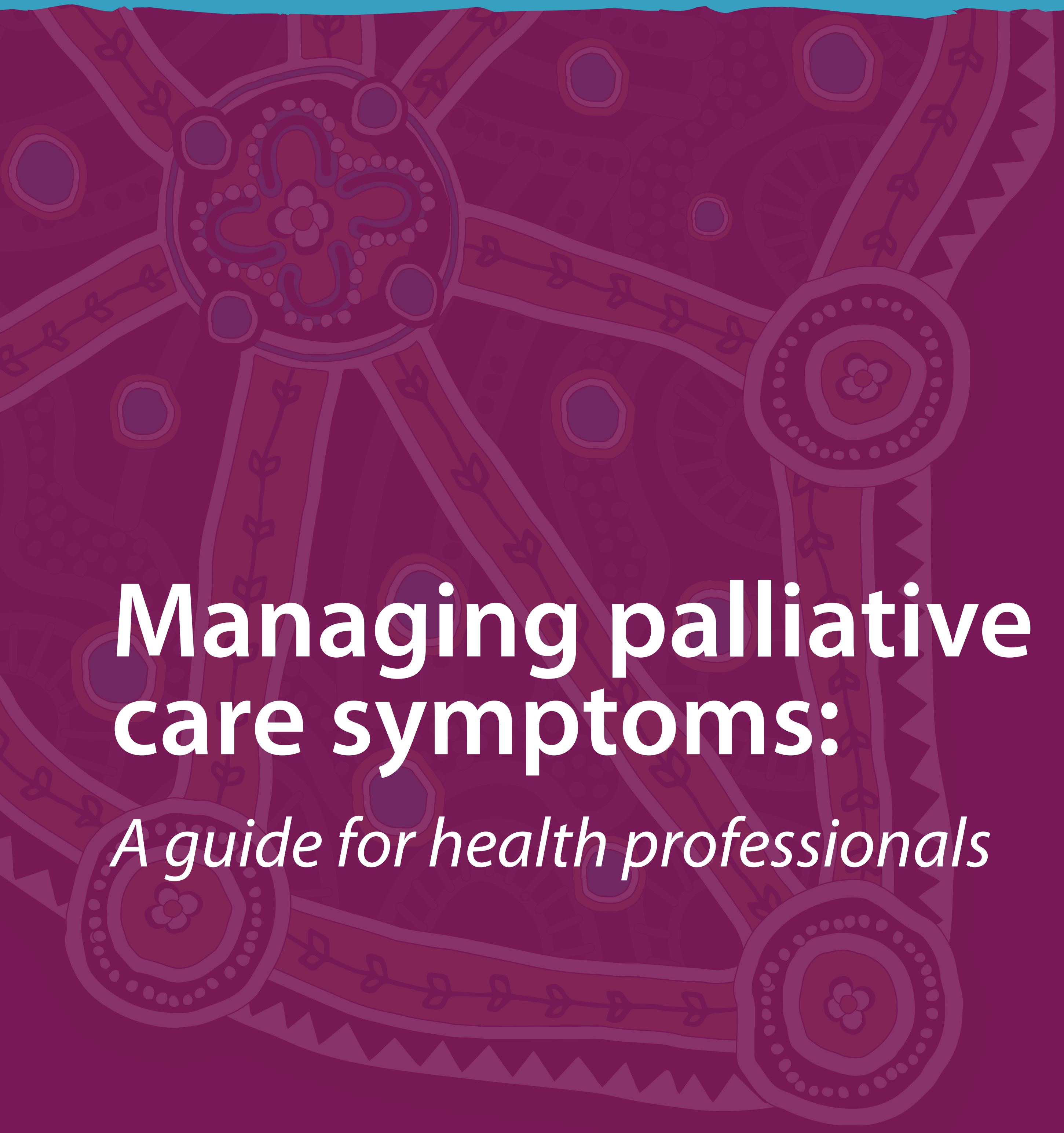

Managing palliative care symptoms:

A guide for health professionals

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@home

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Disclaimer

This document is intended as a guide for health professionals to assist them to support families who are caring for a person who chooses to die at home, if this is possible.

While the Brisbane South Palliative Care Collaborative has exercised due care in ensuring the accuracy of the material contained in this Guide, it is only a general guide to appropriate practice, to be followed subject to the clinician's judgement and the family's preferences in each individual case.

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Acknowledgement

caring@home acknowledges the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander people.

caring@home for Aboriginal and Torres Strait Islander Families is funded by the Australian Government and led by Brisbane South Palliative Care Collaborative.

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PART ONE:

Providing culturally responsive care

Providing culturally responsive care

This Guide focuses on symptom management during end of life. Symptom management is one aspect of holistic palliative care which is person-centred and culturally appropriate.

Care needs to respect the diversity of individuals and cultures within Aboriginal and Torres Strait Islander communities. Differences in beliefs, practices, cultural needs, social conditions and past experiences will impact on an individual's decision-making and needs during end of life.

Recent research highlights the need for health professionals and clinical services to incorporate a trauma-informed approach to care that considers the impact of past individual experiences and past Government policies.

It is beyond the scope of this Guide to educate health professionals about how to provide culturally responsive care but there are many resources available from Federal, State and Territory governments and other jurisdictions. These include plans, frameworks, tools, online learning opportunities and clinical placements.

More information

- Gwandalan provides a series of engaging eLearning modules to support frontline staff to deliver culturally responsive palliative care and an interactive resource for frontline staff containing tools and resources to provide person-centred, culturally responsive palliative and end-of-life care. https://gwandalanpalliativecare.com.au/
- IPEPA provides workshops and resources on culturally responsive palliative care for Aboriginal and Torres Strait Islander people. https://pepaeducation.com/about-ipepa/
- The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation that provides a platform to amplify the voices and lived experience of Stolen Generations survivors and their families. It promotes trauma-aware, healing-informed practice to help government, policymakers, and workforces understand their role in intergenerational healing. https://healingfoundation.org.au/

PART TWO:

Managing common symptoms that may be experienced by people in the terminal phase

Managing agitation/restlessness in the terminal phase (last days of life)

What is it?

Agitation/restlessness, also known as terminal restlessness, is a term that describes agitated/restless and unsettled behaviour.

Agitation/restlessness during the end of life is very common however the causes are not well understood medically.

Agitation/restlessness can begin suddenly or gradually. It can be transient.

Contributing factors/causes

- Emotional, cultural and spiritual reasons such as past trauma, totem mimicking, ancestor beliefs and preparing for the Dreaming
- Disease progression – Parkinson's disease, metabolic disturbances, cancer, organ failure, infection
- Unmet needs – full bladder, soiled bedding
- Uncontrolled symptoms e.g. pain or nausea, bed sores, pressure areas
- Medicines – new, overuse or underuse of existing medicines, side effects of medicines

What impact does it have?

Agitation/restlessness can be distressing for the person and their family.

The person may appear different to normal and act in ways that is hard for the family to understand and cope with.

Management

Educating the carer/family to help manage agitation/restlessness at home

Using the tip sheet for carers/families called 'Helping with restlessness' explain to the carer/family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, when agitation or restlessness begins, what makes it worse, what makes it better
- Assess for reversible causes such as unmet needs - full bladder, pain, dry mouth
- Assess for signs of other causes e.g. soiled clothing, breathing difficulties
- Involve other members of the clinic team or the community e.g. Elders, traditional healers, pastoral care, counselling
- Speak in a calm, quiet voice
- Assess the environment. Is it noisy? Too many people? Is the person overstimulated?
- Encourage the person and their family, if possible and appropriate, to connect to Country and talk about things important to the person

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory sedative medicines
- Teach the family how to manage subcutaneous medicines prescribed for agitation
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

Managing anxiety in the terminal phase (last days of life)

What is it?

Anxiety is a feeling of worry or fear about something with an uncertain outcome.

Anxiety is a common symptom experienced by people at end of life. Anxiety about dying is a common reaction to approaching death. Often it is expressed as fear; of the manner in which a person will die, when it is likely to occur and how their leaving will impact on family.

Feelings associated with anxiety can include fear, dread, sadness, apprehension and uncertainty.

Anxiety can fluctuate in severity.

Contributing factors/causes

- Emotional e.g. thoughts of loss, what happens into the Dreaming, past trauma, past history of anxiety/depression, unresolved conflicts
- Physical e.g. symptoms such as pain, nausea or fatigue, deterioration
- Withdrawal of substances such as alcohol or other recreational drugs

What impact does it have?

Anxiety can cause:

- Physical symptoms such as pain, breathing changes, fast heart rate, dizziness, nausea, upset gut, poor appetite, overeating, substance use, tremors and sweating, restlessness and being unsettled
- Emotional symptoms such as crying, excessive laughing, fast or erratic thoughts, loneliness, guilt, anger, sadness, aggression, frustration.

High levels of anxiety can result in complicated grief for those who cared for the person. In complicated grief, painful emotions become so long lasting and severe that it is difficult to recover from the loss and resume life.

Management

Educating the family to help manage anxiety at home

Using the tip sheet for carers/families called 'Helping with stress' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, what is making the person anxious, what makes it worse, what makes it better
- Check for unmet needs
- Encourage person and their family, if possible and appropriate, to connect to Country and talk about things important to the person
- Involve other members of the clinic team or the community e.g. Elders, traditional healers, pastoral carers, counsellors
- Ensure that you give the sick person and their family accurate information about the condition and what to expect using an open communication style
- Ensure that symptoms are being managed optimally
- Respect for the way the sick person copes and respect their decision about whether or not to explore feelings of anxiety
- Plan strategies and interventions collaboratively and consider discussing trauma-informed approaches

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-anxiety medicines
- Teach the family how to manage subcutaneous medicines prescribed for anxiety
- Troubleshoot if the family is giving subcutaneous medicine - is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

Managing delirium in the terminal phase (last days of life)

What is it?

Delirium refers to a recent onset of fluctuating levels of confusion and altered consciousness. Typically, people show a decreased ability to concentrate and may become agitated. They can become disorientated and impulsive.

Delirium is variable in severity, occurrence and duration.

There may be changes in mood, arousal, and behaviour ranging from hyperactive to hypoactive.

Delirium is a common symptom towards the end of life.

Contributing factors/causes

- Physical causes:
  - Organ failure at end of life particularly renal failure
  - Other e.g. underlying disease, co-morbidities, infection, metabolic imbalances, hypoxia, constipation, retention
- Medicines
- Cultural or spiritual causes e.g. past trauma, totem mimicking, ancestor beliefs and preparing for the Dreaming
- Withdrawal of substances such as alcohol or other recreational drugs

What impact does it have?

Delirium can cause significant distress to patients and carers/families because the person is not behaving in their normal way.

A person can experience hallucinations which can be visual, audible, preceptory, tactile, gustatory and olfactory.

Delirium may cause inappropriate behaviour when communicating with others.

HOW TO

Management

Educating the family to help manage delirium at home

Using the tip sheet for carers/families called 'Helping with worrying visions, sounds, thoughts' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines.
www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and family members
  - Establish whether the changes of consciousness are distressing for the person. If not, encourage the family to simply remain with the person.
  - Ask the family to identify what makes it worse? What makes it better?
- Assess the environment – Is it noisy? Too many people? Person overstimulated? – and help family to provide a calm environment
- Assess for unmet needs
- Collaboratively explore with patient and family other considerations such as cultural or spiritual causes e.g. past trauma, totem mimicking, ancestor beliefs and preparing for the Dreaming
- Involve other members of the clinic team or the community e.g. Elders, traditional healers , pastoral care, counselling
- Reassure the family and provide education and support

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-psychotic medicines
- Teach the family how to manage subcutaneous medicines prescribed for delirium
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

Managing dyspnoea in the terminal phase (last days of life)

What is it?

Dyspnoea is a feeling of shortness of breath, breathing difficulty or inability to breathe.

Dyspnoea can be described differently including: can’t get enough air, feeling suffocated, can’t breathe out, chest tightness, short of wind.

Contributing factors/causes

There are many and varied causes of dyspnoea. Common ones include:

- Worsening conditions e.g. cancer, chronic diseases especially heart disease, lung disease
- Psychological distress
- Symptoms such as pain, anxiety, worry and disconnection.

What impact does it have?

Dyspnoea can be a debilitating and frightening symptom causing fear and panic in the affected person and their family alike.

It can cause changes in the person such as faster heart rate and breathing, “jelly legs”, panic attacks, dizziness, irritability, tiredness, fear and stomach cramps and/or diarrhoea.

Dyspnoea can have other impacts including:

- Inability to interact with other people and do things once enjoyed
- Reduced appetite and food intake
- Fatigue
- Depression.

HOW TO Management

Educating the family to help manage dyspnoea at home

Using the tip sheet for carers/families called 'Helping with short of breath' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, what makes the dyspnoea worse, what makes it better, how distressing is it, when it happens
- Address any barriers for pharmacological management of dyspnoea e.g. fear of opioids
- Involve other members of the clinic team or the community e.g. Elders, traditional healers , pastoral carers
- Help the family to make the person comfortable and relaxed and provide distraction e.g. pets, reading, music, family, friends, looking at photos
- Help the person with breathing exercises to take deeper, slower breaths
- Encourage the person to reduce their activity. Some strategies include getting the person to:
  - Do small achievable tasks e.g. urinate in a bottle rather than using the toilet
  - Stop when they feel breathless so it does not escalate
  - Use a robe instead of towel for drying after a shower
- Change the person's position e.g. to sitting more upright and leaning on chair or table
- Open a window or fan the person to increase cool air flow around the face

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory medicines to treat dyspnoea
- Teach the family how to manage subcutaneous medicines prescribed for dyspnoea
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

Managing nausea and/or vomiting in the terminal phase (last days of life)

What is it?

Nausea is the feeling of sickness in the gut and/or the sensation of wanting to vomit. Vomiting is the forceful expulsion of the contents of the stomach through the mouth.

Nausea may occur with or without vomiting. Vomiting may occur with or without nausea.

Dry retching feels like vomiting but occurs without stomach contents being expelled through the mouth.

Contributing factors/causes

Nausea and vomiting can have many different causes. Often there is more than one cause.

Some causes are:

- Disease progression
- Treatments such as radiation or chemotherapy
- Symptoms e.g. dyspnoea
- Medicines.

People can also experience nausea due to eating or smelling certain odours or just thinking about food.

What impact does it have?

If a person feels nauseous, they may be less likely to want to interact with their family and the people around them. Nausea decreases a person's ability to enjoy life. The person is less likely to eat and drink and may be more likely to be irritable or cranky.

Management

Educating the family to help manage nausea and/or vomiting at home

Using the tip sheet for carers/families called 'Helping with feeling sick in the gut' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

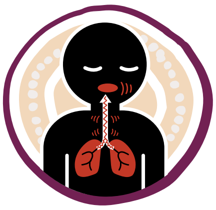
Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, when nausea and/or vomiting occurs and what makes it worse
- Assess and treat if not burdensome, any reversible causes of the nausea and/or vomiting e.g. constipation, severe pain, medicines
- Involve other members of the clinic team or the community e.g. Elders, traditional healers
- Encourage mouth care using swabs and lubricants to the mouth and lips
- Encourage family to avoid activities that causes the person to feel nausea and/or to vomit
- Explain to the family that they should not force the person to eat and drink

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-emetic medicines
- Teach the family how to manage subcutaneous medicines prescribed for nausea and/or vomiting
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.



Managing noisy, rattly breathing in the terminal phase (last days of life)

What is it?

Noisy, rattly breathing is normally caused by secretions building up in the airways. It occurs because as a person approaches death, the brain closes down and people no longer feel the need to swallow or clear secretions in their airways. Often the person is unconscious when noisy, rattly breathing begins.

Contributing factors/causes

- Brain failure as death approaches
- General weakness
- Weakening of the swallowing and breathing muscles
- Unconsciousness or lapsing consciousness
- Heart failure
- Inflammation
- Infection

What impact does it have?

The person is unlikely to be aware of, or distressed by, the rattly breathing noise when it occurs at end of life. However, family can be quite distressed when they hear the sound, fearing that it must be uncomfortable for the person.

Some research and Elder knowledge indicates that noisy rattly breathing is a sign that the person is close to passing.

Management

Educating the family to help manage noisy, rattly breathing at home

Using the tip sheet for carers/families called 'Helping with rattly breathing' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

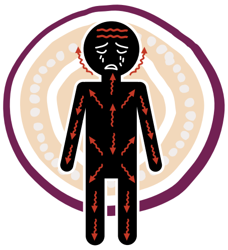
Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Explain that the person is unlikely to be distressed by the noisy, rattly breathing
  - Normalise the symptom
- Involve other members of the clinic team or the community e.g. Elders, traditional healers
- Position the person on their side and elevate the chest and head to potentially change the sound of the breathing; only do this if this does not cause distress to the person
- Show the family how to keep the person's mouth clean and how to moisten and lubricate the lips

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-secretory medicines
- Teach the family how to manage subcutaneous medicines prescribed for noisy, rattly breathing
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.



Managing pain in the terminal phase (last days of life)

What is it?

Pain is a complex personal feeling. It is different for each person and is as intense as the person says it is.

Pain may occur in more than one location and a person may experience more than one type of pain at a time. It can be mild, moderate or severe and can change each day.

Types of pain

Pain can be classified as:

- Soft organ and body tissue pain
  - often described as deep or cramping
- Bony pain
  - often described as aching or throbbing
- Nerve pain
  - often described as burning, tingling, shooting, stabbing or having a numbing sensation

Incidental pain is pain that occurs in certain circumstances e.g. it may occur with particular movements such as getting out of bed or bathing.

Contributing factors/causes

- Physical e.g. disease, injury, wounds
- Cultural or spiritual e.g. past experiences or trauma
- Emotional e.g. sadness, anxiety, lack of sleep, worry
- Other e.g. movement, posture, activity levels

What impact does it have?

Pain can reduce a person's ability to enjoy life and have a negative effect on relationships. It can cause a person to become angry, confused, sad, agitated, withdrawn, more sleepy, frustrated, unsettled, less functional and less independent.

Uncontrolled pain can cause a person to experience unnecessary or unwanted distress at end of life.

It can contribute to complicated grief in family members. In complicated grief, painful emotions become so long lasting and severe that it is difficult to adjust to the loss of the person and for the family to resume life.

HOW TO Management

Educating the family to help manage pain at home

Using the tip sheet for carers/families called 'Helping with pain' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

Emphasise to the family that if the person looks comfortable, they do not need to do anything.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/family are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, how the pain is described, where it occurs, when it occurs, what makes it better or worse
- Answer any questions the carer/family have about managing pain
- Use a pain tool scale to help monitor levels of pain
- Organise support equipment if needed e.g. comfortable mattress
- Address any barriers to optimal pain management e.g. fear of morphine
- Involve other members of the clinic team or the community e.g. Elders, traditional healers, pastoral carers, counsellors
- Help the family to make the person comfortable and to provide distraction e.g. pets, reading, music, family, friends, looking at photos
- Use gentle range of motion exercises or gentle rubbing to warm up the joints and limbs before big movements

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-analgesic medicines
- Teach the family how to manage subcutaneous medicines prescribed for pain
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?
- If incidental pain is occurring, medicine should be given at least 20-30 minutes before any task that requires moving the person is performed.

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

Note that there are many classes of medicines that can be used to manage pain at end of life. Sometimes a person may need more than one type of pain medicine.

Further information

Opioids

Strong pain medicines such as opioids are often used to manage pain at end of life. These medicines are safe and effective.

Opioids can have side effects that can be managed:

- **Constipation**
  This is the most common side effect of opioids. The doctor or nurse practitioner can order laxatives to be taken regularly to correct this.
- **Nausea and/or vomiting**
  This symptom may be limited to when a person first starts taking opioids. The doctor or nurse practitioner can order medicines to correct this.
- **Drowsiness or poor concentration**
  This often only last for a short while after the person starts to use opioids.
- **Dry mouth**
  This can be helped by frequent sips of fluid or other ways to lubricate the mouth.

Other less common side effects that should be reported to the clinic team include: decreased breathing rate, jerking of limbs or confusion.

A common misconception is that pain medicines at the end of life can cause dependence or addiction. Any concern about possible dependence or addiction can lead to under-usage of opioids and can lead to loss of pain control. Concern about physical and psychological dependence is never a reason to delay giving an opioid if required. Encourage conversations to dispel any concerns about the therapeutic use of opioids.

A person's tolerance to a particular medicine may increase and more medicine may be needed as illness progresses. This is quite normal.

Understanding morphine

A booklet, produced by the Cancer Council Queensland for Aboriginal and Torres Strait Islander people, about how morphine can be used to treat pain and shortness of breath may be useful.

Understanding Morphine.pdf (cancerqld.org.au)

Managing seizures in the terminal phase (last days of life)

What is it?

Seizures are abnormal bursts of brain activity in part(s) of the brain that disrupt normal brain function. Seizures can occur at any time, with or without the person knowing, and can occur when awake or asleep.

Some people will have a history of seizures from a known medical condition. Others can develop seizures due to terminal illness.

Types of seizures

- Focal seizures occur in one hemisphere of the brain. They are associated with:
  - awareness that can be altered or retained
  - increased or decreased motor contractions lasting for short or prolonged periods resulting in twitching or tremors
  - sensory features such as changes to vision or aura
  - autonomic features such as nausea, vomiting, pallor, tachycardia.
- Tonic clonic seizures involve both sides of the brain and can occur in different areas of the brain. They result in:
  - changes to levels of consciousness
  - increasing muscle tone, falls or changes to sensation, function or strength
  - jerking of different parts of the body, either one side or both sides of the body or the whole body
  - loss of awareness
  - periods of loss of consciousness post seizure
  - loss of bodily functions.

Precipitating factors/causes

- Physical e.g. brain tumours , haemorrhages or abscesses, fluid and electrolyte imbalances, blood imbalances, changes to blood sugar levels, kidney failure, liver failure, side effects of treatments, infections and fevers
- Drug and alcohol use or withdrawal
- Stress or lack of sleep
- Medicines

What impact does it have?

Seizures at the end of life can be frightening for all involved especially if they last more than a few seconds.

After a seizure the person may be impacted for hours or days and may appear sleepy, confused, stiff and/or withdrawn or they may experience headache and lack of appetite.

HOW TO Management

Educating the family to help manage seizures at home

Using the tip sheet for carers/families called 'Helping with fitting' explain to the family:

- What to look for
- How to help including how to give subcutaneous medicine.

If you need to, complete the online modules about how to teach carers/families to manage breakthrough symptoms at home using subcutaneous medicines. www.caringathomeproject.com.au. There is also education on this topic in Part Five of this Guide.

Non-pharmacological management

- Acknowledge the good work the carer/amily are doing looking after their loved one at home
- Create a therapeutic relationship with the person and their carer/family
- Talk with the person and other family members
  - Carers/families should be encouraged to note, if possible, how long seizures last or anything unusual that happened beforehand
- Educate the family about possible causes and ongoing management of seizures
- Explain to the family how to keep the environment around their loved one safe and reduce the risk of injury and harm
- Educate the family about how to respond to a seizure

Pharmacological management

- Review current medicines
- Liaise with the doctor or nurse practitioner to ensure appropriate medicines are prescribed including anticipatory anti-seizure medicine
- Teach the family how to manage subcutaneous medicines prescribed for seizures
- Troubleshoot if the family is giving subcutaneous medicine. Is the insertion site intact? Are medicines being stored correctly? Are medicines in date?

Remember the person may have a syringe driver connected that delivers background medicine at a constant rate over 24 hours. The syringe-driver cannula has a side port that can be used to administer extra medicines for symptom control. Alternatively, a separate cannula may have been inserted for extra doses of symptom relief.

PART THREE:
Recognising when a person is getting closer to dying/has died

Recognising when a person is getting closer to dying

Recognising when someone is getting closer to dying can be difficult but it is an important skill that allows health professionals to prepare the patient (if possible), the family and carers for what is to happen. Most people do not know what to expect as a person dies and may be afraid. Simple explanations of probable processes are likely to help them through this difficult time.

There are common signs indicating that a person is in the last days of their life. Please note that these signs vary between individuals.

Some common signs include:

- Sleeping more
- Being less responsive and less interested or able to communicate
- Spending more time in bed
- Little interest in food or drink
- Difficulty in swallowing
- Decreased urines output
- Restlessness or agitation
- Changes in breathing patterns e.g. rattly breathing, Cheyne-Stokes breathing
- Changes in skin colour and temperature in the periphery (e.g. toes, feet, fingers, hands).

HOW TO

Prepare the family

- Explain that the person is getting closer to dying and communicate clearly and sensitively with the family about what to expect and how they can help
- Encourage conversations between the person (if possible) and/or family and carers about the person's wishes/goals of care (referring to advance care plans if available) including the person's preferred place of death
- Plan for return to Country if that is the wish of the person and the family
- Reassure the carer/family that they are doing a good job and that their loved one will be well cared even if they feel they can no longer care for the person at home
- Develop an agreed individual plan of care that can include how to provide culturally safe communication (e.g. who to communicate with), food and drink, symptom control and psychological, social and spiritual support for all involved
- Review the plan regularly in accordance with the person's changing condition
- Identify and respect the needs of carer/families and try to meet those needs if possible
- Encourage carer/families to take breaks and care for their own health and wellbeing
- Check that all equipment, medicines etc are readily available and accessible and stored safely
- Provide advice on who to call if they need help especially in a crisis situation or after hours
- Identify specific cultural instructions post death e.g. photos, use of name, rituals or ceremonies
- Talk with the carer/family about the implications of calling an ambulance and strategies to avoid unwanted treatment or transfer to hospital
- Provide a letter or an ambulance plan confirming that the person is a palliative care patient and that their death is/was expected

- Plan for who will complete:
  - the documentation for life extinct (life extinct form) - it is needed for the funeral director to be able to collect the person
  - cause of death certificate (death certificate) - usually completed by the treating doctor or their medical delegate
- Provide written instructions about what to do and who to call when the person dies and ensure the carer/family has the means to make the telephone call

Recognising when a person has died

The following signs indicate that death has occurred:

- Breathing stops – there is no movement of the ribs, chest or abdomen usually associated with breathing and no air can be felt moving in or out of the mouth or nose
- Heart stops – no heartbeat can be felt or heard and no pulse can be felt
- Pupils are fixed and do not respond to light
- The person cannot be woken up.

After death the person's body may relax and release air, noises and other body fluids. The person may look different to the family.

Support the family

The role of a health professional with a carer/family after the death of their loved one will depend on the individual needs of the carer/family that have been identified through sensitive communication before and after death of the person.

The time following death requires continuing support, sensitivity and respect for family, carers and friends, and respect for cultural protocols and practices.

The role could include:

- Explaining to the carer/family that they can remain with person who has died to say their final good-byes in their own time
- Listening to the family to understand cultural wishes
- Ensuring that the wishes of the person/family/carers in regard to the laying out of the body are completed
- Being aware of particular cultural rituals, ceremonies or practices that need to be considered e.g. who touches the body, what name to use, cutting hair, totems, smoking ceremonies
- Contacting the funeral director
- Helping to access financial support for the funeral, if this has not occurred earlier
- Attending the funeral or sorry business or sad news for the person who has died, as appropriate
- Ensuring legal documentation is completed
  Legal requirements vary throughout Australia but always include:
  - A determination that life is extinct (life extinct form) made by appropriate health professional (nurse, paramedic, doctor) that allows the funeral director to collect the person's body (check local jurisdictional requirements)
  - A certification of death (death certificate) must be completed by a doctor but often the doctor does not have to attend the home or see the person
- Visiting the carer/family after the death of the person to provide support.

PART FOUR:
Managing medicines in the terminal phase

Principles of best-practice palliative care medicine management

Deprescribing

Medicine deprescribing is a key component of palliative care. Deprescribing is the withdrawal of medicines that are no longer beneficial, appropriate or desired for an individual patient.

For example, cholesterol lowering medicines are not important when a person only has a short time to live.

In addition, at the end of life, patients are usually poorly responsive or unconscious, and have minimal oral intake, so it may not be possible for them to take their usual medicines.

Assess medicine risks, benefits and potential withdrawal effects, and consider whether the following medicines are still providing benefit:

- Medicine for elevated blood pressure and other cardiovascular conditions
- Medicine for dyslipidaemia
- Anticoagulants and antiplatelet medicine
- Thyroid replacement therapy
- Corticosteroids
- Medicine for mental health, progressive neurological diseases or epilepsy
- Antiviral medicine such as those for HIV or hepatitis viruses
- Medicine for the treatment of cancer.

When possible, changes to medicines should occur over a period of time, but it may be necessary to make immediate changes when a patient is close to death and unable to swallow.

Anticipatory prescribing

Anticipatory medicines are prescribed and dispensed in preparation for a time when a person needs them. They are used to manage symptoms in the home with the goals of rapid relief and avoiding unwanted admission to a healthcare facility.

Off-label use of medicines

Medicines are commonly used off-label for palliative care. However, when medicines are used off-label, they are not subsidised by the Pharmaceutical Benefits Scheme (PBS).

A medicine is 'off-label' when it is used differently to the product information approved by the Australian Therapeutic Goods Administration (TGA). For example, the medicine may be used for a non-registered indication, route of administration or patient population, or used at a non-registered dose.

Administering medicines

The subcutaneous cannula

A subcutaneous cannula is a device that allows medicines to be given under the skin, avoiding the need for lots of needles that can be painful. The medicines are then absorbed into the body via the small blood vessels in the fatty layer of the skin.

Each cannula has two ends, as shown in the picture.

A thin plastic tube that is inserted by the nurse under the person's skin

A Y-arm that has a needle-free connector where the medicine is given

Your clinical service may use a different subcutaneous cannula to the one shown here.

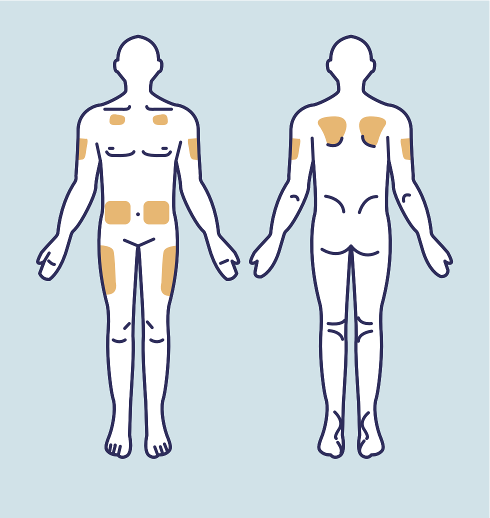
Why is a subcutaneous cannula used?

A subcutaneous cannula is a safe and effective way of delivering medicines in certain situations. For instance, if the:

- Person is having trouble swallowing oral medicines
- Person is vomiting frequently
- Doctor/nurse practitioner thinks that medicines taken by mouth are not being absorbed properly
- Doctor/nurse practitioner thinks that subcutaneous medicines will be more effective or efficient than oral ones.

Where is the subcutaneous cannula inserted?

The common sites for subcutaneous cannula insertion are shown in the image.



Inserting two subcutaneous cannulas is considered best practice. Note that this is in addition to a syringe pump infusion cannula. The insertion of a second cannula ensures that the person can still have timely access to medicines, even when a health professional is not immediately available to replace the blocked cannula. Place cannulas in positions according to your workplace policies and procedures or the person's preference.

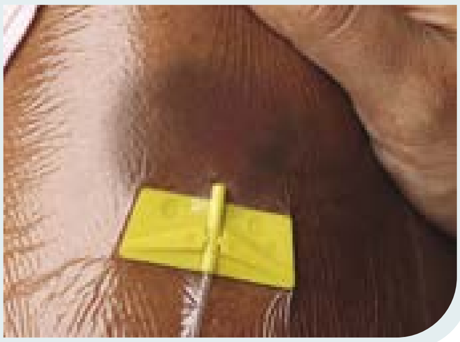
When will the subcutaneous cannula need to be replaced?

The subcutaneous cannula will be changed if:

- It is hard to push the medicine into the cannula
- There is evidence of swelling, redness, inflammation or leakage around insertion site
- There is ongoing pain or discomfort when the medicine is given
- It is due for a scheduled change according to the regular practice of the clinical service.

Example of insertion site suitable for use

Example of insertion site unsuitable for use



How to insert a subcutaneous cannula

Inserting a subcutaneous cannula: *A step-by-step guide*

caring
@home
Symptom management for palliative patients

PLEASE NOTE: This step-by-step guide was specifically produced for non-paid carers looking after a person who has chosen to be cared for, and to die at home, if possible. For resolution of detail in the photographs no personal protective equipment (PPE) was worn. Please follow the local policy and procedures regarding the insertion of a subcutaneous cannula and wearing of PPE.

More information is available from **www.caringathomeproject.com.au**

STEP 1

Wash hands with soap and water and dry them well

STEP 2

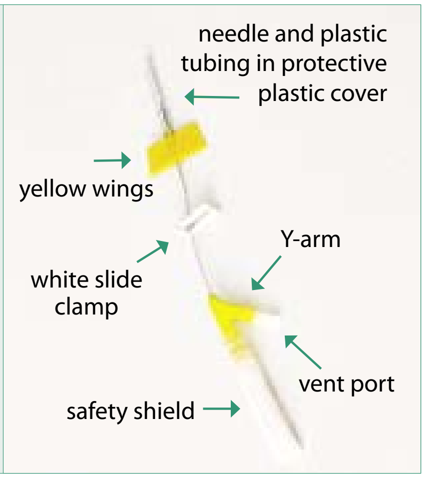
Collect the following items:

- A clean plastic container to put equipment in
- A subcutaneous cannula
- A transparent waterproof dressing
- An alcohol wipe or similar
- A smart-valve connector
- A sharps container
- A rubbish bag or bin

STEP 3

Prepare the cannula

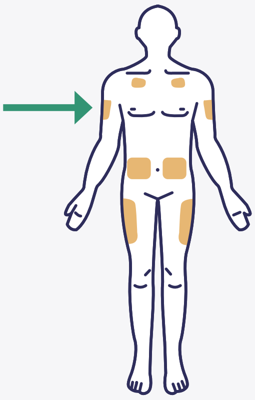
- Open the cannula packet keeping it in its clear case
  - Remove the white slide clamp
  - Rotate the safety shield tube 360 degrees clockwise to make sure that the needle moves freely in its protective plastic cover
  - Remove the plastic vent port from the Y-arm
  - Open the smart-valve connector packet, remove the clear plug and screw the connector onto the Y-arm until it is tight
  - Place the cannula into the plastic container
- Open the transparent waterproof dressing packaging and place the dressing in the plastic container
- Put the alcohol wipe in the plastic container

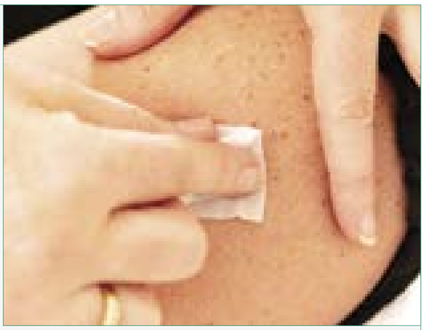


STEP 4

Prepare to insert the cannula

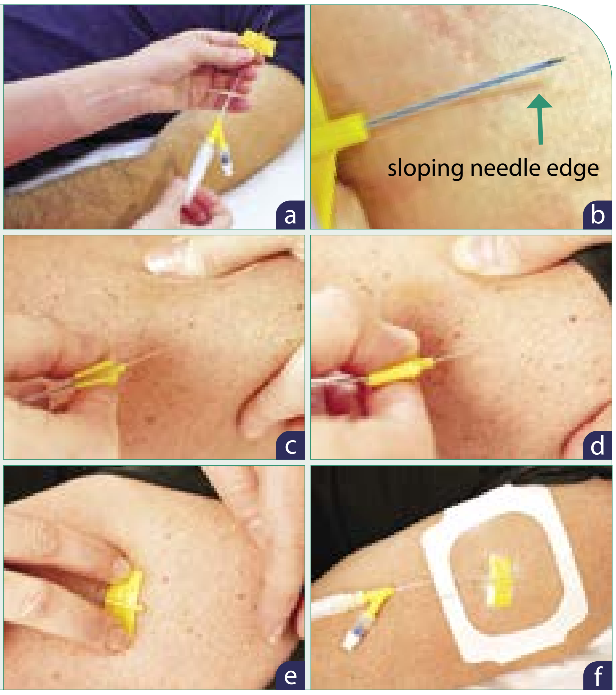
- Select a site to insert the cannula
- Use the alcohol wipe to clean the skin





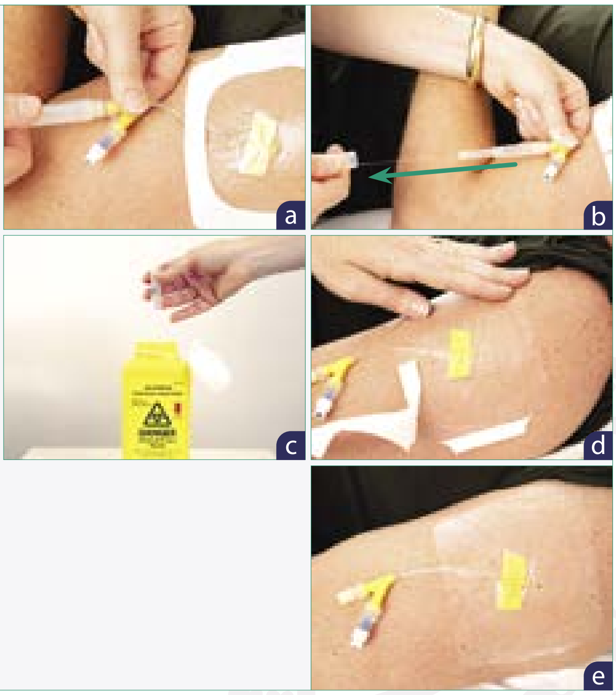
STEP 5
Insert the cannula

- Peel the printed backing off the transparent waterproof dressing and leave it sticky side up
- Remove the protective plastic cover from the cannula needle and plastic tubing **(a)**
- Use the white safety shield to rotate the needle so that the sloping edge is on top **(b)**
- Gently gather the person’s skin between your thumb and fingers and hold it firmly **(c)**
- Using your other hand, lift the edges of the yellow wings of the cannula so that the raised triangles on the wings come together **(c)**
- Hold the wings together and push the needle and plastic tubing into the skin, at a 45-degree angle until the whole needle is under the skin **(d)**
- Flatten the yellow wings against the person’s skin **(e)**
- Stick the transparent dressing over the needle entry site, making sure that it also covers the flattened yellow wings of the cannula. **This is important to hold the cannula in place. (f)**



STEP 6
Set up the cannula

- Hold the yellow Y-arm firmly in one hand. **This is important, otherwise you may pull the plastic tubing out of the person, instead of just the needle**. **(a)**
- With your other hand, pull back **in a straight continuous motion** on the loosened white safety shield until the safety shield and needle separates from the cannula **(b)**
- Discard the safety shield with its needle into the sharps container **(c)**
- Remove the white backing, if present, from the outer edge of the dressing and smooth the edges onto the person’s skin **(d)**
- Check the needle entry site to ensure the plastic tubing has stayed under the skin **(e)**
- Write the insertion date on the waterproof dressing.



Continuous infusion via a syringe pump and a subcutaneous cannula

A syringe pump is a portable battery-operated device that delivers medicine at a constant rate over an extended period (usually 24 hours) to maintain a steady blood level of the medicine.

The syringe pump delivers medicine through a system including:

- A subcutaneous cannula is placed in the subcutaneous tissue and held in place by a clear dressing
- An extension set – the subcutaneous cannula is connected to the syringe pump via a variable length of sterile tubing often called an extension set
- The syringe – the extension set is attached to a syringe which can contain various medicines as prescribed by a doctor or nurse practitioner for symptom control.

The syringe pump pushes the syringe plunger at a steady rate and medicine is delivered through the extension tube and subcutaneous cannula under the person's skin. The medicine can then be absorbed into the body.

Why are syringe pumps used?

Continuous subcutaneous infusion of medicines administered using a syringe pump is a common and accepted practice in palliative care for assisting with pain and symptom management when other routes of administration are inappropriate or ineffective.

Use of a syringe pump, particularly in the last days of a person's life, can ensure that they remain comfortable.

What are the advantages of syringe pumps?

Syringe pumps are:

- Portable
- Suitable for all clinical settings
- Pre-set to deliver medicines over a fixed time period
- Able to provide a constant level of medicine, ensuring that the plasma concentration remains at the optimum therapeutic level with no peaks or troughs
- More acceptable to the person being cared for than intramuscular or intravenous routes
- Flexible and can be used intermittently or discontinued if symptoms can later be managed by the oral route
- Protected by an external lockbox for syringes up to 30 mL.

What are the main indications for use of syringe pumps?

Syringe pumps are used when the administration of oral medicines is inappropriate or likely to be ineffective, e.g. if the person has:

- Persistent nausea and vomiting
- Dysphagia
- Gastrointestinal obstruction
- Poor absorption of oral medicines
- Weakness and/or alteration in the level of consciousness.

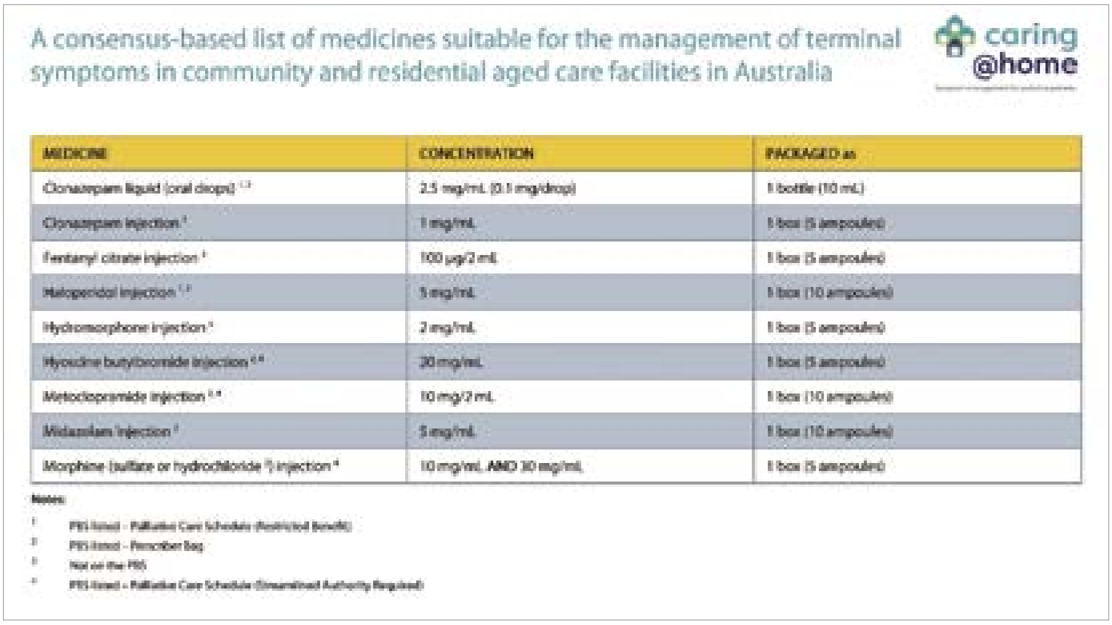
Intermittent subcutaneous administration via a subcutaneous cannula

Medicine can also be given subcutaneously, occasionally or 'intermittently' when needed. Giving subcutaneous medicine for breakthrough symptoms is an example of intermittent administration.

Quick guide to commonly used subcutaneous medicines in the terminal phase and frequent side effects

Commonly used medicines

Eight medicines are endorsed by the Australian and New Zealand Society of Palliative Medicine for use in community-based palliative care patients to manage symptoms in the terminal phase.



A consensus-based list of medicines suitable for the management of terminal symptoms in community and residential aged care facilities in Australia

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MEDICINE	CONCENTRATION	PACKAGED as
Clonazepam liquid (oral drops) [1,2]	2.5 mg/mL (0.1 mg/drop)	1 bottle (10 mL)
Clonazepam injection [3]	1 mg/mL	1 box (5 ampoules)
Fentanyl citrate injection [3]	100 µg/2 mL	1 box (5 ampoules)
Haloperidol injection [1,2]	5 mg/mL	1 box (10 ampoules)
Hydromorphone injection [3]	2 mg/mL	1 box (5 ampoules)
Hyoscine butylbromide injection [2,4]	20 mg/mL	1 box (5 ampoules)
Metoclopramide injection [2,4]	10 mg/2 mL	1 box (10 ampoules)
Midazolam injection [3]	5 mg/mL	1 box (10 ampoules)
Morphine (sulfate or hydrochloride [3]) injection [4]	10 mg/mL AND 30 mg/mL	1 box (5 ampoules)

Notes:

[1] PBS listed – Palliative Care Schedule (Restricted Benefit)
[2] PBS listed – Prescriber Bag
[3] Not on the PBS
[4] PBS listed – Palliative Care Schedule (Streamlined Authority Required)

The person's doctor/nurse practitioner may prescribe other appropriate medicines, but not all can be listed here.

Frequent side effects

As well as the desired benefits for which they have been prescribed, medicines may cause side effects. Not everyone taking a medicine will experience side effects. It is difficult to predict who will experience side effects or which ones.

There are many ways to treat side effects including changing the medicines, if necessary.

The table below lists eight common subcutaneous medicines used in the last weeks of life and their most frequent side effects.

Name of medicine	Frequent side effects
Fentanyl **Hydromorphone** **Morphine**	Constipation, nausea and vomiting, dry mouth, itchy skin, decreased breathing rate, drowsiness, small muscle jerks
Clonazepam **Midazolam**	Drowsiness, dizziness, light-headedness, memory loss, shaky and unsteady movements, slurred speech, blurred vision, increased saliva
Hyoscine butylbromide	Dry mouth, difficulty breathing
Haloperidol	Sedation, blurred vision, repetitive movements of the face or limbs, restlessness
Metoclopramide	Restlessness, drowsiness, dizziness, headache

More information

palliMEDS app

Information about common palliative care medicines that are prescribed by primary care providers to manage pain in the terminal phase. The medicines are part of a list of 8 medicines endorsed by the Australian & New Zealand Society of Palliative Medicine (ANZSPM) for terminal care.

(Downloadable from the app store and Google Play).

Therapeutic Guidelines. Palliative Care

Accurate, independent and practical treatment advice for a wide range of clinical conditions associated with palliative care. It includes explicit instructions for therapy, assisting practitioners in making decisions to ensure their patients receive optimum treatment.

Available online via subscription at: https://tgldcdp.tg.org.au/etgAccess

PART FIVE:

Teaching carers/families to manage breakthrough symptoms at home using subcutaneous medicines

Overview

Carers/families may wish to try to keep their loved one at home for as long as possible and may be willing to help manage symptoms. This is likely to involve non-pharmacological and pharmacological strategies.

The *caring@home* tip sheets have information about what non-pharmacological things to teach carers/families to do to help keep their loved one comfortable.

Some people, but not all, will require subcutaneous medicines to adequately manage symptoms at home.

If subcutaneous medicines for breakthrough symptoms are required, not all carers/families will choose to do this. It is **very important** that carers/families are not pressured to do this. It is a voluntary decision and reassurance must be given that if the family chooses not to do this task that the person will still be well cared for.

Research has shown that when carers/families are given accurate information and appropriate support they can manage subcutaneous medicines effectively and safely.

The *caring@home* information brochure for families called 'Helping to manage symptoms at home' and video 'Helping to manage symptoms at home' can act as an introduction to carers/families about giving subcutaneous medicines.

Breakthrough symptom

Even with regular medicine to help control a symptom, sometimes the symptom can unexpectedly get worse and become distressing for the person being cared for. When this occurs, it is called a 'breakthrough' symptom.

Breakthrough symptoms may require an extra dose of medicine, in addition to the regular medicine, to make sure the person remains as comfortable as possible.

How to teach carers/families if they are willing to give subcutaneous medicines

All the resources needed to teach carers/families to manage subcutaneous medicine can be found:

- in the *caring@home* Palliative Care Clinic Box
- on the *caring@home* website – www.caringathomeproject.com.au
- on the *caring@home* app.

This Guide contains a brief outline of how to teach carers to manage subcutaneous medicines, but it is recommended that health professionals complete two online education modules about the *caring@home* resources and how they can be used to teach carers to help manage breakthrough symptoms safely using subcutaneous medicines. The online modules take 40 minutes to complete. www.caringathomeproject.com.au

Who can teach carers/families to give subcutaneous medicines?

Registered nurses, nurse practitioners and doctors can teach carers/families to give subcutaneous medicines. Other suitably qualified and registered health professionals may be able to teach carers/families to give subcutaneous medicines depending on jurisdictional requirements.

What to teach carers/families?

You can use the Training checklist and carer/family post-training competency assessment to guide your training. It contains key elements for carers/families to know if they are to give subcutaneous medicines safely.

This is a content guide only and you will need to use your clinical experience to best determine how to teach the carer/family. A flexible approach is important. A lot will depend on your preferred teaching style and the needs and learning style of the carer/family.

Your training session(s) with a carer/family is the most important tool that you have to enable them to develop confidence to take on the role of helping to manage breakthrough symptoms for the person they are caring for. You may need to have many conversations with carers/families about giving subcutaneous medicines before actually teaching them. They need to have a good understanding of the role they will be taking on and how it will help

You may find that your current clinical practice varies from that described in the resources for carers/families. An aim of this project is to encourage a consistent approach and the resources have been developed using best practice principles. It is an opportunity for you to review your current practice.

Topics to teach carers/families include:

- How to manage symptoms at home using subcutaneous medicines (see page 49)
- How to recognise breakthrough symptoms (see page 51)
- How to rate how worrying breakthrough symptoms are (see page 52)
- How to know what medicine to use for each symptom (see page 53)
- How to write a label, open an ampoule and draw up medicine (see page 54)
- How to give medicine using a subcutaneous cannula (see page 57)
- How to complete the Medicines book (see page 60)
- How to store and dispose of medicines (see page 61)
- How and when to get help from the clinic (see page 61)

How to assess if a carer is competent to manage subcutaneous medicines

Competency can be defined as the ability to do something successfully.

Competency to manage subcutaneous medicines can be assessed using the practice demonstration kit and other resources and recorded in the Training checklist and carer/family post-training competency assessment. The checklist should be filed in the patient's notes.

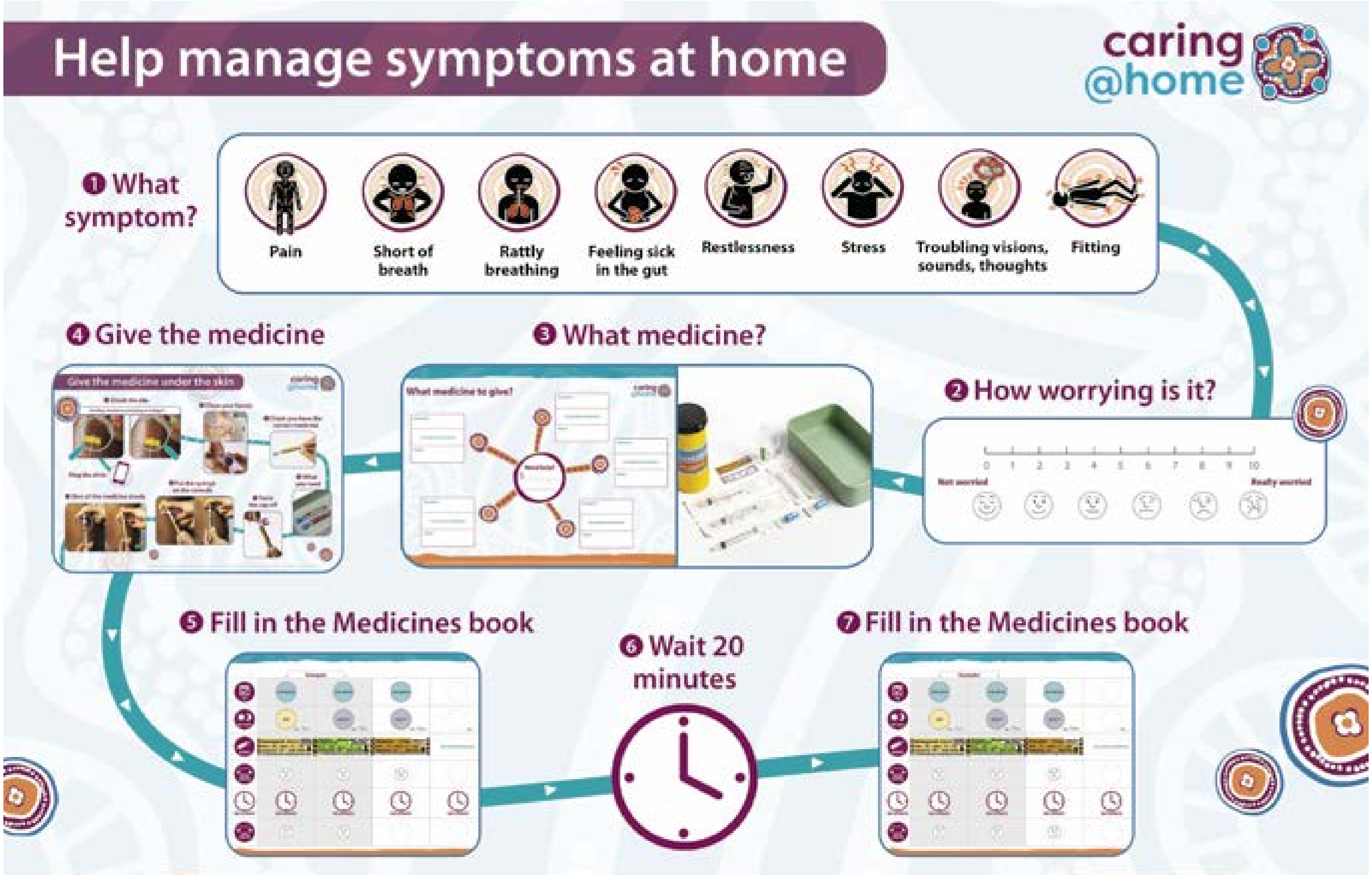
If a carer is having difficulty demonstrating competency in managing subcutaneous medicines, you will need to consider strategies of how to respond in accordance with your workplace policies and procedures.

How to manage symptoms at home using subcutaneous medicines

The *caring@home* resources support a standardised approach to teaching carers/families how to manage symptoms at home. The step-by-step guide (on the next page) outlines the approach.

Standardised teaching linked with the quality resources ensures that carers can safely manage subcutaneous medicines.

Use the step-by-step guide – Help manage symptoms at home – to give an overview to carers/families about how to give subcutaneous medicines using the *caring@home* resources.



Help manage symptoms at home

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❶ What symptom?

- Pain
- Short of breath
- Rattly breathing
- Feeling sick in the gut
- Restlessness
- Stress
- Troubling visions, sounds, thoughts
- Fitting

❷ How worrying is it?

❸ What medicine?

❹ Give the medicine

❺ Fill in the Medicines book

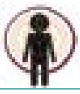
❻ Wait 20 minutes

❼ Fill in the Medicines book

How to recognise breakthrough symptoms

Recognising breakthrough symptoms when they occur is important. Often if symptoms are allowed to get worse, they can become much harder to treat successfully.

In the last weeks of life, common breakthrough symptoms that may occur include:

Clinical name	Term used in tip sheets for carers/families	Icon representing the symptom
Agitation/restlessness	Restlessness	
Anxiety	Stress	
Delirium	Troubling visions, sounds, thoughts	
Dyspnoea	Short of breath	
Nausea and/or vomiting	Feeling sick in the gut	
Noisy breathing	Rattly breathing	
Pain	Pain	
Seizures	Fitting	

This Guide contains sections on recognising and managing each of these symptoms in the terminal phase (See Part One)

The best way to tell if a person is experiencing a breakthrough symptom is simply to ask them. If the person is unable to say how they feel, then the carer/family will need to rely on other signs.

You can teach carers/families to recognize a particular symptom using the *caring@home* tip sheets for carers/families. Each tip sheet lists:

- What they should look for – see and hear
- What they can do

Check carer competency by asking carer how they would identify a symptom.

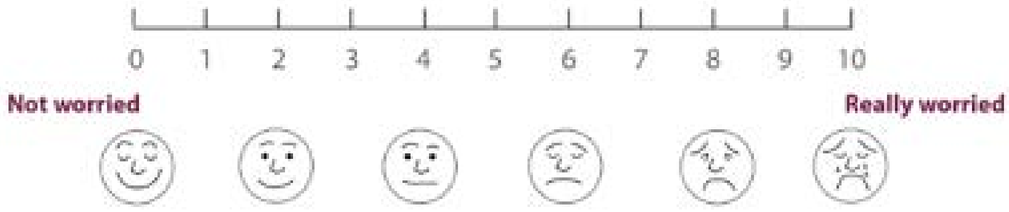
A person may experience more than one symptom at the same time. For example, they may have shortness of breath and anxiety.

It is important to tell the family/carer to inform you straight away if the person develops a new symptom.

How to rate how worrying a breakthrough symptom is

A common way that health professionals talk about how distressing or worrying symptoms might be is to use a symptom rating scale ranging from zero (0) to ten (10).

In this scale, a rating of 0 represents no symptom distress/worry and 10 represents the worst possible symptom distress/worry. The faces can be used to help make the decision.



ADAPTED FROM: Wong-Baker Faces® Pain Rating Scale and the Edmonton Symptom Assessment Scale.

If possible, ask the person to look at the scale and pick the number or face that matches how they feel. Explain to them that 0 means no worry from the symptom and 10 is really worried.

Rating a symptom is best done before, and about 20 minutes after, subcutaneous medicine is given. Comparison of the before and after rating can provide an indication of how effective the medicine has been.

You can teach carers/families to rate how worrying a symptom is by using the rating scale on the last page of the Medicines book.

Explain that:

- If the person cannot say how they feel, the family should trust their own judgement and knowledge of the person to identify the breakthrough symptom and give a rating for the symptom on behalf of the person.
- They will need to record the symptom rating in the Medicines book before, and about 20 minutes after, giving the subcutaneous medicine. This helps you to decide if the medicine has worked.

Check carer competency by asking carer to show how they would use the symptom rating scale.

How to know what medicine to use for each symptom

Each breakthrough symptom can be treated by giving a medicine prescribed by the doctor/nurse practitioner.

Subcutaneous medicine is drawn up into a syringe from an ampoule.

You may do this for the family - draw-up the medicine, label the syringe and store in the fridge or esky for later use. Or you may teach the family to draw up the medicine.

In either case, for safety, every syringe with medicine in it must be labelled correctly using a colour-coded sticky label. The label has the name of the **medicine** and the **symptom** this medicine is being given for already printed on it.

Midazolam (Orange) ANXIETY
Dose: 5 mg in 1 mL
Prepared by: KD Date: 1/4/22
For Subcutaneous Single Dose Use Only

Before giving any subcutaneous medicine always check the label on the syringe to make sure that it is the right medicine for the symptom. This is essential.

As an extra check, the wall chart lists the subcutaneous medicines prescribed by the doctor/nurse practitioner to treat each breakthrough symptom. The medicines are colour-coded on the wall chart to match the syringe labels. The labels contain icons that match icons on the tip sheets.

For easy reference for the carer/family, complete the wall chart by writing the symptom, sticking on a syringe label and adding any notes.

You can teach carers/families to give the correct medicine for the symptom by reinforcing which particular medicine to use for each symptom, depending on the doctor's/nurse practitioner's instructions.

You can teach the family to carefully read each syringe label and to use the colour-coded system (labels and wall chart) as an extra check to ensure to safely select the right medicine for a particular symptom (even if it is late at night and/or the family are tired).

Check carer competency by asking carer to identify the correct medicine for a particular symptom.

How to write a label, open an ampoule and draw up medicine

Clinical services in Australia have different policies about teaching carers/families to draw up medicine. Some services do not teach carers to draw up medicines; the health professional draws up all medicines and the carer stores them in the fridge. In other services, the health professional does not draw up the medicine; carers are taught to do it. The *caring@home* resources are flexible enough to be used in either situation. You should ensure you are aware of the policies of your clinical service.

Best practice is illustrated in the step-by-step guide (see next page).

Note the need to:

- **Calculate how much medicine to draw up in the syringe**
  If the carer is to draw up medicine, you will need to show the carer how to draw up the correct dose required as per the doctor's/nurse practitioner's prescription. This may involve a calculation depending on the medicine and the dose prescribed. Calculate the volume of the medicine to be drawn into the syringe based on the dose in the medicine order and the concentration of the medicine in the ampoule.
- **Label a syringe**
  All syringes must be correctly labelled. The labels supplied as part of the *caring@home* resources already have printed on them: the name of the medicine and its colour code and the symptom and its representative icon. As a health professional you have a legal obligation to prepare and administer medicine as per doctor/nurse practitioner orders, after you have carefully checked them.

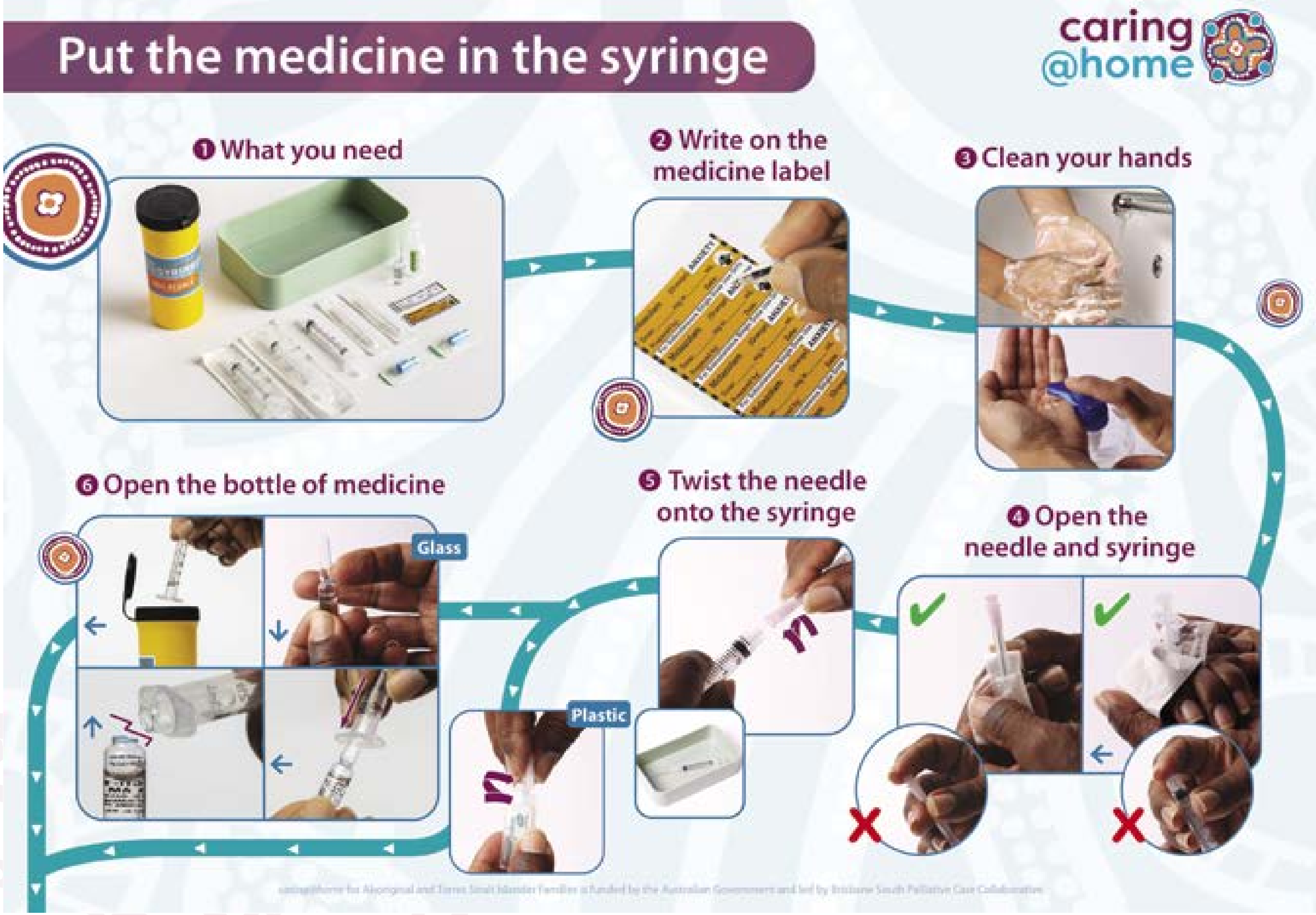
You or the carer (depending on who is drawing up the medicine) must write in the dose in the syringe e.g. 2.5 mg in 1 mL, the date the dose is prepared and initials of person drawing up the medicine.

The label states that the syringe is for subcutaneous single dose use only. Explain to the carer that only one dose of the medicine will be contained in each syringe. The number of units (e.g. 2.5 mg) of the medicine in the syringe will match the dose written on the medication order.

If a carer cannot calculate the volume of subcutaneous medicine to draw up into the syringe, then they cannot be assessed as competent to do this task.

If appropriate, teach carers/families how to draw up medicine and label a syringe using the step-by-step guide - Put the medicine in the syringe. If carers/families are not required to draw up medicines into syringes this step can be skipped.

Check carer competency by asking them to demonstrate steps using the practice demonstration kit or actual medicine (if that is appropriate).



Put the medicine in the syringe

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❶ What you need

❷ Write on the medicine label

❸ Clean your hands

❹ Open the needle and syringe

❺ Twist the needle onto the syringe

❻ Open the bottle of medicine

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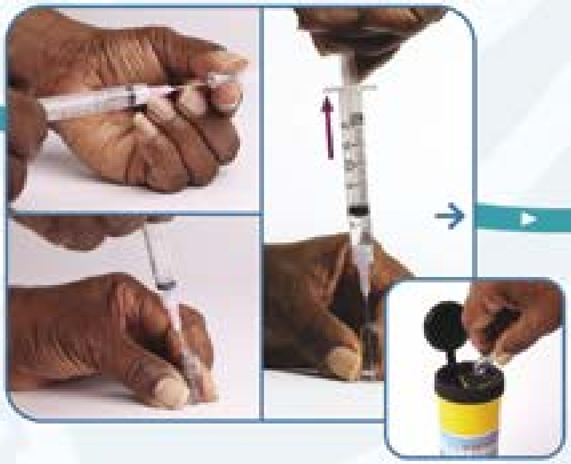
❼ Put medicine in the syringe



❽ Remove any air bubbles

❾ Check the medicine level

❿ Twist the needle off

⓫ Twist the cap on the syringe

⓬ Put the label on the syringe

⓭ Repeat steps to put sodium chloride in another syringe (the flush)

⓮ Put syringes in a clean container

Need help? Ring the clinic. 📱 T: ……………………………………

How to give medicine using a subcutaneous cannula

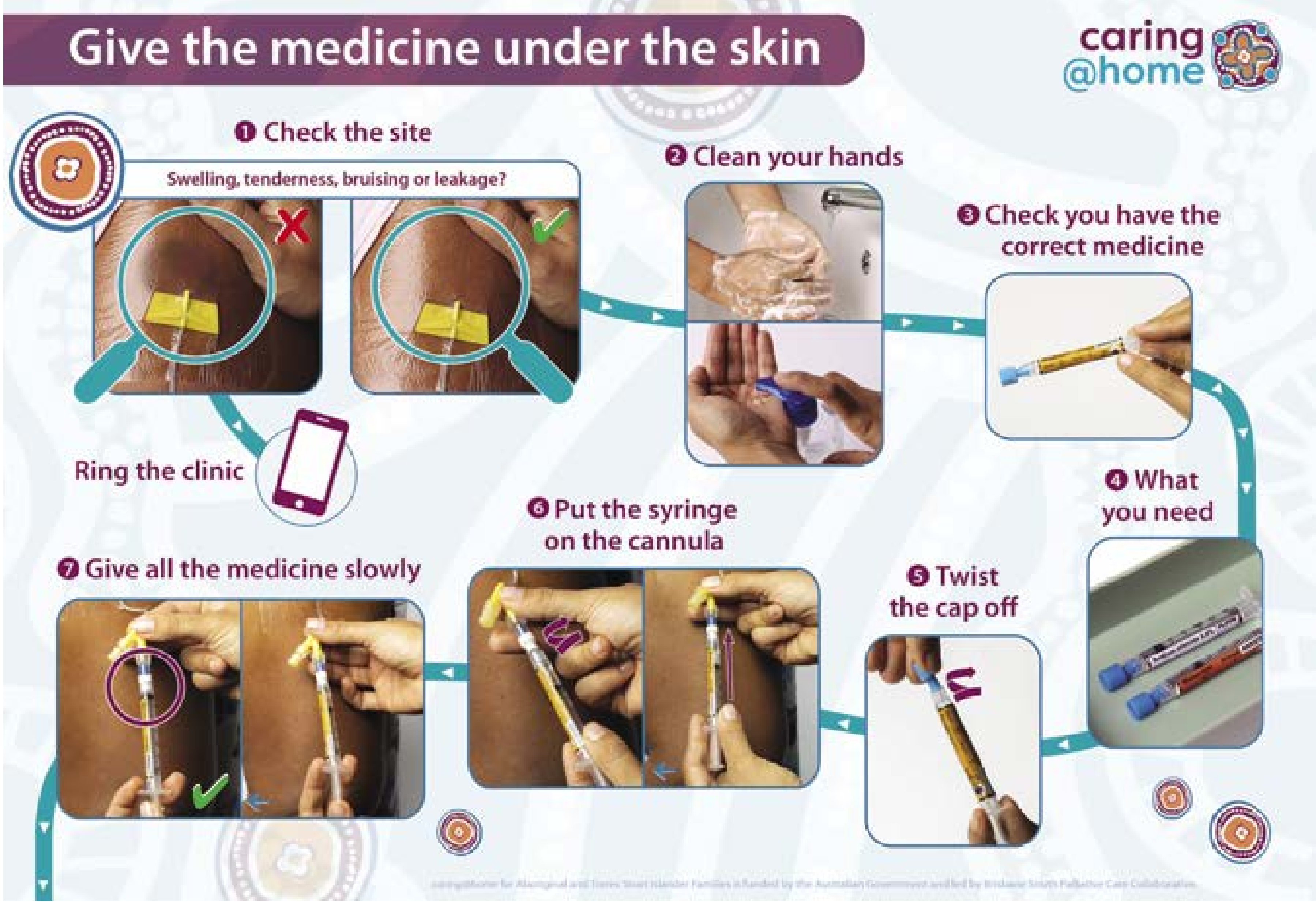
Clinical services vary in the techniques/procedures they use for giving medicine via a subcutaneous cannula. *caring@home* in consultation with the sector has developed resources that reflect consensus-based best practice in Australia.

HOW TO

Best practice is illustrated in the step-by-step guide (see next page). Note the need to:

- **Insert two subcutaneous cannulas**
  Note that this is in addition to syringe pump infusion cannulas. The insertion of a second cannula ensures that the person can still have timely access to medicines, even when the health professional is not immediately available to replace the blocked cannula. Place cannulas in positions according to your workplace policies and procedures or the person's preference.
- **Use a needleless technique**
  To maximize patient, carer and staff safety and reduce the incidence of needle stick injury, it is considered best practice to use a needleless technique when giving subcutaneous medicine
- **Flush the cannula**
  It is important to flush the subcutaneous cannula following a dose of subcutaneous medicine so that the complete dose of medicine is given. If multiple medicines are given at the same time, it is only necessary to flush once – after the last dose. From Sues list of (REF)
- **Flush with sodium chloride 0.9%**
  To maintain site longevity, best practice is to use sodium chloride 0.9% for the flush following delivery of medicine using the subcutaneous cannula. The recommended volume for the flush is 0.5mL.

Teach carers/families how to give medicine through the subcutaneous cannula using the step-by-step guide - Give the medicine under the skin.
Check carer competency by asking them to demonstrate steps using the practice demonstration kit or actual medicine (if that is appropriate to circumstances).



Give the medicine under the skin

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❶ Check the site

Swelling, tenderness, bruising or leakage?

Ring the clinic

❷ Clean your hands

❸ Check you have the correct medicine

❹ What you need

❺ Twist the cap off

❻ Put the syringe on the cannula

❼ Give all the medicine slowly

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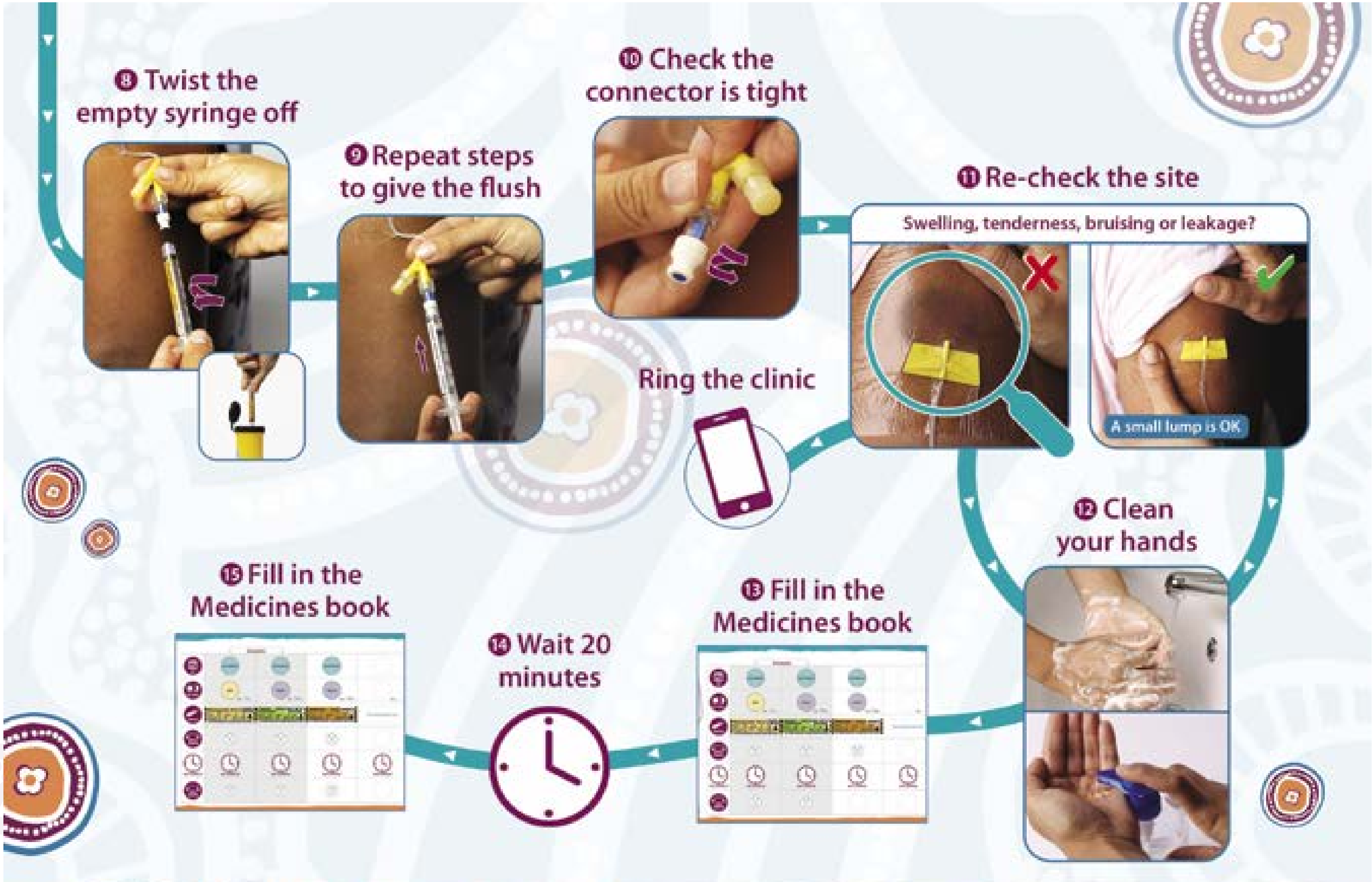

❽ Twist the empty syringe off

❾ Repeat steps to give the flush

❿ Check the connector is tight

⓫ Re-check the site

Swelling, tenderness, bruising or leakage?

A small lump is OK

Ring the clinic

⓬ Clean your hands

⓭ Fill in the Medicines book

⓮ Wait 20 minutes

⓯ Fill in the Medicines book

Need help? Ring the clinic. T: ....

How to complete the Medicines book

It is very important to write in the Medicines book after each medicine is given. This allows the family to keep track of the amount of medicines used. And importantly, it allows you to assess if the medicines need to be changed.

For each medicine given, the following details need to be recorded in the Medicines book:

- Day
- Time
- The medicine label
- The 'before' symptom rating
- The 'after' symptom rating.

Details can be recorded by writing in the Medicines book or by using the stickers.

Use the *caring@home* Medicines book to teach families how to record any medicines they give.

Check carer competency by asking them to record an administration of a subcutaneous medicine in the Medicines book.

How to store and dispose of medicines

Medicines need to be stored safely and disposed of safely.

Storage of medicine

- Keep all medicines out of view and reach of children
- Store all medicine ampoules in a secure container
- Store labelled, filled syringes in a secure container in the fridge or esky
- Store the sharps container out of reach of children
- Keep medicine for the appropriate length of time

Disposal of unused medicine

- The correct disposal technique will depend on location
- Return all unused medicines to your local chemist/clinic/other

Discuss with carers/families how to store medicines safely.

Teach carers/families what the appropriate disposal process is for their location.

Check carer competency by asking the carer to explain how they will store and dispose of medicines.

9. How and when to get help from the clinic

Carers/families report that they need access to a health professional who can provide clinical advice 24/7.

Ensure that if your clinical service teaches a carer/family to give subcutaneous medicine, advice is available 24 hours. This could mean your clinical service provides out-of-hours coverage or negotiates coverage with another suitable clinical services such as the local hospital or GP practice.

Explain to carers/families how to contact the clinical service 24/7. Give them contact details including a 24-hour number that they can contact to seek advice or reassurance.

The contact numbers can be written on the wall chart, tip sheets and step-by-step guides.

As part of checking the competency of the carer, they should be able to show you where the 24-hour number is written.

PART SIX:
Getting help

Specialist Palliative Care Services

Your local Specialist Palliative Care Service can provide advice.
https://palliativecare.org.au/im-a-health-professional/

Helplines

Need help?	
If you need help, contact your Specialist Palliative Care Service or the appropriate telephone support service available in some states/territories:	
New South Wales	Palliative Care After Hours Helpline **1800 548 225** For palliative care patients, their carers, families and health professionals Weekdays: 5pm–9am (AEST) Weekends: 5pm Friday–9am Monday Public holidays (National and NSW): from 5pm the day before to 9am the following business day
Queensland	**1300 PALLDR*** (1300 725 537) 24/7 palliative care advice hotline for doctors, NPs, paramedics and pharmacists **1300 PALLCR*** (1300 725 527) 24/7 hotline for nurses and allied health in all care environments
South Australia	Statewide 24/7 palliative care support line (for clinician use only) **1300 673 122**
Victoria	Palliative Care Advice Service (for all) **1800 360 000** advice@pcas.org.au For palliative care patients, their carers, families and health professionals Everyday 7am–10pm
Western Australia	**1300 558 655** Statewide 24/7 palliative care support line (for clinician use only) **1800 573 299** For palliative care patients, their carers and families Everyday 9am–5pm (including public holidays)

Notes

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