active, the patient's family should be reminded that, if the device does discharge, it is by means of a low energy internal shock which is harmless to anyone in physical contact with the patient.

Dealing with complications before they arise

The following clinical features may be useful triggers to initiate a conversation about switching off the ICD.

- advanced age
- with refractory symptoms despite optimal therapy
- who have had at least three hospital admissions with decompensation in less than six months
- who are dependent for more than three activities of daily living
- with cardiac cachexia
- with resistant hyponatraemia
- with serum albumen of less than 25g/l
- who experience multiple shocks
- with a comorbidity with a poor prognosis, such as terminal cancer.

However, few such patients have discussed deactivation of their device beforehand. If any discussion has taken place, generally this has been put off until the very late stages of the illness – within the last few days, hours or even minutes of the patient's life.

There are 2 types of implantable defibrillator:

1. Combined implantable defibrillator with pacemaker
2. Implantable defibrillator only

Both devices need to be deactivated in the same way as death approaches.

Decisions regarding switching off the defibrillator

- When a patient is heading towards the end of their life, if time allows, it can be arranged with the Cardiology department at the local acute hospital for the defibrillator to be switched off in anticipation of the last hours of life. This is normally only done in normal working hours..
- Turning off the defibrillator means that the patient will not be shocked should they have a ventricular tachyarrhythmia. If it is a combined defibrillator and pacemaker device, the pacemaker will continue to function, as it is only the defibrillator component that is turned off.

What to do if a patient commences the Liverpool Care Pathway and their implantable defibrillator is still switched on

- If a patient dies with their defibrillator functioning, it will repeatedly shock during the periods of ventricular tachyarrhythmia (VT or VF) that precedes asystole in a dying heart. This can be distressing to the patient, family and staff. There is also a risk of shock to anyone touching the patient.
- To prevent this, when a patient with a functioning implantable defibrillator is approaching the last hours of life, a MAGNET should be taped securely using SLEEK or similar strong dressing tape, onto the chest of the patient OVER THE DEFIBRILLATOR/PACEMAKER BOX, or as near as is practically possible if the patient is cachexic. With the magnet in situ, there is NO risk of shock to anyone touching the patient, e.g. family, or during normal nursing cares. But do not attempt to remove the defibrillator.

What to do after a patient has died

- The magnet should be left in place for ONE HOUR after the patient has died, and the magnet can safely be removed without the risk of shock TO THE PATIENT OR STAFF.
- If a patient dies with a functioning defibrillator in situ, it needs to be turned off before it is removed. Need to identify what local procedures need to be followed.
- It is necessary for the device to be removed after death regardless of how the body is to be disposed of. It is essential that the undertakers are informed that a device is STILL in situ when the body leaves the hospice, especially if the patient is to be cremated.

Plan ahead, use an advanced care plan if appropriate.

Guidelines for the Management of Neutropenic Sepsis

**THIS IS A LIFE THEATENING EVENT - DO NOT DELAY.
TRANSFER URGENTLY TO THE ACUTE TRUST.**

Key elements of the history and examination that suggest a risk of neutropenia

History of recent chemotherapy or extensive radiotherapy whether with curative or palliative intent. Time for most risk of toxicity from chemotherapy is 7 to 10 days since cycle completed.

- history of previous problems with chemotherapy induced low blood count
- history of previous bone marrow or stem cell transplant
- evidence of infection – oropharynx (including oral infections), sinuses, perineum, central venous lines, skin lesions, chest, abdomen, urine etc
- evidence of shock, hypoxia, renal failure or disseminated intravascular coagulation (DIC)
- Co-morbidities such as COPD or ischaemic heart disease

Early signs and symptoms of neutropenic sepsis:

Feeling generally unwell

Temperature of 38°C at anytime or 37.4°C on two separate readings an hour apart

Shivering, hot and cold, spontaneous rigor

Diarrhoea

Patient will be warm and alert and not look too unwell

BUT they can change rapidly and death can follow

Late signs and symptoms of neutropenic sepsis:

Cold and clammy

Restless, anxious, confused

Hyperthermic

Hypotensive

Tachycardic

Any temperature above 37.4 °C should be acted upon Remember that both NSAIDs and Paracetamol can reduce a fever so do not solely rely on the temperature.

If the patient refuses to consider admission to the Acute Trust – assess patient's capacity – remember they may be septic so their capacity may be impaired.

If they have capacity

- explain the reason for the transfer and why you feel it is essential
- explain the implications of not being transferred including the risk of death.
- Explain the risks the limited management options at the hospice
 - Iv fluids
 - Oral antibiotics based on likely focus of infection
 - 2hourly observations – with clear plan if these observations deteriorate – transfer or move into end of life care

Doctor or nurse must inform the most senior doctor available at the hospice, as soon as possible, if the patient is felt to be at risk of neutropenic sepsis and is declining transfer.

If they lack capacity

Act in the patient's best interests which in most circumstances will be transfer to the Acute

**Identification and Management of Neutropenic Sepsis of Patients involved with Trinity Hospice and Palliative Care Services
(Flow Diagram)**

**Neutropenic sepsis can be FATAL. Early recognition can prevent death.
Symptoms may be vague. There may be no obvious focus of infection.
The patient may not have a high temperature**