



Department of Health and Social Care

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Care of dying adults in the last days of life

Improving care at the very
end of life.

Foreword

We will all experience death, whether it is our own or that of a loved one. The bereaved person's perception that they have witnessed a "good" death can significantly improve their ability to adjust and move forward, while a "bad" death can have a long-lasting negative impact on their well-being. Therefore the care given must be of the highest standard and must recognise and strive to accommodate the wishes of the dying person and their loved-ones, if it is to provide not just the comfort that the dying person deserves but also the solace the bereaved need.

The document 'One Chance to get It Right' (2014) highlighted the need to help staff recognise, assess, communicate and provide individualised care and support for dying people (Leadership Alliance for the care of Dying People 2014). The Alliance's five Priorities for Care puts people and those important to them at the centre of decisions about their treatment and care, and follows the recommendation made by the independent Neuberger (2014) review of the LCP.

More recently the National Institute for Health and Care Excellence (NICE) guideline 'Care of the Dying Adult' (2015) gives professionals a comprehensive, humane and evidence-based framework for giving dying people, their families and others important to them, the best possible care based on each individual's needs and wishes.

This guideline will help support doctors, nurses and other healthcare professionals in the Isle of Man in giving consistent, compassionate and high quality clinical care for every person at the end of their life. The approach should be applied irrespective of the place in which someone is dying: hospital, hospice, community and during transfers between different settings.

Please note that there are several other documents (Rapid Discharge Plan, Just In Case Box Policy And End of Life Form) which are used to support these guidelines. They have not been included as the whole document would be too onerous.

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Priorities of Care for the Dying Person

Published June 2014 by the Leadership Alliance for the Care of Dying People

The Leadership Alliance for the Care of Dying People have set out five priorities for care of a person when it is thought that they may die within the next few days or hours.

1. Recognise

The possibility that a person may die within the next few days or hours is recognised and communicated clearly. All decisions and actions taken should be in accordance with the person's needs and wishes. Individuals are regularly reviewed and decisions revised accordingly. Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

2. Communicate

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. Involve

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

4. Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. Plan & Do

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Recognising Dying

If it is thought that a person may be entering the last few days of life

1. Gather and document information on:
 - the person's physiological, psychological, social and spiritual needs.
 - current clinical signs and symptoms.
 - medical history and the clinical context, including underlying diagnoses.
 - the person's goals and wishes.
 - the views of those important to the person about future care.
2. Assess for changes in signs and symptoms and review any available investigation results that may suggest a person is entering the last days of life.
 - signs such as agitation, Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions.
 - symptoms such as increasing fatigue and loss of appetite.
3. Functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal. Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering. Avoid undertaking investigations that are unlikely to affect care in the last few days of life unless there is a clinical need to do so.
4. Use the knowledge gained from the assessments and other information gathered from the multi-professional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving.
5. Monitor the person at least every 24 hours and update the individualised care plan.
6. Seek specialist palliative care advice when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

Communication

1. Establish the communication needs and expectations of people who may be entering their last days of life, taking into account:
 - if they would like a person important to them to be present when making decisions about their care
 - their current level of understanding that they may be nearing death
 - their cognitive status and if they have any specific speech, language or other communication needs
 - how much information they would like to have about their prognosis
 - any cultural, religious, social or spiritual needs or preferences.

2. Identify the most appropriate available multi-professional team member to explain the dying person's prognosis. Base this decision on the professional's:
 - competence and confidence
 - rapport with the person.

3. Discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.

4. Provide the dying person, and those important to them, with:
 - accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
 - an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
 - information about how to contact members of their care team
 - opportunities for further discussion with a member of their care team

5. Explore with the dying person and those important to them
 - whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
 - whether the dying person has understood and can retain the information given about their prognosis.

6. Discuss the dying person's prognosis with other members of the multi-professional care team, and ensure that this is documented in the dying person's record of care.

Involve

Please also refer to the recommendations on shared decision making in NICE's guideline on patient experience in adult NHS services.

1. Establish the level of involvement that the dying person wishes to have and is able to have in shared decision making, and ensure that honesty and transparency are used when discussing the development and implementation of their care plan.
2. As part of any shared decision making process take into account:
 - whether the dying person has an advance statement or an advance decision to refuse treatment in place, or has provided details of any legal lasting power of attorney for health and welfare
 - the person's current goals and wishes
 - whether the dying person has any cultural, religious, social or spiritual
3. Identify a named lead healthcare professional, who is responsible for encouraging shared decision making in the person's last days of life. The named healthcare professional should:
 - give information about how they can be contacted and contact details for relevant out of hours services to the dying person and those important to them.
 - ensure that any agreed changes to the care plan are understood by the dying person, those important to them, and those involved in the dying person's care.

Support

1. Health and care staff must regularly assess and address (if possible) the needs of those important to the dying person, and offer information about getting access to other sources of help and support.
2. Health and care staff in in-patient facilities must ensure those important to the person are welcome and enabled to spend time with the dying person.
3. Those who wish to participate in caring for the dying person must be supported by staff to do so, e.g. by showing them simple practical techniques.
4. Health and care staff must acknowledge that the needs of the dying person, and those important to them may differ. Differences must be acknowledged and addressed in a sensitive way.
5. Respect those who do not wish to talk openly about death and dying. However staff must find a sensitive way to remain clear in their communication, and to avoid euphemisms.
6. Health and care staff must offer information and explanations to those important to them to prepare them for what happens when a person is close to death, whether the death is occurring at home or in an institution.
7. When a person is imminently dying, the responsible nurse or other healthcare professional must check with the dying person's family and those important to them about how they would best wish to be supported. Some prefer to be left alone; others prefer a staff member to briefly check in with them every now and then; others may need more support. Importantly, they need to know where staff are if they are needed.
8. Those important to the dying person, including carers, may have their own spiritual and religious needs which may, or may not, be similar to that of the dying person. Staff must involve chaplains or relevant religious leaders if the family and those important to the person want this.

9. When a person has died, the wellbeing of the bereaved must be considered, and health and care staff must ensure adequate support is available for their immediate needs. They must be allowed time with the deceased person, if they wish, without being put under pressure.
10. Those important to the dying person will require additional support if the death has been unexpected or if it occurs after a very short deterioration, for example help to understand post mortem, coroners' and death certification procedures, and to have their questions answered.

Plan & Do

1. Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.
2. In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:
 - personal goals and wishes
 - preferred care setting
 - current and anticipated care needs
 - preferences for symptom management
 - needs for care after death, if any are specified
 - resource needs.
3. Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multi-professional care team.
4. Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.
5. While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.
6. Ensure that shared decision making can be supported by experienced staff at all times. Seek further specialist advice if additional support is needed.

Maintaining hydration

1. Support the dying person to drink if they wish to and are able to. Check for any difficulties, such as swallowing problems or risk of aspiration. Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person's care.
2. Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed. Offer the person the following, as needed:
 - help with cleaning their teeth or dentures, if they would like.
 - frequent sips of fluid.
3. Encourage people important to the dying person to help with mouth and lip care or giving drinks, if they wish to. Provide any necessary aids and give them advice on giving drinks safely.
4. Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.
5. Discuss the risks and benefits of clinically assisted hydration with the dying person and those important to them. Advise them that, for someone who is in the last days of life:
 - clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems.
 - it is uncertain if giving clinically assisted hydration will prolong life or extend the dying process.
 - it is uncertain if not giving clinically assisted hydration will hasten death.
6. Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.
7. When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:

- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment.
 - their level of consciousness.
 - any swallowing difficulties.
 - their level of thirst.
 - the risk of pulmonary oedema.
 - whether even temporary recovery is possible.
8. Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.
9. For people being started on clinically assisted hydration:
- Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
 - Continue with clinically assisted hydration if there are signs of clinical benefit.
 - Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.
10. For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life:
- Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
 - Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.

Pharmacological management of common symptoms

This section focuses on the pharmacological management of common symptoms at the end of life and includes general recommendations for non-specialists prescribing medicines to manage these symptoms.

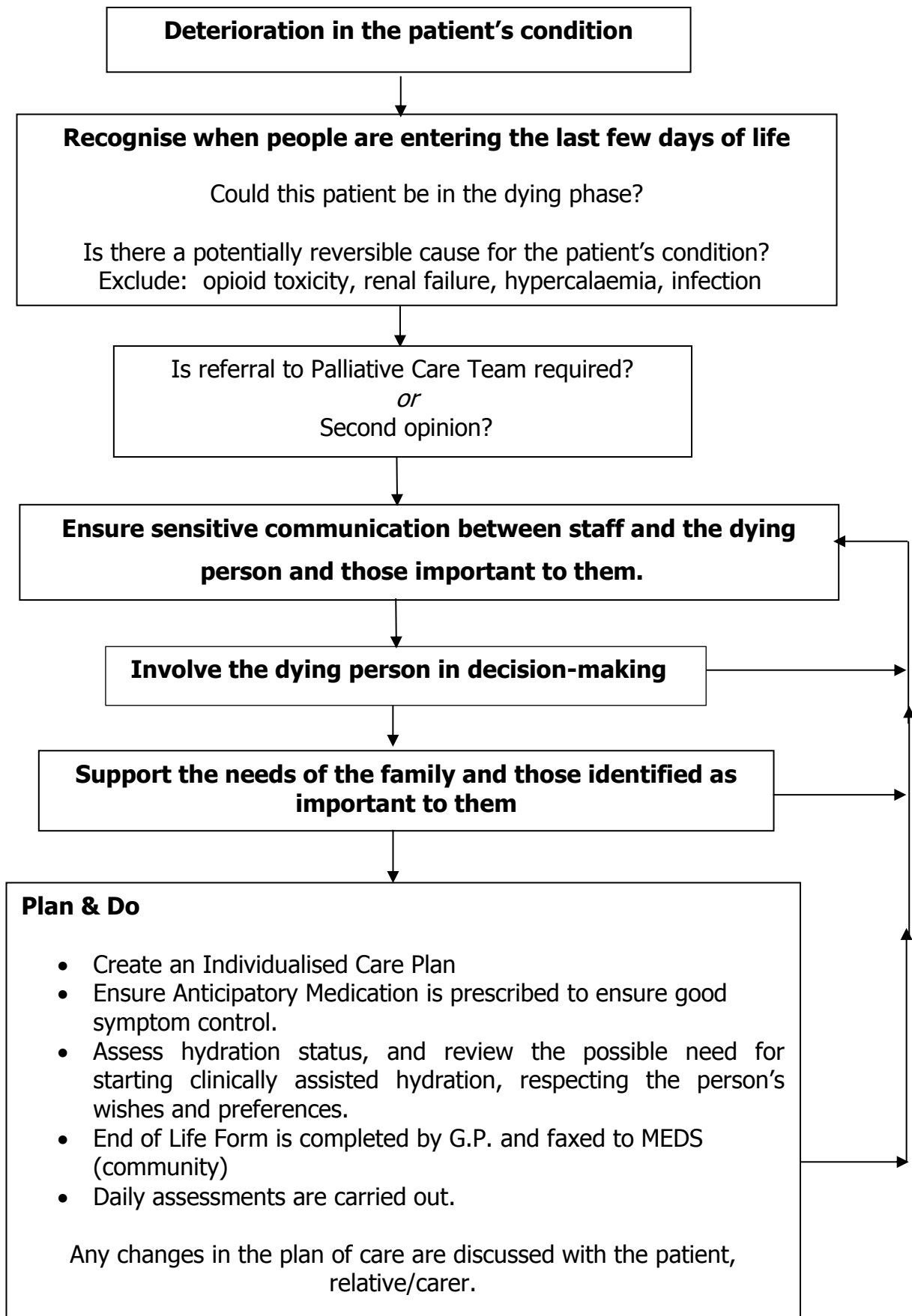
1. When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.
2. When involving the dying person and those important to them in making decisions about symptom control in the last days of life:
 - Use the dying person's individualised care plan to help decide which medicines are clinically appropriate.
 - Discuss the benefits and harms of any medicines offered.
3. When considering medicines for symptom control, take into account:
 - the likely cause of the symptom.
 - the dying person's preferences alongside the benefits and harms of the medicine.
 - any individual or cultural views that might affect their choice.
 - any other medicines being taken to manage symptoms.
 - any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.
4. Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.
5. Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.

6. Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.
7. For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.
8. Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.
9. Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

Anticipatory prescribing

1. Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed.
2. Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain). Discuss any prescribing needs with the dying person, those important to them and the multi-professional team.
3. Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.
4. When deciding which anticipatory medicines to offer take into account:
 - the likelihood of specific symptoms occurring.
 - the benefits and harms of prescribing or administering medicines.
 - the benefits and harms of not prescribing or administering medicines.
 - the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed.
 - the place of care and the time it would take to obtain medicines.
5. Before anticipatory medicines are administered, review the dying person's individual symptoms and adjust the individualised care plan and prescriptions as necessary.
6. If anticipatory medicines are administered:
 - Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
 - Adjust the individualised care plan and prescription as necessary.

Supporting Care for the Dying Person and their Family



Pain

Managing pain

1. Consider non-pharmacological management of pain in a person in the last days of life.
2. Be aware that not all people in the last days of life experience pain. If pain is identified, manage it promptly and effectively, and treat any reversible causes of pain, such as urinary retention.
3. Assess the dying person's level of pain and assess for all possible causes when making prescribing decisions for managing pain.
4. Follow the general principles of pain management, taking into account the person's wishes.
5. Use a validated behavioural pain assessment if the person is unable to communicate effectively.

Breakthrough Pain

This medication should be given at the first sign of an unwanted symptom, before it has a chance to build up, remembering that medications can take up to 20minutes to take effect.

- PRN dosage will be calculated as a **sixth** of the **total 24 hour syringe pump infusion**.

Analgesic Route

- The oral route is the preferred if the person is able to swallow.
- Transdermal Fentanyl is appropriate in the setting of severe continuous pain in individuals who cannot use the oral route; **however, it is not suitable for unstable pain** .
- The subcutaneous route is preferred when a parenteral route is needed. The intramuscular route should be avoided as it is generally more painful, and has variable absorption, compared to other routes.
- If the syringe pump is being used to administer opiate analgesia such as **Diamorphine**, then extra breakthrough analgesia must be prescribed and administered as a subcutaneous injection.

The commonly used drugs listed below must **NOT** be given by the SC route as they may cause tissue necrosis:

- Antibiotics
- Diazepam
- Chlorpromazine
- Prochlorperazine (Stemetil®)

Opioid Equianalgesic Table

This chart should be only used as a guide. The titration to optimum pain control should always be individualised.

(Initial dose conversions should be conservative; it is preferable to under-dose the individual and use rescue medication for any shortfalls).

Oral Morphine 4 hrly	MST or Zomorph 12hrly	MXL daily	Oral Oxynorm <i>(Oxycodone IR)</i> 4hrly	Oxycontin <i>(Oxycodone MR)</i> 12hrly	Transtec Patch <i>(Buprenorphine patch)</i> 72hrly	Durogesic and Durogesic D-trans <i>(Fentanyl Patch)</i> 72hrly
2.5mg	10mg		1.5mg	5-10mg	35mcg/hr	
5mg	15mg	30mg	2.5mg	10mg	35mcg/hr	
10mg	30mg	60mg	5mg	20mg	52.5mcg/hr	25mcg/hr
20mg	60mg	120mg	15mg	40mg	70mcg/hr	25-50mcg/hr
30mg	90mg	180mg	20mg	60mg	105mcg/hr	50mcg/hr
40mg	120mg	240mg	25mg	80mg	140mcg/hr	50-75mcg/hr
50mg	150mg	300mg	30mg	100mg		75-100mcg/hr
60mg	180mg	360mg	40mg	120mg		100mcg/hr
70mg	210mg	420mg	45mg	140mg		125mcg/hr
80mg	240mg	480mg	55mg	160mg		125-150mcg/hr
90mg	260mg	540mg	60mg	180mg		150mcg/hr
100mg	300mg	600mg	65mg	200mg		150-175mcg/hr
110mg	330mg	660mg	75mg	220mg		175mcg/hr
120mg	360mg	720mg	80mg	240mg		200mcg/hr
140mg	420mg	840mg	95mg	280mg		225-250mcg/hr
160mg	480mg	960mg	105mg	320mg		250-275mcg/hr
180mg	540mg	1080mg	120mg	360mg		300mcg/hr

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)

Date of issue: 01/06/2016

Date of review: 01/06/2018

Opioid Equianalgesic Table

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For further guidance especially with renal failure – refer to Palliative Care Resource File

MST or Zomorph 12hrly	MXL daily	Durogesic and Durogesic D-trans (Fentanyl Patch) 72hrly	Transtec Patch (Buprenorphine patch) 72hrly	Diamorphine SC PRN 2hrly PRN	Diamorphine SC Syringe Pump Over 24hrs	Morphine SC PRN 2hrly PRN	Morphine SC Syringe Pump Over 24hrs
10mg			35mcg/hr	2.5mg	5-10mg	5mg	10-15mg
15mg	30mg		35mcg/hr	2.5mg	10mg	5mg	15mg
30mg	60mg	25mcg/hr	52.5mcg/hr	5mg	20mg	7.5mg	30mg
60mg	120mg	25-50mcg/hr	70mcg/hr	5-10mg	40mg	10-15mg	60mg
90mg	180mg	50mcg/hr	105mcg/hr	10mg	60mg	15mg	90mg
120mg	240mg	50-75mcg/hr	140mcg/hr	15mg	80mg	20mg	120mg
150mg	300mg	75-100mcg/hr		15-20mg	100mg	20-30mg	150mg
180mg	360mg	100mcg/hr		20mg	120mg	30mg	180mg
210mg	420mg	125mcg/hr		20mg	130mg	30mg	200mg
240mg	480mg	125-150mcg/hr		20-30mg	160mg	30-45mg	240mg
260mg	540mg	150mcg/hr		30mg	190mg	45mg	280mg
300mg	600mg	150-175mcg/hr		3mg	200mg	45mg	300mg
330mg	660mg	175mcg/hr		30-40mg	220mg	45-60mg	330mg
360mg	720mg	200mcg/hr		40mg	240mg	60mg	360mg
420mg	840mg	225-250mcg/hr		40-50mg	290mg	60-75mg	430mg
480mg	960mg	250-275mcg/hr		50-60mg	330mg	75-90mg	490mg
540mg	1080mg	300mcg/hr		60mg	360mg	90mg	540mg

Oxycontin 12hrly	5 mg	10 mg	20 mg	40 mg	60 mg	80 mg	100 mg	120 mg	130 mg	160 mg	170 mg	200 mg	220 mg	240 mg
Oxynorm Syringe pump 24hrs	5-10 mg	15 mg	25-30 mg	50-55 mg	80 mg	110 mg	135 mg	160 mg	175 mg	215 mg	230 mg	270 mg	300 mg	320 mg

These tables have been generated using values *that may* differ from manufacturers' recommendations, but are based on expert opinion

Taken from Merseyside and Cheshire Palliative Care Guidelines 2010

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)

Date of issue: 01/06/2016

Date of review: 01/06/2018

Transdermal Fentanyl Patches

- Transdermal fentanyl is for use in individuals with **stable** pain.
It should **NOT** be used for titration against rapidly escalating pain.
- Never use transdermal fentanyl patches in opioid naïve individuals, as this may lead to dangerous respiratory depression.
- The starting dose of transdermal fentanyl is calculated on the basis of the oral Morphine sulphate equivalent dose as listed in the conversion chart below.

Total 24 hour oral morphine mg	Fentanyl patch mcg/hour
60-134	25
135-224	50
225-314	75
315-404	100

- Continue to administer oral Morphine Sulphate for 12 hours after applying the first patch, i.e.:
 - Immediate release Morphine Sulphate 4 hourly for 12 hours, or the final dose of modified release Morphine Sulphate, taken at the same time as applying the first patch.
 - For breakthrough pain, prescribe immediate release Morphine Sulphate equivalent to the 4 hourly dose. This may be required for the first 24-48 hours of transdermal Fentanyl use.

In the terminal Phase

When considering the use of transdermal Fentanyl it may be appropriate to discuss the individual's requirements with the Palliative Care Team.

- **Do not remove** the patch when the person can no longer tolerate oral medication
- Continue with the current dosage and change every 72hrs as previously
- Use subcutaneous injections to deliver breakthrough medication and a syringe pump to deliver the increasing analgesia requirements

- If a new, opioid responsive pain develops, use subcutaneous morphine/diamorphine as required for breakthrough pain. Use the conversion chart to calculate the dose.
- The diamorphine via the syringe pump should be used **in addition** to the fentanyl patch.

$$\text{4hourly dose of Diamorphine} = \frac{\text{Fentanyl patch strength (micrograms /hour)}}{5} \text{ Subcutaneously (mg)}$$

Fentanyl is approximately 4 times more potent than oral Morphine; this table provides a guide to dose conversions, but if in doubt seek advice.

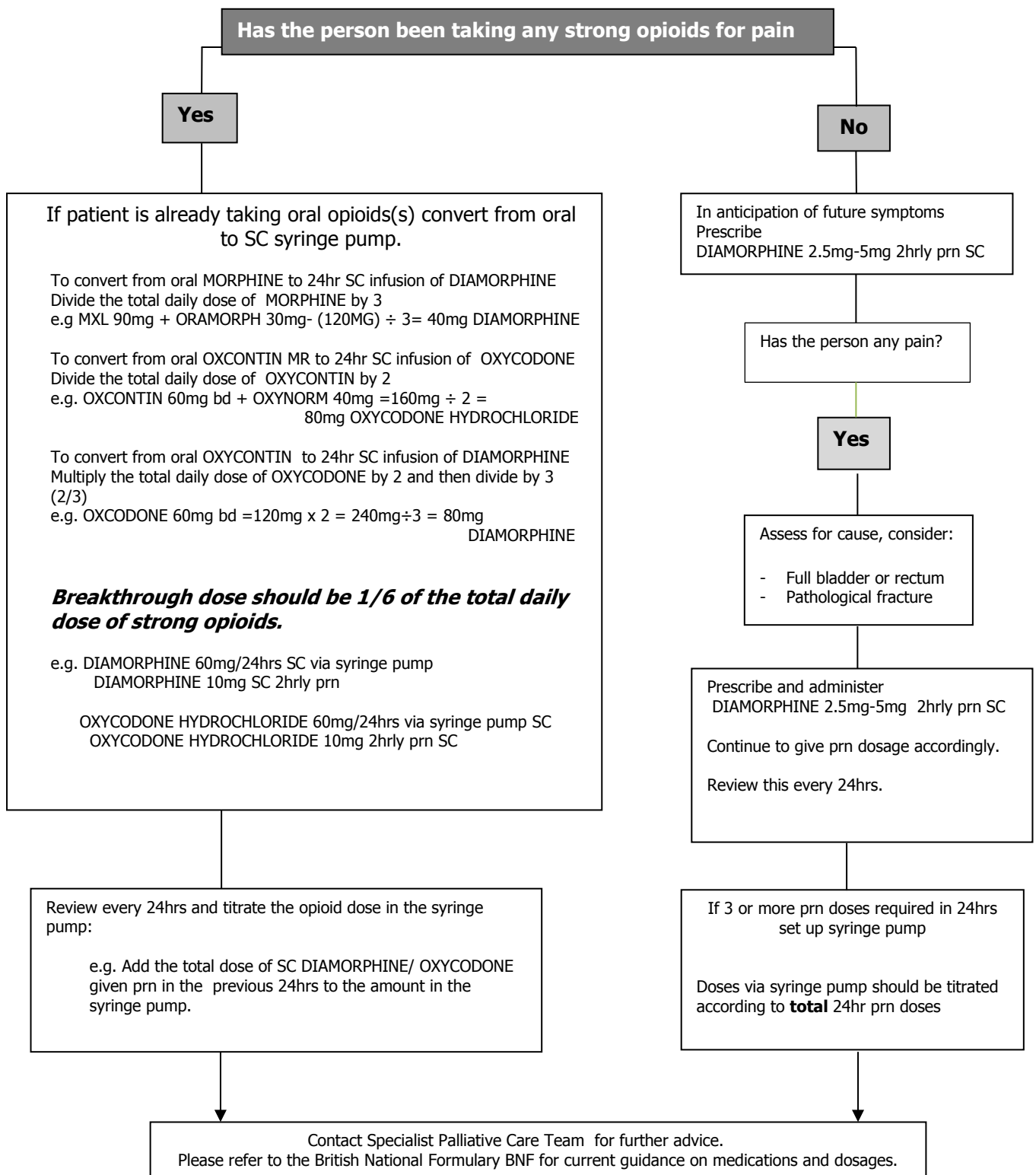
Breakthrough doses of subcutaneous DIAMORPHINE and MORPHINE for an individual on transdermal FENTANYL		
FENTANYL patch strength (micrograms / hour)	4 hourly dose of DIAMORPHINE subcutaneously (mg)	4 hourly dose of MORPHINE subcutaneously (mg)
25	5	5-10
50	10	15
75	15	25
100	20	30
150	30	45
200	40	60

Discontinuation of transdermal Fentanyl

- Discontinuation of transdermal Fentanyl is not straightforward, primarily because of the intradermal reservoir of drug which remains following removal of the patch.
- Caution must be exercised, since the addition of alternative opioids may result in significant respiratory depression.
- For advice on discontinuing fentanyl and using another opioid, **always** contact the Palliative Care Team, or hospice out-of-hours.

Example

PAIN



Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)

Date of issue: 01/06/2016

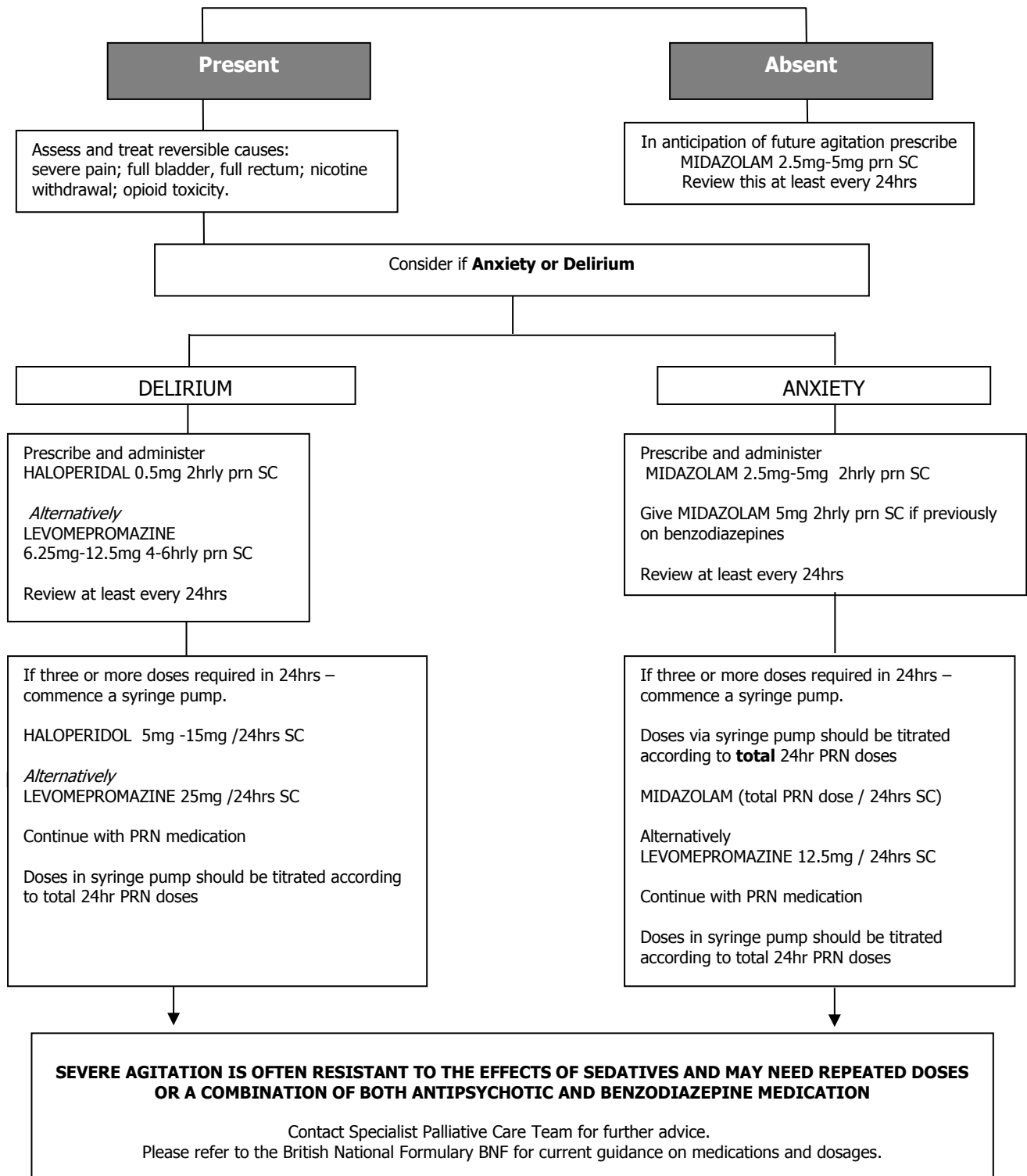
Date of review: 01/06/2018

Anxiety delirium and agitation

- Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them.
- Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.
- Consider non-pharmacological management of agitation, anxiety and delirium in a person in the last days of life.
- Treat any reversible causes of agitation, anxiety or delirium, for example, psychological causes or certain metabolic disorders (for example renal failure or hyponatraemia).
- Consider a trial of a benzodiazepine to manage anxiety, agitation or delirium.
- Consider a trial of an antipsychotic medicine to manage delirium or agitation.
- Seek specialist advice if the diagnosis of agitation or delirium is uncertain, if the agitation or delirium does not respond to antipsychotic treatment or if treatment causes unwanted sedation.

Example

Anxiety delirium and agitation



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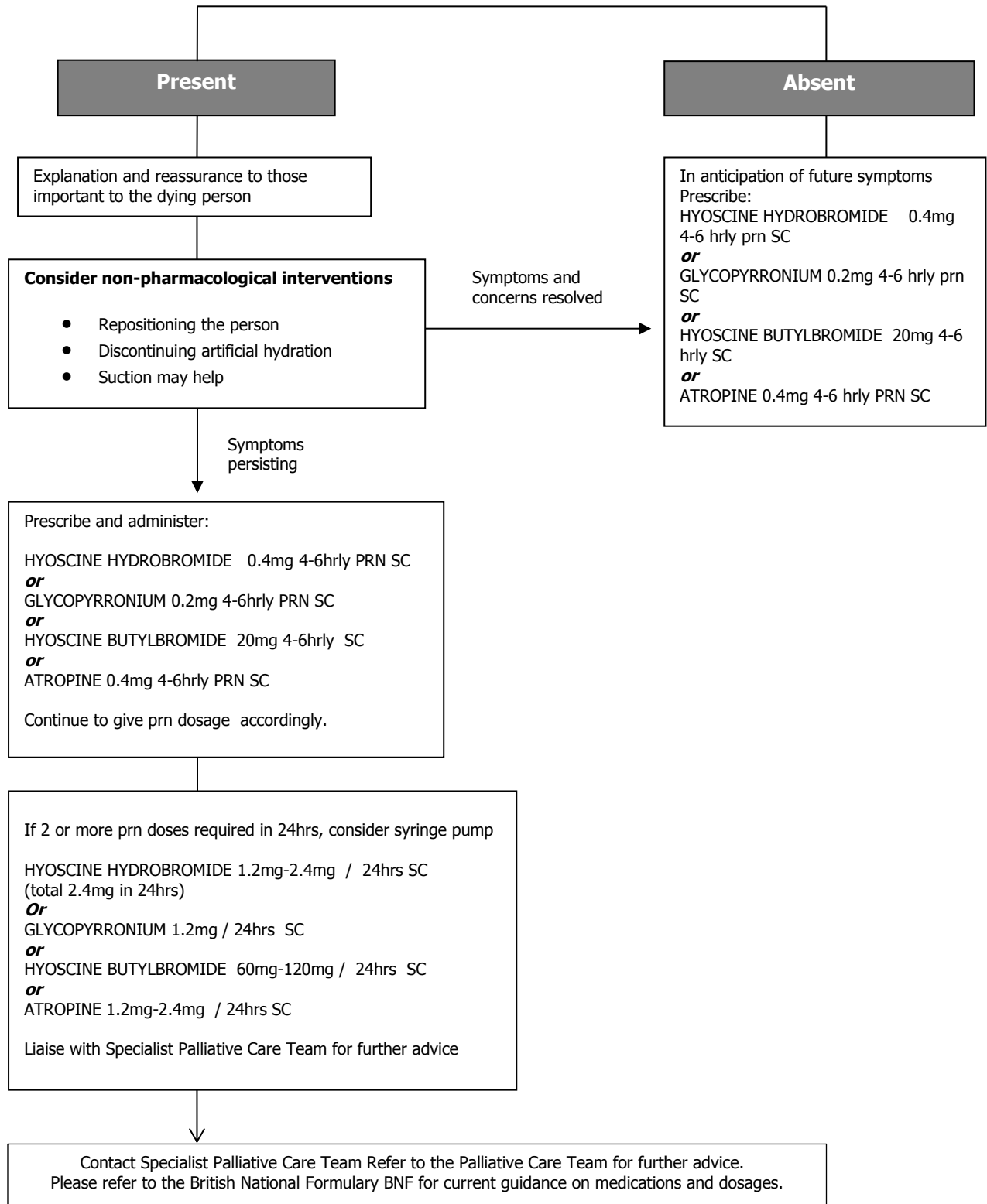
Respiratory tract secretions

Managing noisy respiratory secretions

1. Assess for the likely causes of noisy respiratory secretions in people in the last days of life. Establish whether the noise has an impact on the dying person or those important to them. Be prepared to talk about any fears or concerns either may have. Reassure those important to the dying person that, although the noise can be distressing, it is unlikely to cause discomfort.
2. Consider non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress in people at the end of life.
3. Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person's individual needs or circumstances, using **one** of the following drugs:
 - ATROPINE or
 - GLYCOPYRRONIUM or
 - HYOSCINE BUTYLBROMIDE or
 - HYOSCINE HYDROBROMIDE.
4. When giving medicine for noisy respiratory secretions:
 - Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
 - Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when using atropine³ or hyoscine hydrobromide³.
 - Treat side effects, such as dry mouth, delirium or sedation
5. Consider changing or stopping medicines if noisy respiratory secretions continue and are still causing distress after 12 hours (medicines may take up to 12 hours to become effective).
6. Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.

Example

Respiratory tract secretions



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Date of issue: 01/06/2016

Date of review: 01/06/2018

Nausea and vomiting

Assess for likely causes of nausea or vomiting in the dying person. These may include:

- certain medicines that can cause or contribute to nausea and vomiting
recent chemotherapy or radiotherapy
- psychological causes
- biochemical causes, for example hypercalcaemia
- raised intracranial pressure
- gastrointestinal motility disorder
- ileus or bowel obstruction

Discuss the options for treating nausea and vomiting with the dying person and those important to them

- consider non pharmacological methods for treating nausea and vomiting in a person in the last days of life

When choosing medicines, take into account:

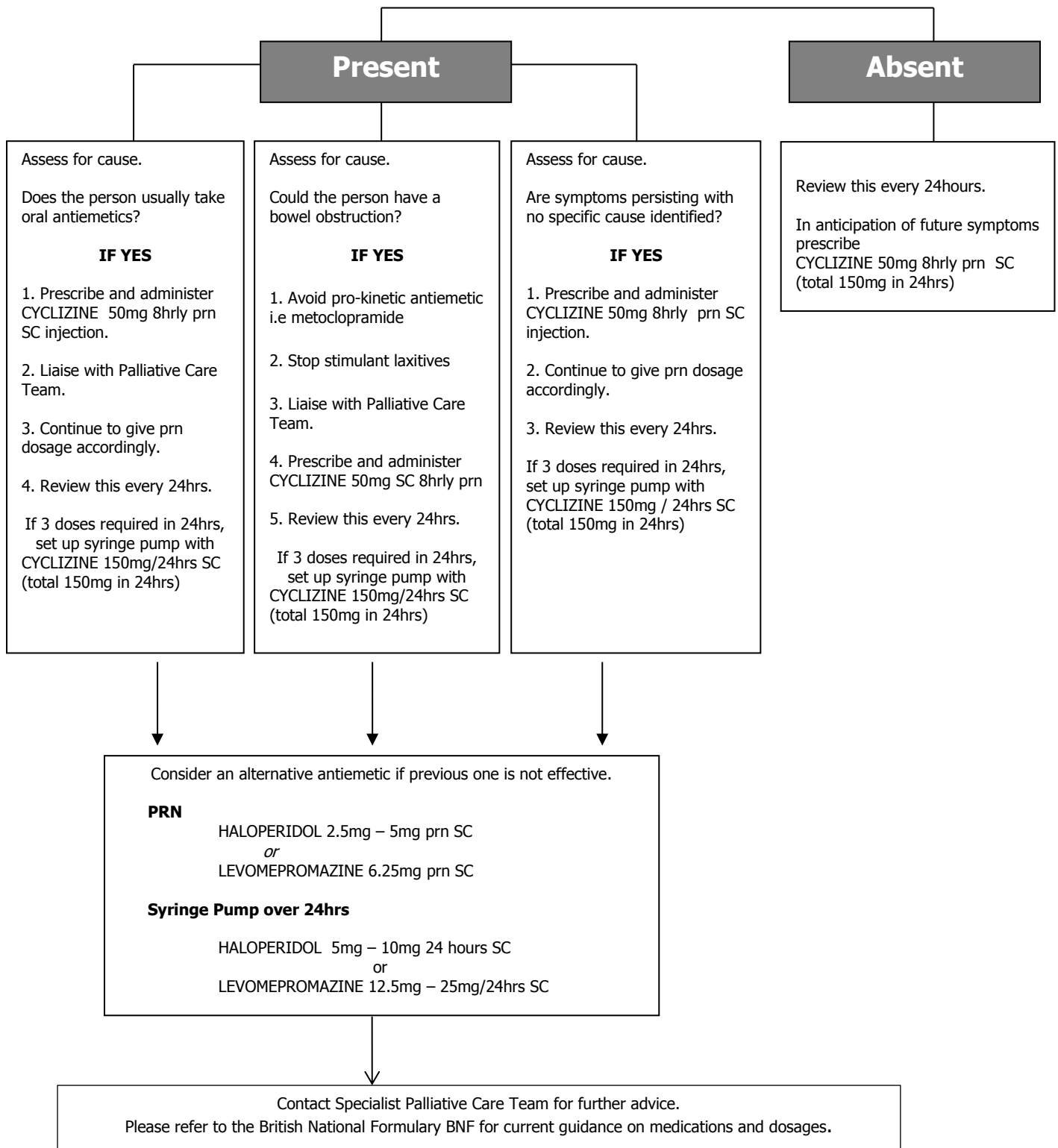
- the likely cause and if it is reversible
- the side effects, including sedative effects, of the medicine
- other symptoms the person has
- the desired balancing of effects when managing other symptoms
- compatibility and drug interactions with other medicines the person is taking

For people in the last days of life with obstructive bowel disorders consider:

- HYOSCINE BUTYLBROMIDE as the first line pharmacological treatment
- OCTREOTIDE if the symptoms do not improve within 24 hours of starting treatment with HYOSCINE BUTYLBROMIDE
- CYCLIZINE is **not** recommended in people with heart failure.

Example

Nausea and Vomiting

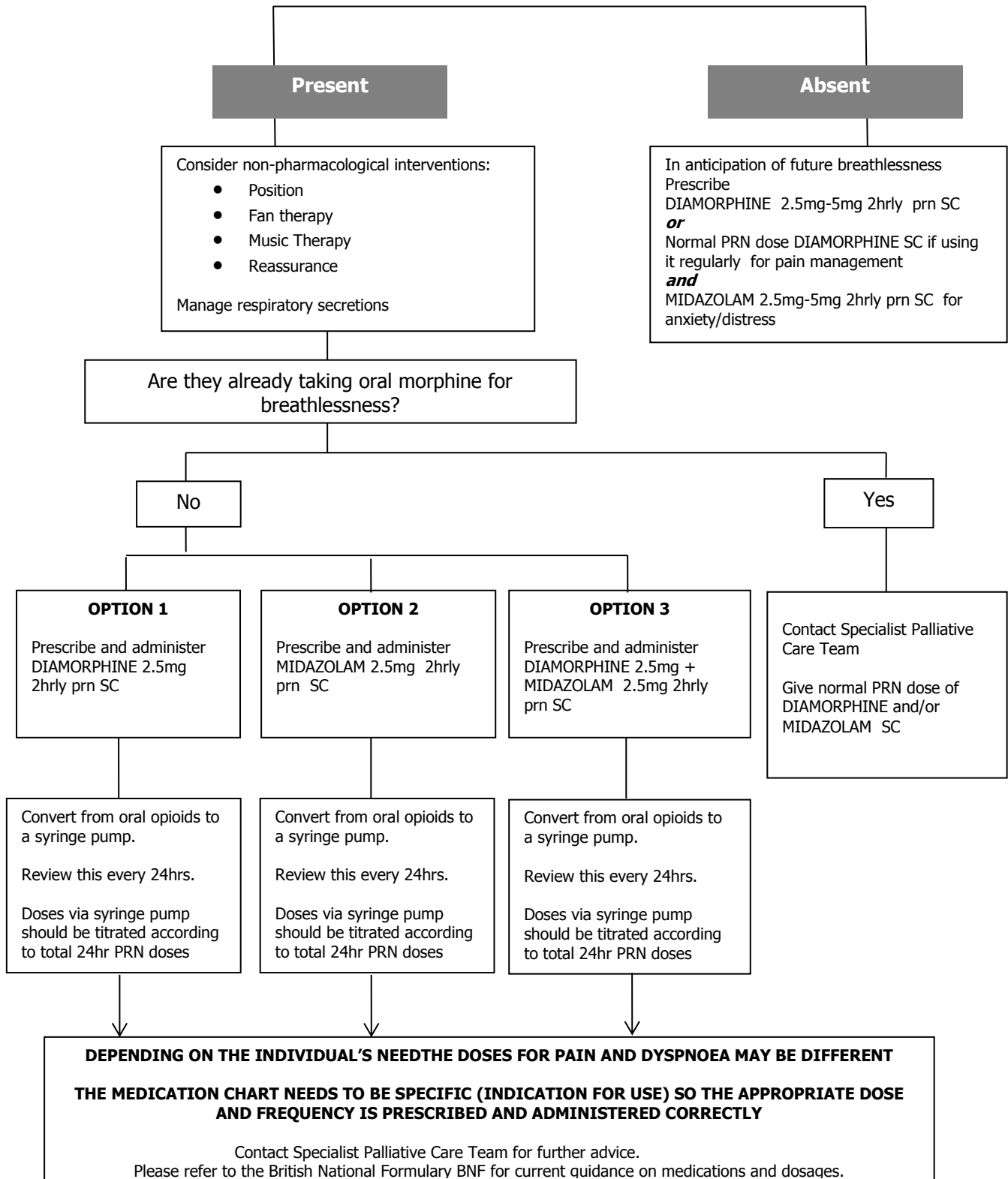


Dyspnoea

Managing breathlessness

1. Identify and treat reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion.
2. Consider non-pharmacological management of breathlessness in a person in the last days of life. Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.
3. Consider managing breathlessness with:
 - an opioid¹ or
 - a benzodiazepine¹ or
 - a combination of an opioid¹ and benzodiazepine¹.

¹At the time of publication (December 2015), this medication did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

EXAMPLE**Dyspnoea**

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)

Date of issue: 01/06/2016

Date of review: 01/06/2018

Community Anticipatory Prescribing for the Dying Person.

Use an individualised approach to prescribing anticipatory taking into account symptoms such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain.

When deciding which anticipatory medicines to offer take into account the place of care and the time it would take to obtain medicines especially out of hours.

Community Prescriptions can be written using the following wording:

Analgesic:

Diamorphine Hydrochloride injection (5mg ampoules)
Dose: 2.5mg-5mg, 2hourly prn SC for **pain** or **breathlessness**.
Supply 5 (five) 5mg ampoules.

Anxiolytic sedative:

Midazolam injection (10mg in 2ml ampoules)
Dose: 2.5mg-5mg, 2hourly prn SC for **anxiety/distress/myoclonus**.
Supply 10 (ten) 2ml ampoules.

Anti-secretory:

Hyoscine Hydrobromide injection (400mcg/ml ampoules)
Dose: 400mcg, 6hourly prn SC for **respiratory secretions**.
Maximum of 2400mcg (2.4mg) in 24 hours via syringe pump SC
Supply 5 ampoules.

Antiemetic:

Cyclizine injection (50mg/ml ampoules)
Dose: 50mg, 8 hourly prn SC for **nausea**.
Supply 5 ampoules.

or

Levomopromazine injection 25mg/ml
Dose: 6.25mg, 6 hourly prn SC for **nausea**.
Supply 5 ampoules.

Dilution

Water for injection 10mls
Supply 20 ampoules

Syringe Pump

The CME McKinley T34 syringe pump is a portable, battery operated device for delivering medication by continuous subcutaneous infusion (CSCI).



This syringe pump is the **only 24 hour pump** to be used (on the Isle of Man) for symptom management of palliative care individuals when the oral route cannot be used.

ALL STAFF WHO USE THE McKINLEY T34 SYRINGE PUMP MUST HAVE TRAINING BEFORE THEY USE THE PUMP AS PART OF THEIR CARE.

Breakthrough Pain

- If the syringe pump is being used to administer opiate analgesia such as Diamorphine, then extra breakthrough analgesia must be prescribed and administered as a subcutaneous injection
- Dosage will be calculated as a **sixth** of the **total 24 hour infusion**
- Separate subcutaneous injections should be prescribed as required

If a patient can no longer swallow oral meds and is in pain consider initially managing them with SC bolus injections, if they need 2 -3 or more injections in 24 hours set up a syringe pump.

Start the syringe pump immediately if the person has pain and:

- is not currently on any opioid OR
- is receiving opioid on an `as required` basis OR
- is receiving immediate release oral opioid preparation e.g. Oramorph; Oxynorm.
- persons on modified release oral opioid preparation e.g. MST®; MXL®

Ideally, start the syringe pump when the next dose of modified release preparation is due, but particularly in the community setting, this may not be a convenient or safe time. A decision on an appropriate time should be based on the clinical status of each individual person. All drugs should be mixed with water for injection unless contraindicated.

- **Octreotide, Ketorolac, Ketamine should be mixed with *normal saline*.**
- Please use conversation charts and flow diagrams for guidance when prescribing medication for a syringe pump.

Drug compatibility

It is common to see two drugs in a syringe pump, but if more drugs than this are required for symptom management it is advisable to contact the Palliative Specialist team for advice, as not all drugs are compatible or stable. Some drugs may be physically or chemically incompatible. Please check the BNF for drug compatibilities.

- Use a **20ml luer lock syringe** and draw up the prescribed medication and diluents to **17mls**.
- If a **30ml luer lock syringe** is recommended, draw up the medication and diluents to **23.5ml**.

Factors which may affect stability/compatibility are:

- drug concentration; brand/formulation; diluents; time interval; temperature of surroundings; exposure to light; order of mixing; delivery system material.

Oral treatment is to be re-started

If an oral modified release preparation is being commenced, the continuous subcutaneous infusion should be stopped when the first dose of modified release oral opioid is administered. The person may require breakthrough medication more frequently until therapeutic levels are reached.

Key references

Dickman A: *The syringe driver: continuous subcutaneous infusions in palliative care*. 2nd Edition, 2004. OUP.

Community / Care Home Guidance

Is the person dying? BEFORE YOU CALL 999...

- H HAS!** –the individual got DNA-CPR (do not attempt cardiopulmonary resuscitation) or an Advanced Directive to Refuse Treatment (ADRT)?
- O OPTIONS!** – are the symptoms acute or longstanding? What medication / treatments have been trialled? Might symptoms be better managed with a different route of administration?
- S SYMPTOMS!** - can any of the symptoms be reversed by any treatment that you can give? Have you liaised with the G.P./Palliative Care Team for advice?
- P PPC!** Does the individual have an advance care plan e.g. Preferred Priorities for Care (PPC)? Consider, does the individual wish to be transferred to hospital or to be managed within the care home?
- I IS!** the individual entering the dying phase of their life? Consider if the person is well enough to be moved.
- T TEAM!** Has the multidisciplinary team (MDT) identified this individual as coming to the end of their life? If so, have the MDT been involved in the decision to transfer the individual to hospital.
- A AMBULANCE SERVICE!** If the individual has a PPC, ADRT and/or DNA-CPR in place and needs to be transferred by ambulance to hospital, you need to inform the service and have copies of these documents available with the transfer form.
- L LISTEN TO THE INDIVIDUAL & FAMILY!** Have you discussed with the individual/family their possible admission to hospital? Have you discussed with the individual/family that PPC may not be achieved if they are admitted to hospital.

N.B If the individual is not in the dying phase of life and symptoms are acute and potentially reversible then admission would be appropriate with a view to rapid discharge back home.

Points to Remember

1. Recognise deterioration in a person – could this be a sign that they are dying?
2. Keep the person / family informed of any changes in care.
3. Stop unnecessary treatment and medication.
4. Prescribe anticipatory medication on an individual basis only - convert oral to SC medication if they are unable to swallow medication or if unlikely to be able to within the next few days.
5. Review the Do Not Attempt Cardiopulmonary Resuscitation Order. Documentation completed. Communication with the person (if conscious and willing) and those important to them.
6. Assess and monitor symptoms as they occur or at least every 24hrs.
7. Consider a syringe pump - discuss as far as possible the reasoning with the person and those important to them.
8. Support the person to take food and fluids by mouth for as long as tolerated. Communicate to them if appropriate, and those important to them the reduced need for food and fluids in the dying phase.
9. Assess the need for artificial hydration taking into account the person's wishes and needs.
10. If the person has an Implantable Cardioverter Defibrillator (ICD), contact the person's cardiologist. Refer to ECG technician and to local guidelines re deactivating it.
11. Prepare for any specific religious, spiritual or cultural need a person might have and support as necessary.
12. If the person is an Insulin Dependent Diabetic, contact Diabetes CNS for further guidance.
13. On rare occasions a person's condition may improve.
Seek a second opinion or specialist palliative care support as needed.

Hospice Isle of Man

Specialist palliative care services offer telephone advice, a single assessment visit or a period of specialist care according to need.

Referral

Can be made for an individual who has any life limiting illness, and is in or is entering the end of life phase of their illness, if they have;

- complex end of life care needs.
- uncontrolled pain or other symptoms.
- complex physical, psychological, spiritual or family needs that cannot be met by the staff

A referral should be sent or faxed to Hospice Isle of Man. Referrals will be triaged at 9.30am each morning. Please be aware individuals may not be seen on the same day as referral sent. If a visit is needed as a matter of urgency please contact the service to see if arrangements can be made.

Palliative Care Clinical Nurse Specialist Team (CNS)

Available Monday to Friday 9am-5pm

Hospice Isle of Man

Tel. 01624 647475 (team office with answerphone)

01624 647400 (hospice reception)

Fax: 01624 647460

Palliative Care out of hours

- Contact Hospice Isle of Man Reception. A senior doctor and/or nurse is available to give telephone advice on complex symptom management.
- Contact Manx Emergency Doctors Service (MEDS) – may need to visit and review individual.