

Person Name:

NHS No:

DOB:

Calderdale Community Individualised Care of the Dying Document

Guidance for clinical staff, trained carers

What is this document?

This care plan is a document that helps clinical staff who are caring for a dying person in the last hours or days of their lives. It guides them in delivering the best care that they can in order to meet the needs of person and their families.

When should it be used?

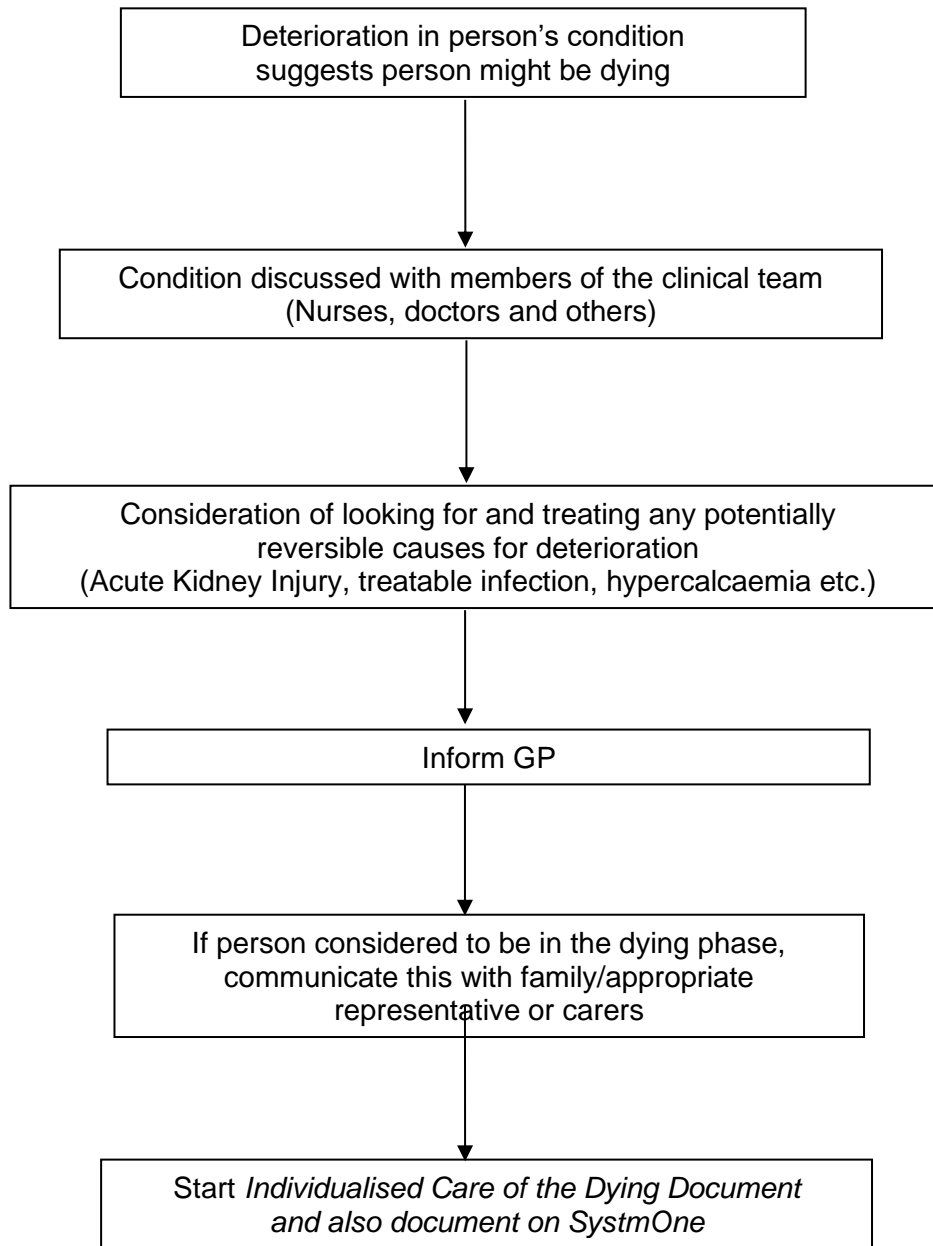
This care plan should be used when the doctors and nurses caring for a person believe that he or she is dying from an irreversible condition, and a decision has been made that the focus of care is now on quality and comfort. See the flowchart on page 2 for further guidance.

What are the important aspects of this care plan?

- Clear and unambiguous communication between doctors and nurses so that all are aware of the phase of care.
- Communicating with the person if possible and with their family/appropriate representative/carers to ensure that they are aware that the person is dying and that our priority now is comfort, care and support.
- Review of the appropriateness of continuing to give non-essential drugs, monitoring routine observations, measuring routine blood tests etc. This review must ensure that decisions have been made about which aggressive or invasive treatments would benefit the person. Any limits on these treatments should be clearly documented and communicated to the person, families and carers where appropriate.
- The person must be supported to drink and eat as long as they are able to, and wish to do so.
- After discussion with the person's family/appropriate representative, ensure they receive the information leaflet *The Care of the Dying Person*.
- If the person improves and the *Individualised Care of the Dying Document* is no longer appropriate, this should be documented and standard documentation reinstated. This decision should be communicated within the clinical team and to the person and their family/appropriate representative.

During office hours contact your local Palliative care Team for advice on 01422 310874. Out of hours palliative medicine advice is available from on call consultants via hospital switchboard on 01422 357171. Advice is also available from Overgate Hospice on 01422 379151

Decision-making flowchart for using the *Individualised Care of the Dying Document*



Clinical team decision

*In order to use the Individualised Care of the Dying Document, there must be a full assessment, **and** there must be agreement between the nurse and GP, that the person is dying. The professional documenting this decision must indicate the name of the carer/nurse and the doctor below.*

Nurse's signature:Date: Time:

GP this has been discussed with Date: Time:

To permit the verification of expected death by community nursing staff, the GP must have seen the person within the last 28 days before death

SPECIALIST PALLIATIVE CARE ADVICE FOR CALDERDALE COMMUNITY PATIENTS

IN WORKING HOURS

Monday-Sunday
0900-17.00

Please contact
The Community Specialist Palliative Care team
Clinical Nurse Specialists
Tel 01422 310874

The team secretary will take a message or a
message can be left on the answerphone

If the matter is urgent you can contact the specialist
palliative care nurse
on their mobile via CHFT switchboard.

Please be aware that if the mobile phone is not
answered immediately the nurse may be with a
patient or driving. Please leave a message and we
will get back to you as soon as possible.
Consultant advice is also available via CRH
switchboard on 01422 357171

Patients/relatives should be advised to contact the
District Nurse Team in the first instance.

OUT OF HOURS

Patients and relatives should be advised to contact the
district nurse team in the first instance

District nurses
Day time 8-6pm 01422 652291
Out of hours 07917106263

Specialist palliative care advice can be sought by
Health care professionals only

Advice can be sought from Overgate hospice on
01422 379151

OR

On-call Consultant advice is also available via CRH
switchboard

Patient name: DOB: NHS no:	This is a multidisciplinary document- all members of the team have a responsibility to contribute to its completion.
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All personnel completing the *Individualised Care of the Dying Document* please sign below

Name (print)	Full signature	Initials	Professional title	Date

Person Name:	NHS No:
DOB:	

This is a multidisciplinary document – all members of the team have a responsibility to contribute to its completion.

Initial Assessment - Diagnosis and baseline information

Diagnosis:

Co-morbidities

Female/Male.....

In this document, the word “family” is used to mean the family or appropriate representative of the Dying Person

Physical condition

At the time of the assessment is the person						
conscious	semi-conscious	unconscious		Confused	Yes	No
In pain		Yes	No	Able to swallow safely	Yes	No
Agitated		Yes	No	Continent (bladder)	Yes	No
Nauseated		Yes	No	Catheterised	Yes	No
Vomiting		Yes	No	Continent (bowels)	Yes	No
Breathless		Yes	No	Other symptoms (e.g. oedema, itch)	Yes	No
Respiratory tract secretions		Yes	No			

Communication/understanding

Have you explained the following to the family?		
That the person is believed to be dying	Yes	No
The common symptoms that might occur (falling conscious level, chest secretions, breathing changes, etc.)	Yes	No
That the prognosis is likely to be short, i.e. hours – days	Yes	No
That decisions may need to be made in the person’s best interests, but will be discussed with nominated family members (unless someone has LPA for Health and Welfare)	Yes	No
Have you given the family the opportunity to ask questions?	Yes	No

Name of the person spoken to:

Relationship to dying person: Date/Time:

If you have answered no to any of the previous, what steps have you taken to address this?

.....

Patient Name: DOB: NHS No:	This is a multidisciplinary document- all members of the team have a responsibility to contribute to its completion.
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Have you explained to the family that an individualised Care Plan will ensure high quality and comfort care?	Yes	No
Have you given the family "Care & Support of the Dying Person Information for relatives & carers" leaflet?	Yes	No
Have you given the family a Comfort Bag? (Care Homes only)	Yes	No

Name of person:

Relationship to patient:.....Date/time.....

If you have answered no to any of the above, please clarify:

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Communication/understanding/Best Interests decisions

Does the person understand that they are dying?	Yes	No
If no, please clarify:		
Is a DOLS authorisation in place?*	Yes	No
If the person loses capacity, is a DOLS authorisation appropriate?	Yes	No

***A trained nurse or doctor can verify the death if they have a DOLS in place.**

Best Interests Decisions

These may need to be made to ensure comfort/symptom control in people who lack capacity to consent to specific treatments. Examples include catheterisation to relieve urinary retention, or to reduce skin problems from incontinence; administration of medicines for the relief of pain, distress or agitation; or upward titration of medicines via CSCI to control distress.

Refer to your organisation’s existing Best Interests and MCA documentation.

The reason for not applying for a DOLS order is that the person is believed to be dying, has a very short prognosis (days) and a best interest decision has been made for their care to be delivered in hospital/care home/hospice.

(Reference: The Law society- identifying a Deprivation of liberty, a practical Guide, 2015)

Patient Name:
DOB:
NHS No:

Advance Care Planning

Person has a documented Advance Care Plan / statement of wishes & preferences	Yes	No
Person has valid Advance Decision to Refuse Treatment (ADRT)	Yes	No
Person/relative has Lasting Power of Attorney (LPA) for health and welfare	Yes	No
If appropriate contact: Tissue donation (incl corneas); 0113 820 0803 Full body donation : Sarah Wilson, office hours -01133434297, out of hours - 01133435494	Yes Yes	No No

If the answer to any of the above is yes, please note any specific wishes or plans below:

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Implantable Cardiac Defibrillator

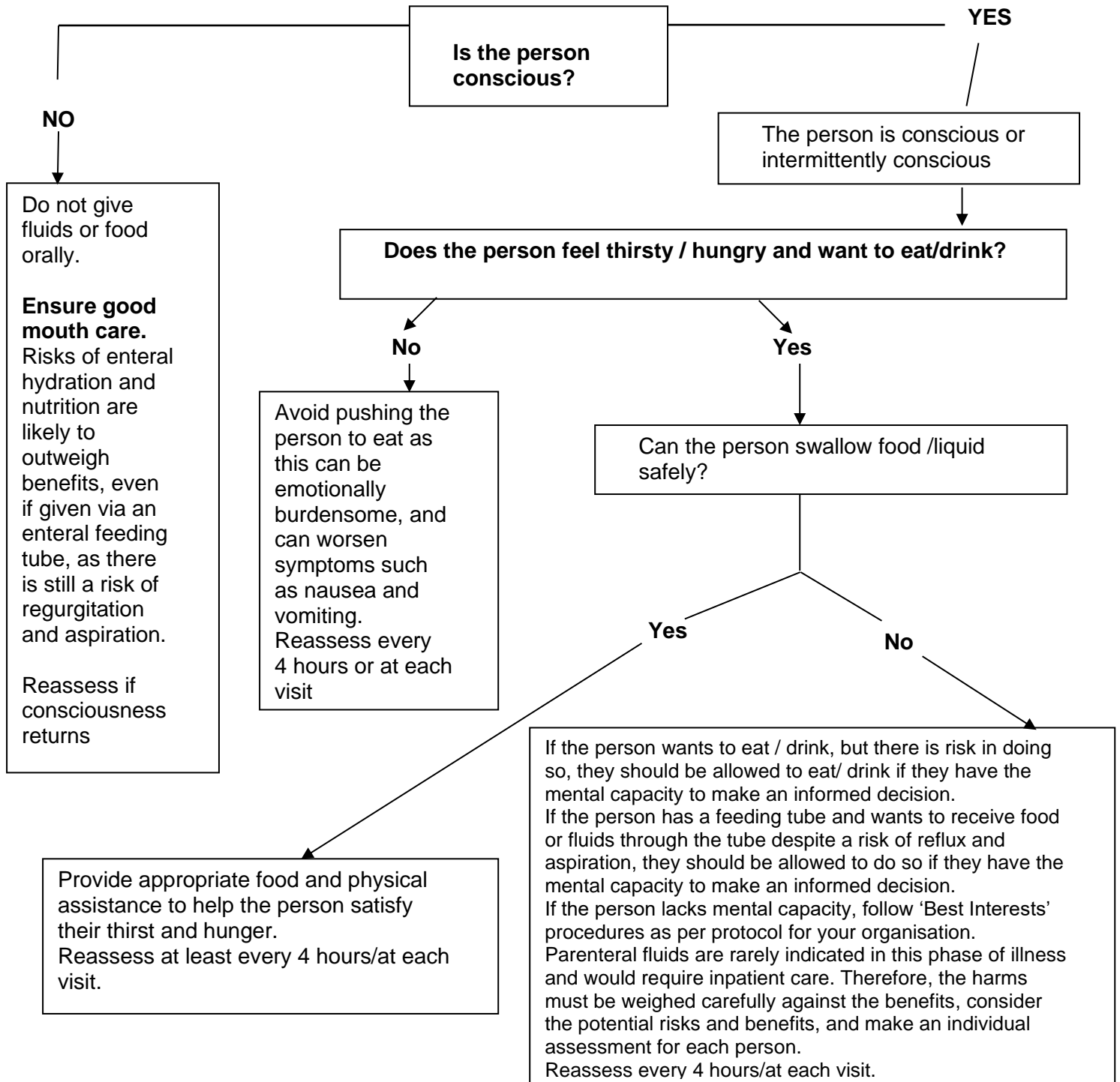
Does an Implantable Cardiac Defibrillator (ICD) require deactivation?	Yes	No	Not applicable
To deactivate , contact the appropriate area number, see below: Calderdale: Mon-Fri 9-5pm ring Cardiology Department at Calderdale Royal Hospital on (01422) 224310. Out of hours ring CRH switchboard on 01422 357171 and ask for cardiologist on call.			
Valid DNACPR/ReSPECT decision in place If no, complete a DNACPR/ReSPECT form and discuss with person (if appropriate) and /or family	Yes	No	

Hydration/Nutrition

This guidance is for use when it is thought that the person is in the last days or hours of life, and reversible causes for the deterioration have been considered. **At this stage of an illness, the prognosis will not be altered by providing hydration and nutrition, orally or parenterally.**

Parenteral Fluids

A Cochrane review of “medically assisted hydration to assist palliative care persons”¹ (2011) concluded that there was insufficient evidence to recommend either way about parenteral fluids. There is limited evidence; some studies show no difference, some suggest sedation and myoclonus may improve as a result of treating dehydration, but some suggest fluid retention symptoms (pleural effusion, peripheral oedema and ascites) were significantly higher in the hydration group.



Person Name:
DOB:
NHS No:

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Hydration

The person must be supported to take fluids by mouth for as long as they are able and wish to do so. A reduced need for fluids is part of the normal dying process. Good mouth care is essential.

Ensure a discussion has taken place concerning artificial hydration.

Name of appropriate representative spoken to:

Date/Time:

Nutrition

The person must be supported to take food by mouth for as long as they are able, safe and wish to do so. In most people the use of clinically assisted (artificial) nutrition will not be required. A reduced need for food is part of the normal dying process.

Ensure that a discussion has taken place concerning nutrition.

Name of appropriate representative spoken to:

Date/Time:

For additional guidance, please refer to the hydration/nutrition guidance on the page 8.

Person Name:	NHS No:
DOB:	Hospital No:

This is a multidisciplinary document – all members of the team have a responsibility to contribute to its completion.

Assessment of wishes/feelings/faith and values

Does the person or their family have concerns of a wider nature? These may be:

- Religious, or
- Cultural concerns, or
- Worries about something else

Is there someone they would like to speak to about these concerns for example, a social worker, a doctor or nurse, carer, chaplain? Yes/No

If yes, what have you done to facilitate this?

Date/Time

Does the person/family member have a religious faith or tradition? Yes/No

Is there someone they would like support from?

Chaplain/ Imam/ Priest/ Religious leader Yes/No

What have you done to facilitate this?

Date/Time:

Are there any particular needs:

Now

At the time of death

After death

Do they have a preferred place of death

Guidelines concerning the care of the deceased person and traditions around the time of death can be found on the Trust intranet.

Guidelines about Faiths and Cultures is on the trust intranet or from the Palliative and end of life Educators on 01422 379151.

Person Name:	NHS No:
DOB:	Hospital No:

Information for family/appropriate representative members

Please indicate how the family members are to be informed of a person’s impending death or changes in clinical condition:

- Inform at any time Yes/No
- Please inform between these times:
- Family member wishes to stay overnight Yes/No

First contact name/relationship/Tel No

.....

Alternative contact name/relationship/Tel No

.....

Any additional instructions/requests:

.....

Other Guidance

Family member made aware of whom to contact first for advice or assistance?	Yes	No
Family advised that their deceased relative would ideally be moved to the funeral directors within a few hours of death.	Yes	No
Family advised that they could make an appointment to view their relative at the funeral directors	Yes	No

Person Name:	NHS No:
DOB:	

Guidance / Information for everyone

Reviewing drugs in the last few days of life

The focus of drug management in the last days of life is on good control of pain, agitation and other symptoms. In the weeks prior to death, drugs whose main role is prevention of conditions such as stroke, angina, hyperglycaemia etc. may be discontinued, but once a person begins to struggle with their medications and/or become unconscious and unable to take them, further changes are needed.

Opioid analgesics should be converted to the appropriate parenteral formulation; oral morphine should be switched to subcutaneous morphine and oral oxycodone to subcutaneous oxycodone. Transdermal opioids should be continued. However, renal impairment may require an opioid switch to oxycodone or alfentanil. Please contact the Specialist Palliative Care Team for advice.

A continuous subcutaneous infusion (CSCI, syringe pump) may also be required to control symptoms of agitation, respiratory secretions or intestinal obstruction. The syringe pumps used in Calderdale are the McKinley T34 syringe pumps.

Ensure that where a syringe pump is prescribed, that the reason for this is explained to a family member.

Syringe pump discussed with:

..... Date/Time:.....

Anticipatory medication

PRN medication should always be written up for the common symptoms which people experience at the end of life:

Pain	Analgesia (SC)	Yes	No
Agitation	Sedative (SC)	Yes	No
Respiratory tract secretions	Anticholinergic (SC)	Yes	No
Breathlessness	Opioid and/or benzodiazepine (SC)	Yes	No
Nausea and vomiting	Antiemetic (SC)	Yes	No
Mouthcare	Artificial saliva/oral gel	Yes	No
Fever	Paracetamol (oral/rectal)	Yes	No

Remember:

- **Anticipatory prescribing of PRN morphine, midazolam, haloperidol and hyoscine butylbromide is good practice**
- **If a patient is on a transdermal patch (fentanyl or buprenorphine) it should be continued even when syringe pump is commenced. (Please seek specialist advice)**

For additional guidance, please refer to the symptom control flowcharts on pages 16 -19.

Review the role of investigations/treatments

Routine blood tests	Not being done	Discontinued	Continued	Commenced
Intravenous antibiotics	Not being done	Discontinued	Continued	Commenced
Blood glucose monitoring	Not being done	Discontinued	Continued	Commenced
Routine recording of vital signs	Not being done	Discontinued	Continued	Commenced
Oxygen therapy	Not being done	Discontinued	Continued	Commenced

Review of other medication

The following drugs can safely be stopped in the last days of life:

Statins	Digoxin
Vitamins/supplements	Anticoagulants (including low molecular weight heparin)
Antidepressants	Antiarrhythmics
Antihypertensives	Inhalers (bronchodilators, steroids etc.)
Beta blockers	Eye drops for glaucoma
Antianginals	Diuretics

A person on insulin, steroids, anticonvulsants and dopamine agonists (anti-Parkinsonian drugs) must not have these medications stopped suddenly.

Is the person diabetic?	Yes	No
Is the person on oral steroid medication?	Yes	No
Is the person on oral anticonvulsants?	Yes	No
Is the person taking oral anti-Parkinson's medications?	Yes	No

If the answer is yes to any of these questions, see the relevant section commencing on page 13/14.

If the answer is no to all these questions, you have completed the Initial Assessment.

Pages 15 -18 contain symptom management guidelines.

Management of Diabetes in end of life care

See CHFT intranet for updated guidance *

A person with Type 1 diabetes mellitus will rapidly develop unpleasant symptoms from diabetic ketoacidosis if their insulin is suddenly stopped;
Those with Type 2 diabetes mellitus will more slowly develop rising blood sugars and hyperosmolar non-ketosis. Follow the guidance as indicated below.

Insulin dependent Type 1 diabetes	Insulin treated Type 2 diabetes	Drug controlled Type 2 diabetes
Continue daily long-acting insulin	Reduce and aim to stop insulin	Stop oral hypoglycaemics
Check daily blood glucose prior to insulin administration	Check daily blood glucose	Check blood glucose only if distressed (to rule out hyperglycaemia)
Aim for blood glucose 10-15mmol	Treat if blood glucose over 20mmol or symptomatic	

Additional advice may be obtained from the Diabetic Specialist Nurse team (or from palliative medicine consultant, including out of hours).

The following drugs should not be stopped routinely but consideration given for alternatives and/or continuation of a different formulation:

Oral Steroids

It may be necessary to continue this medicine. Where these are used for the symptom management of headaches or raised intracranial pressure in people with primary or secondary brain tumours, and where they have been taken for more than 3 weeks, consider conversion to the subcutaneous administration.

Equivalent doses

Oral dexamethasone mg	2	4	6	8
SC dexamethasone mg	1.65	3.3	4.95	6.6

Anticonvulsants

When oral anticonvulsants are unable to be taken orally convert to midazolam 30mg/24 hours via syringe pump, in order to maintain good seizure control (or seek Specialist Care Advice)

Anti-Parkinsonian medication

Sudden cessation of levodopa preparations should be avoided and the person converted transdermal rotigotine.

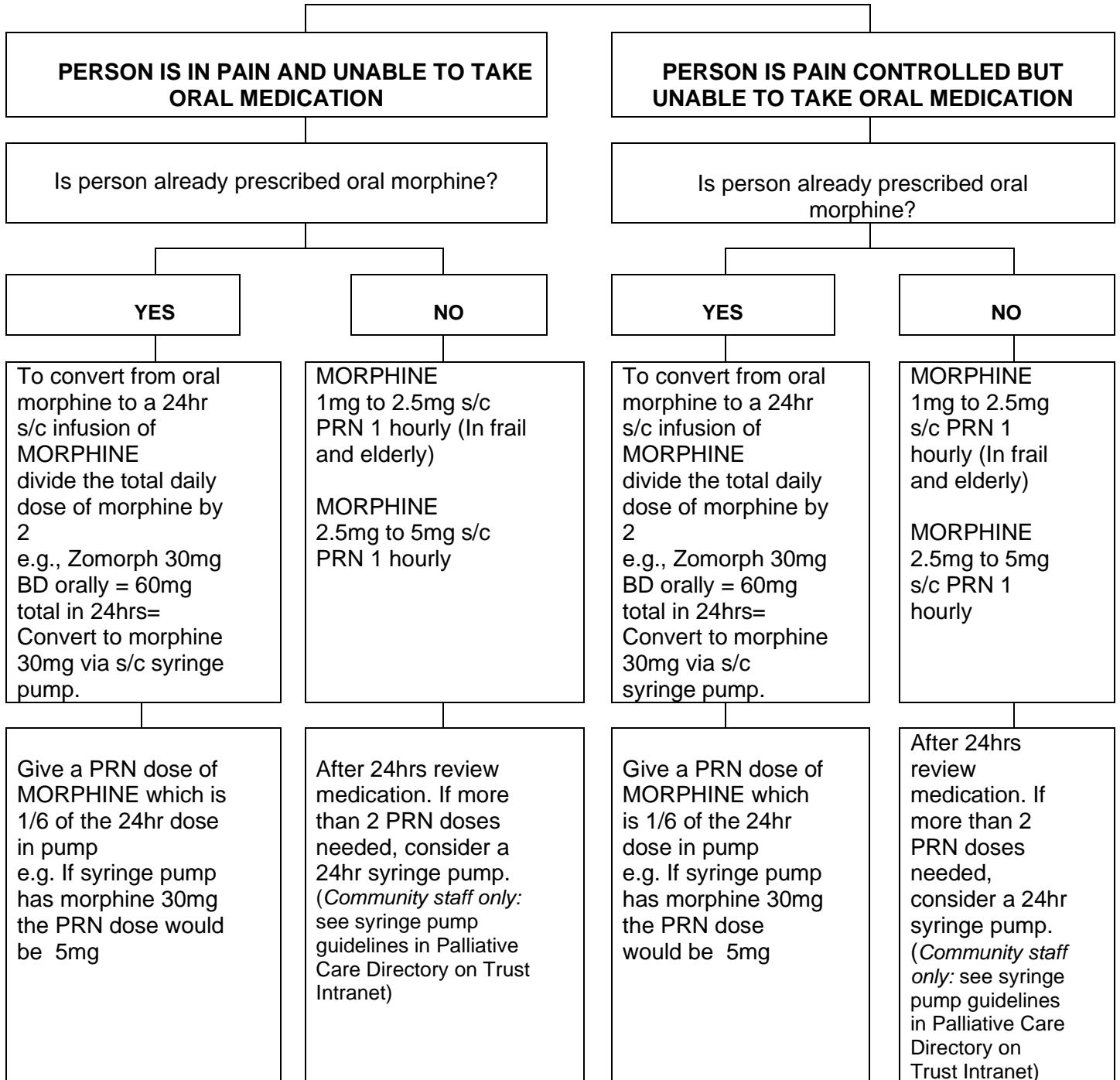
100mg of levodopa controlled release is equivalent to 2mg/24 hours of rotigotine.

Advice around any of the above is available from the Specialist Palliative Care Team, see page 3, or from the palliative care consultant out of hours.

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PAIN

NB Prescription of these medications is at the discretion of the prescriber but is recommended in the last few days of life



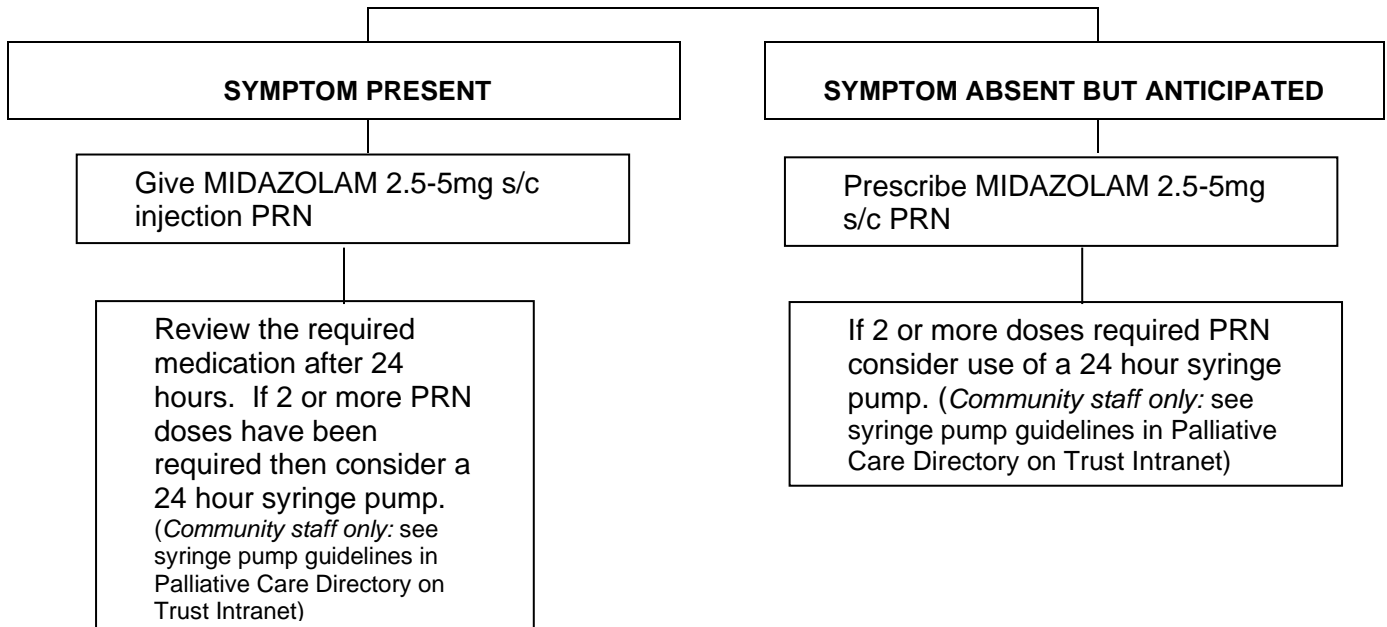
NB: If eGFR is less than 40, use oxycodone; seek advice. If eGFR is less than 10, seek specialist advice. In elderly, frail patients, dose reduction may be required.

To convert from other opioids and other palliative care advice please contact the relevant Specialist Palliative Care Team, (see page 3).

TERMINAL RESTLESSNESS AND AGITATION

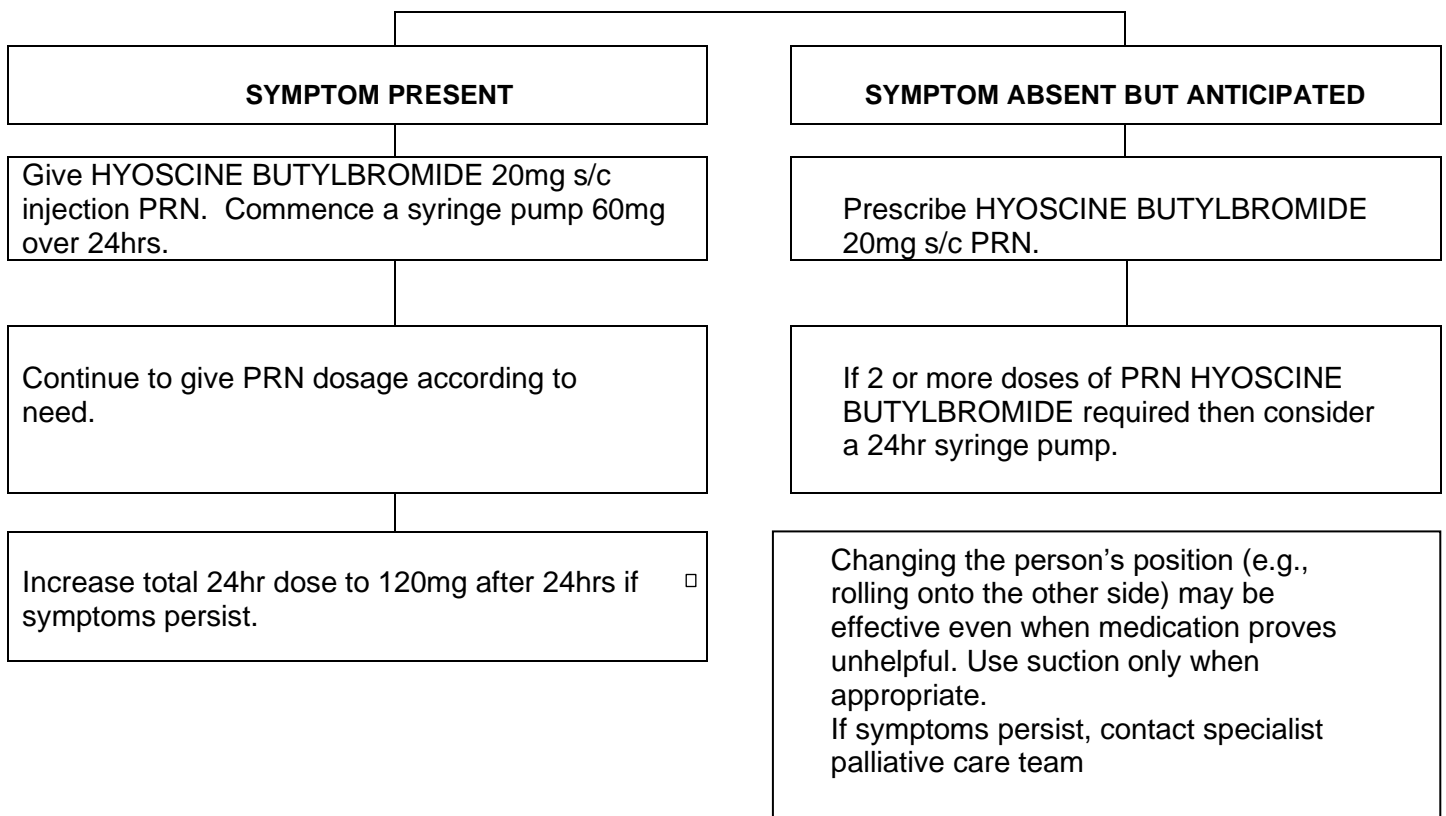
NB Prescription of these medications is at the discretion of the prescriber but is recommended in the last few days of life

EXCLUDE urinary retention, constipation/faecal impaction and ensure all spiritual or psychological issues have been addressed



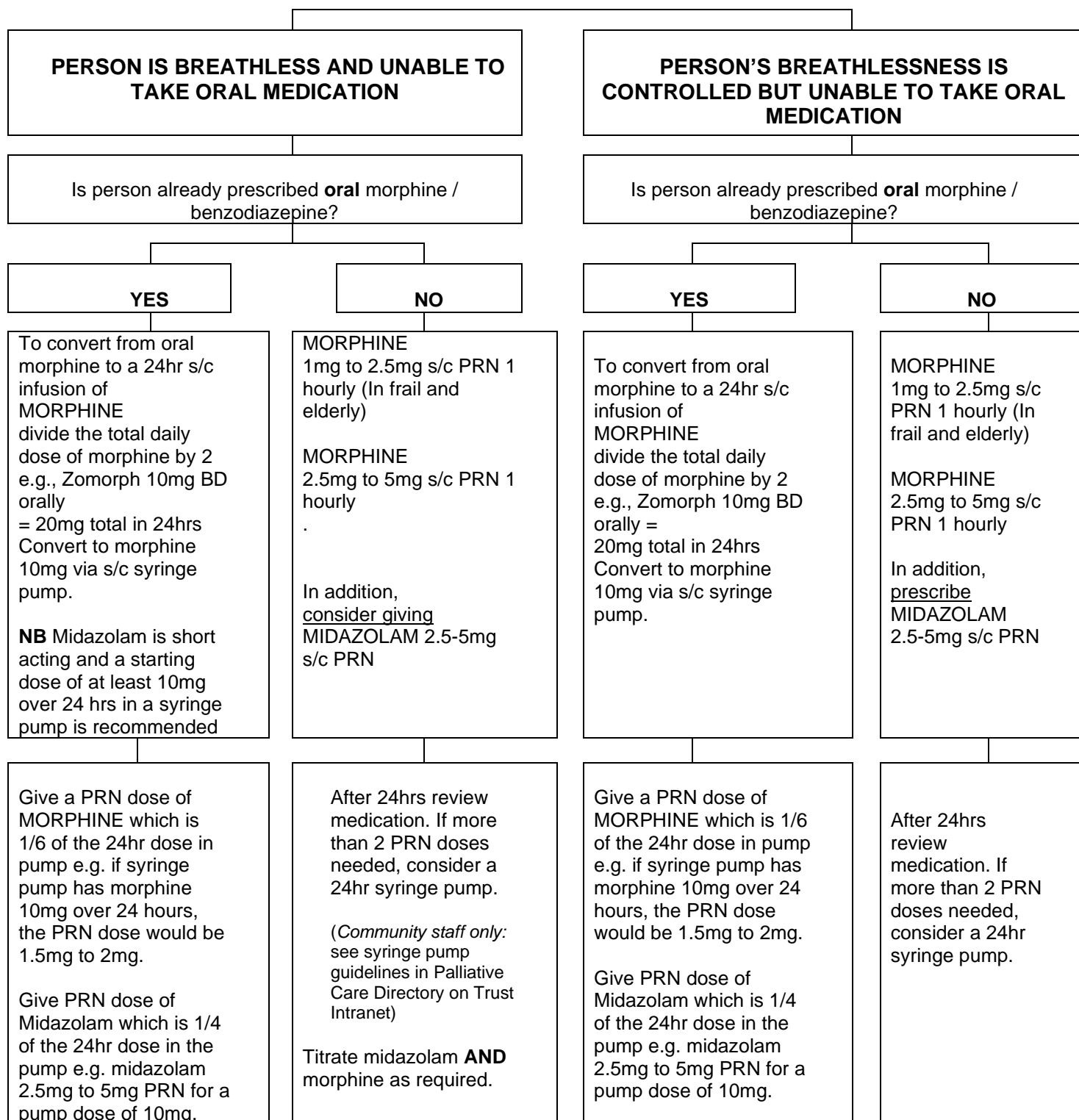
In elderly, frail individuals, dose reduction can be considered

RESPIRATORY TRACT SECRETIONS



If symptoms persist, contact the relevant Specialist Palliative Care Team, see page 3.

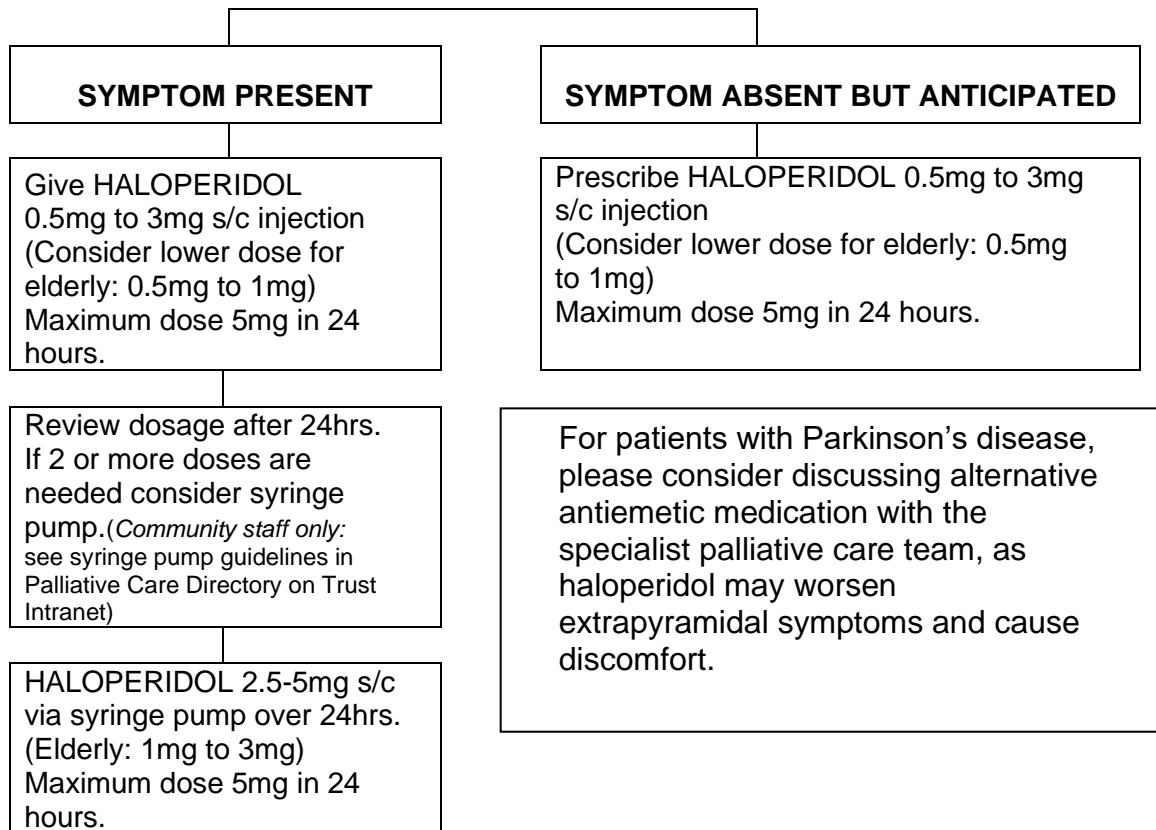
BREATHLESSNESS



NB: If EGFR less than 40, use oxycodone; seek advice. If EGFR less than 10, seek specialist advice. In elderly, frail individuals, dose reduction may be required.

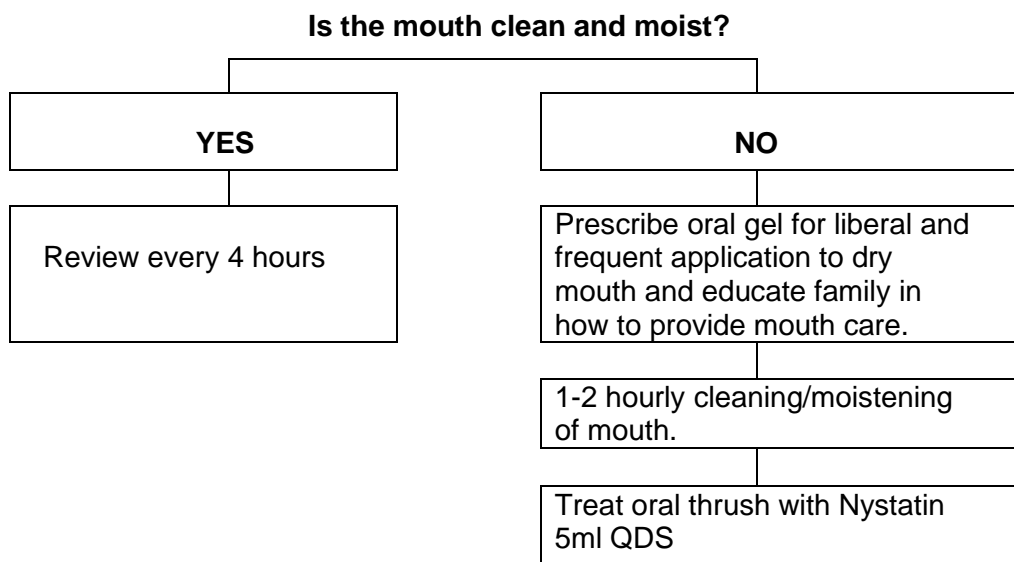
To convert from other opioids, contact the Palliative Care Team Page 3.

NAUSEA/VOMITING



Remember that other antiemetics may be helpful. If haloperidol is ineffective after 2 doses or symptoms persist contact the relevant Specialist Palliative Care Team, see page 3.

MOUTH CARE



Remember that anticipatory prescribing of PRN morphine, midazolam, haloperidol and hyoscine butyrbromide is good practice for all end-of-life care/palliative patients, even if they are not actively dying.

Prescription of anticipatory medications is the discretion of the prescribing clinician but is recommended in the last few days of life.

End of Life Care Plan: Individual needs	Person Name:
	DOB:
	NHS No:

Please sign and document the time to confirm that you addressed each of these areas. If intervention/action is needed document in the evaluation section.	Date	Date	Date	Date	Date	Date
	Time	Time	Time	Time	Time	Time
1. Are there any continence needs? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
2. Is there any hygiene needs? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
3. Is the person in pain? Yes/No If yes report to Nurse	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
4. Is the person agitated? Yes/No If yes, report to Nurse	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
5. Does the person have chest secretions? If yes, report to Nurse	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
6. Is the person nauseated/vomiting? Yes/No If yes, report to Nurse	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
7. Is the person breathless? Yes/No If yes, report to Nurse	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
8. Does the person need repositioning? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
9. Oral intake-does the person want food and drink? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
If not eating and drinking, has mouth care been provided? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
10. Is there anything else you can do for the person or family? Consider spiritual, psychological, emotional, physical needs. Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
11. Do they have any further questions you can help with? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
12. Any other problems? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
13. Is a visit or review by the Doctor necessary to review medications or prescriptions, support family, and answer questions/address concerns/review suitability of care plan?	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
14. Is there enough anticipatory medication to allow PRN doses and an increase of syringe pump doses? If not please contact GP during hours to ensure person will not run out overnight/weekend/long weekend	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N

Please complete the individual care plan at each visit if in persons home, or every 4 hours if in a care home. Additional care plans can be used according to the individual persons requirement (e.g. pressure area care, catheter care)

End of Life Care Plan: Individual needs	Person Name:
	DOB:
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4. Is the person agitated? Yes/No If yes, report to RN	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
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	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
10. Is there something else you can do for the person or family? Consider spiritual, psychological, emotional, physical needs. Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
11. Do they have any questions that you can help with? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
12. Any other problems?	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
13. Is a visit by the doctor necessary to review medications/prescriptions, support family, and answer questions/address concerns/review suitability of care plan? Yes/No	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N
14. Is there enough anticipatory medication to allow PRN doses and increase of syringe pump doses? If not contact GP during hours to ensure person will not run out overnight/weekend/long weekend.	Y/N	Y/N	Y/N	Y/N	Y/N	Y/N

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