A practical handbook for carers:

Helping to manage breakthrough symptoms safely using subcutaneous medicines
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Acknowledgements
This practical handbook was developed as part of caring@home, a project undertaken by a consortium of Metro South Health, operating through Brisbane South Palliative Care Collaborative (lead agency), Aged & Community Services Australia, Australian Primary Health Care Nurses Association, Flinders University (through CareSearch), Leading Age Services Australia, National Prescribing Service, Pharmaceutical Society of Australia, The Royal Australian College of General Practitioners and University of Technology Sydney.

We acknowledge and thank all the health professionals and carers who contributed to the development of this handbook.

Funding statement
caring@home is funded by the Australian Government, Department of Health.

Suggested reference

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E: caringathome@health.qld.gov.au

Disclaimer
This practical handbook is intended as a guide for carers to assist them to help manage breakthrough symptoms.

While the Brisbane South Palliative Care Collaborative has exercised due care in ensuring the accuracy of the material contained in the handbook, the handbook is only a general guide to appropriate practice, to be followed subject to the clinician’s judgement and the carer’s preference in each individual case.

The Brisbane South Palliative Care Collaborative does not accept any liability for any injury, loss, or damage incurred by use of, or reliance upon, the information provided within this handbook.

References
The reference list for this practical handbook can be found at:
Introduction

This handbook is one part of the caring@home package for carers. It should be used with all the other materials in the package, particularly the one-on-one training that will be provided to you by a nurse.

The purpose of the caring@home package is to provide practical information and skills so that you can help manage a person’s breakthrough symptoms safely using subcutaneous medicines.

You are not alone. Using the caring@home package, you, together with your health care team, can help recognise and manage breakthrough symptoms if they occur.

The decision to help manage breakthrough symptoms is voluntary and yours to make. Your health care team will not pressure you to accept this task. If you do not want to be involved, simply tell the team of your decision.

What do other carers say?

Carers who have given subcutaneous medicines say they feel a strong sense of achievement and satisfaction from being able to contribute to the comfort of the person they are caring for.

Carers report being pleased they have been able to help keep the person at home, because that is what they wanted.

What is a symptom?

A symptom is a personal sensation that can result from an illness and can be distressing.

What is a breakthrough symptom?

Even when taking regular medicine to help control a symptom, sometimes the symptom can unexpectedly get worse and become distressing for the person you are caring for. When this occurs it is called a “breakthrough symptom” and may require an extra dose of medicine.

What is subcutaneous medicine?

Medicine that is given using a small plastic tube placed under the person’s skin (not into a vein) is called subcutaneous medicine.

“We knew when the pain hit we were able to do something to try and relieve it immediately, without having to sit waiting, powerless, for someone else to come and do it. I believe it gave me the confidence to keep him at home to the very end.”
## Components of the *caring@home* package for carers

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<th></th>
<th>Description</th>
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<td><strong>One-on-one training session with a nurse</strong></td>
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<td>A nurse will teach you how to help manage breakthrough symptoms safely using subcutaneous medicines.</td>
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<td>2</td>
<td><strong>A practical handbook for carers: Helping to manage breakthrough symptoms safely using subcutaneous medicines</strong></td>
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<td>The handbook provides written information and pictures you may need to help manage breakthrough symptoms safely using subcutaneous medicines.</td>
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<td>This illustrated guide explains how to write a label for a syringe, open an ampoule and draw up medicine using a step-by-step approach.</td>
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<td>The medicines diary is used to record all the subcutaneous medicines that you give to the person you are caring for.</td>
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<td><strong>Colour-coded labelling system</strong></td>
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<td>The colour-coded labelling system acts as an extra safety check to help you to select the correct medicine for each breakthrough symptom. It includes:</td>
</tr>
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<td>• Colour-coded sticky labels for syringes and</td>
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<td><strong>A practice demonstration kit</strong></td>
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<tr>
<td></td>
<td>The demonstration kit can be used to practise giving medicines using a subcutaneous cannula.</td>
</tr>
<tr>
<td>8</td>
<td><strong>Short training videos</strong></td>
</tr>
<tr>
<td></td>
<td>The videos show you how to help manage breakthrough symptoms using subcutaneous medicines.</td>
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“None of this is easy, but you are never alone. Everything that you are doing is helping them.”
“The written practical handbook and the videos suited us. Everything that we needed was there. We felt good about the process and we would recommend it to anyone.”
Using this handbook

Your nurse will give you this handbook and will use it to guide the one-on-one training session with you. During this training session you will be encouraged to ask questions at any time.

You will be taught how to:
- Recognise breakthrough symptoms
- Identify common subcutaneous medicines
- Complete a colour-coded syringe label
- Open and draw up medicine from an ampoule
- Give medicine using a subcutaneous cannula (and practise, using the demonstration kit)
- Make a record in the medicines diary
- Check the subcutaneous cannula and insertion site
- Store medicines in your home
- Dispose of unused medicines
- Make sure that you always have enough medicines in your home to treat breakthrough symptoms

Your nurse will give you a 24-hour telephone number so that you can contact a health care professional if you need advice, support or reassurance.

“It makes you feel that you are part of it, that you are helping. It’s part of the business. At least you are contributing, you are not sitting there as an onlooker. You are in the picture.”
Recognising breakthrough symptoms

Even when taking regular medicine to relieve a symptom, sometimes the symptom can unexpectedly get worse and become distressing for the person you are caring for. When this occurs, it is called a breakthrough symptom. Breakthrough symptoms may require an extra dose of medicine to make sure the person remains as comfortable as possible.

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 pain, shortness of breath, noisy ‘rattly’ breathing, nausea, vomiting, restlessness/agitation, anxiety and/or confused thinking.

In the one-on-one teaching session your nurse will teach you how to recognise breakthrough symptoms.

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

Remember, you are likely to know the person you are caring for better than any health care professional. If the person cannot communicate how they are feeling, trust your own judgement in recognising what breakthrough symptom they are experiencing.

The list below may help you recognise some common breakthrough symptoms.

<table>
<thead>
<tr>
<th>Pain</th>
<th>You may notice the person:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>– Grimacing, frowning or groaning</td>
</tr>
<tr>
<td></td>
<td>– Moving around as if trying to get in a comfortable position</td>
</tr>
<tr>
<td></td>
<td>– Resisting when you try to move them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Shortness of breath</th>
<th>You may notice any of the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>– Rapid or shallow breathing</td>
</tr>
<tr>
<td></td>
<td>– Agitated behaviours and expressions of anxiety</td>
</tr>
<tr>
<td></td>
<td>– Facial paleness or bluish tinge around the lips or tips of fingers</td>
</tr>
<tr>
<td></td>
<td>– Difficulty in talking or completing sentences</td>
</tr>
<tr>
<td></td>
<td>– Exaggerated movements of the chest, neck and/or shoulders</td>
</tr>
<tr>
<td></td>
<td>associated with breathing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Noisy ‘rattly’ breathing</th>
<th>You may hear noisy or ‘rattly’ breathing.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The person who is being cared for is unlikely to be aware of, or distressed by, this noise when it occurs at the end of life.</td>
</tr>
<tr>
<td></td>
<td>However, often carers can be quite distressed when they hear the sound, fearing that it must be uncomfortable for the person experiencing it.</td>
</tr>
<tr>
<td>Symptom</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Nausea and/or vomiting</strong></td>
<td>You may notice that the person is sweaty, clammy, or dry retching especially on movement. Nausea can be difficult to identify, especially if the person cannot talk. Nausea can occur occasionally, or it might be there all the time. Nausea may occur with or without vomiting. Vomiting may occur with or without nausea.</td>
</tr>
<tr>
<td><strong>Restlessness/agitation</strong></td>
<td>You may notice changes in the person's behaviour including: – Fidgety movements – Constant calling out – Inability to settle, or expressing a sense of urgency to get up and move These symptoms may be more distressing at night and can occur more frequently in the last days of life.</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>Sometimes it is difficult to identify anxiety. You may notice the person: – Has a furrowed brow – Appears tense – Is constantly scanning their room</td>
</tr>
<tr>
<td><strong>Muddled thinking or new confusion</strong></td>
<td>You may notice that the person is: – Behaving in a way that is out of character – Unable to concentrate – Rambling as they speak, or you may have trouble making sense of what the person is saying – Hearing or seeing things that are not present</td>
</tr>
</tbody>
</table>

The list above is limited to common symptoms. The person you are caring for may experience other breakthrough symptoms that need to be managed. If so, talk to your health care team.

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 your nurse straight away if the person develops a new symptom.

If you need advice about breakthrough symptoms, please contact your nurse or doctor/nurse practitioner.
Rating breakthrough symptoms

A common way that health care teams talk about how distressing breakthrough symptoms might be is to use a rating scale ranging from zero (0) to ten (10). In this scale, a rating of 0 represents no symptom distress and 10 represents the worst possible symptom distress.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No symptom distress</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Worst possible symptom distress</td>
</tr>
</tbody>
</table>

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.

In the one-on-one teaching session your nurse will teach you about rating symptoms and how to record them in the medicines diary. Based on the rating, your nurse will also advise you when a breakthrough symptom needs treatment.

If possible, ask the person how they would rate their symptom on a scale of 0 to 10. Explain to them that 0 means no distress from the symptom and 10 is the worst possible symptom distress.

If the person cannot tell you how they feel, trust your own judgement and your knowledge of the person to identify the breakthrough symptom, and give a rating for the symptom on behalf of the person.

You will need to record the symptom rating in the medicines diary before, and about 20 minutes after, giving the subcutaneous medicine. This helps you to decide if the medicine has worked. The medicines diary will also be checked regularly by your health care team.

If you are unsure or concerned, contact your nurse or doctor/nurse practitioner for further advice.

“Things became harder when he could no longer tell me how he was feeling. I had to make these decisions, but I knew him well after 45 years of living together.”
Knowing what subcutaneous medicine to use for each breakthrough symptom

Each breakthrough symptom can be treated by giving a medicine prescribed by your doctor/nurse practitioner. You will need to get the medicine(s) from your local chemist.

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

Your nurse may do this for you and label the syringe for you to put in your fridge for later use or your nurse may teach you 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.

In the one-on-one teaching session your nurse will reinforce which particular medicine to use for each symptom, depending on the doctor’s/nurse practitioner’s instructions. They will also teach you how to carefully read each syringe label and to use a colour-coded system (labels and fridge chart) as an extra check to help you safely select the right medicine for a particular symptom (even if it is late at night and/or you are tired).

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

As an extra check, the fridge chart lists the subcutaneous medicines prescribed by your doctor/nurse practitioner to treat each breakthrough symptom. The medicines are colour-coded on the fridge chart to match the syringe labels.

“The fridge chart was really helpful. It was a double check. It gave me extra confidence that I was choosing the correct medicine.”
1. **Collect the following items:**
   - A pen
   - The colour-coded sticky label(s) for the medicine(s) and flush syringe(s)
   - The ampoule(s) of medicine(s)
   - The ampoule of sodium chloride 0.9% for flushing
   - The screw-tip syringe(s)
   - The blunt drawing-up needle(s)
   - The cap(s) to screw onto the syringe(s)
   - A clean container to put the equipment in
   - A sharps container

2. **Write the following details onto a sticky label for each medicine syringe to be prepared:**
   - The dose of the medicine contained in the syringe
   - Initials of the person who prepared the syringe
   - The date prepared

   *The syringe containing sodium chloride 0.9% (the flush syringe) also needs to be labelled.*

3. **Wash your hands with soap and water and dry them well**

4. **Attach the blunt drawing-up needle to the syringe by:**
   - Removing the syringe and the needle (with its protective cover) from the packaging without touching the open end of the syringe or the needle
   - Twisting the needle, with its protective cover, onto the syringe

5a. **Open a glass ampoule by:**
   - Holding the ampoule upright and gently flicking the top of the ampoule, with your finger, to move any medicine from inside the top of the ampoule to the bottom
   - Placing your other thumb just above the neck of the ampoule and snapping the neck of the ampoule away from you

   *If there is a dot on the top of the ampoule make sure the dot is facing away from you.*

   *If an ampoule shatters, discard it into the sharps container and start again.*

   *Some people like to use non-slip material to hold the top of the ampoule.*

   *Some services use ampoule openers – if so your nurse will teach you how to use one.*
5b. Open a plastic ampoule by:
   – Twisting the top of the ampoule until it is removed

6. Draw the medicine into the syringe by:
   – Removing the protective cover from the blunt drawing-up needle
   – Inserting the needle into the ampoule then slowly pulling back on the syringe plunger

7. Remove air bubbles from the syringe by:
   – Pointing the syringe upwards and flicking it with your finger to move any air bubbles to the top of the syringe
   – Pushing the syringe plunger upwards slowly, until most of the air bubbles are removed and until you have the correct volume of medicine left in the syringe (you may see a small droplet of medicine come out – this is OK)

8. Twist the blunt drawing-up needle off the syringe and then place it in the sharps container

9. Twist the cap onto the end of the filled syringe

10. Place the completed label on the blank side of the syringe, trying to avoid all black line volume markings on the syringe

11. Dispose of the open ampoule(s) into the sharps container

12. Wash your hands with soap and water and clean up the work surface

If you are unsure or concerned, contact your nurse or doctor/nurse practitioner for further advice.
## Giving medicine using a subcutaneous cannula: A step-by-step guide

**1. Check the subcutaneous cannula insertion site for:** Swelling, tenderness, redness or leakage and any changes in the cannula position. If any of these are present, contact your nurse for advice before continuing.

**2. Wash your hands with soap and water and dry them well**

**3. Read the label on the syringe to make sure that you have selected the right medicine, as prescribed, for the breakthrough symptom to be treated**

**4. Place the following items into a clean container:**
- The labelled syringe(s) filled with medicine
- The labelled flush syringe

*Some subcutaneous medicines can cause discomfort when being given. To help avoid this, roll the syringe between your palms for a couple of seconds to warm the contents.*

**5. Twist the cap off the syringe**

**6. Hold the Y-arm of the cannula and push the syringe into the centre of the needle-free connector and twist until secure**

*Optional: Some services request that you first swab the end of the needle-free connector with an alcohol wipe.*
<table>
<thead>
<tr>
<th>Step</th>
<th>Instruction</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>Slowly push the syringe plunger in until all the medicine has been given</td>
</tr>
<tr>
<td>8.</td>
<td>Hold the Y-arm of the subcutaneous cannula and twist the syringe to remove it</td>
</tr>
<tr>
<td>9.</td>
<td>Dispose of the empty syringe safely</td>
</tr>
<tr>
<td>10.</td>
<td>Repeat steps 5–9 for each medicine to be given</td>
</tr>
<tr>
<td>11.</td>
<td>Repeat steps 5–9 using 0.5mL of sodium chloride 0.9% (the flush syringe) to make sure all the medicine remaining in the subcutaneous cannula has been given to the person</td>
</tr>
<tr>
<td>12.</td>
<td>Re-check the insertion site for: Swelling, tenderness, redness or leakage and inform your nurse if you notice changes. <strong>It is normal for medicine to form a small lump at the insertion site immediately after giving it. The lump will disappear as the medicine is absorbed into the bloodstream.</strong></td>
</tr>
<tr>
<td>13.</td>
<td>Wash your hands with soap and water and clean up the work surface</td>
</tr>
<tr>
<td>14.</td>
<td>Fill out the medicines diary</td>
</tr>
<tr>
<td>15.</td>
<td>Check the person about 20 minutes later and put the new symptom rating in the medicines diary</td>
</tr>
</tbody>
</table>

If you are unsure or concerned, contact your nurse or doctor/nurse practitioner for further advice.
Checking the subcutaneous cannula

The subcutaneous cannula is a thin plastic tube inserted by the nurse under the person’s skin. The place where it goes into the skin is called the insertion site. The cannula is secured to the person’s skin using a clear, waterproof film that enables you to wash around the area.

Your nurse may insert two subcutaneous cannulas to make sure that there is a back-up if one stops working. This ensures there will be no delay in giving medicines to the person you are caring for.

In the one-on-one teaching session your nurse will explain how to check the subcutaneous cannula.

To check the subcutaneous cannula, you should:

• Look at the insertion site
• Contact your nurse immediately if you notice any of the following:
  – Swelling
  – Tenderness
  – Redness
  – Leakage around the cannula site
• Check that the cannula and the clear film have not been dislodged

If you are unsure or concerned, contact your nurse or doctor/nurse practitioner for further advice.

“The nurse was great with me and my sister. She showed us how to see if there was a problem with the cannula and I always checked it before I gave him any medicine.”
Recording in the medicines diary

As part of the caring@home package you will be given a medicines diary. It is very important to write in the diary when each medicine is given. This allows you to keep track of the amount of medicines used. Importantly, it allows your nurse and/or doctor/nurse practitioner to assess if the medicines need to be changed.

In the one-on-one teaching session your nurse will teach you how to fill out your medicines diary.

For each medicine given, you need to complete the following details in the medicines diary:

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Medicine</th>
<th>Dose</th>
<th>Reason for medicine</th>
<th>‘Before’ symptom rating (0-10)</th>
<th>‘After about 20 mins’ symptom rating (0-10)</th>
<th>Comments/Other things you want to note or mention</th>
</tr>
</thead>
<tbody>
<tr>
<td>29/10/18</td>
<td>4.30am</td>
<td>Morphine</td>
<td>2 mg</td>
<td>Shortness of breath</td>
<td>9</td>
<td>4</td>
<td>Settled and comfortable after 20 minutes</td>
</tr>
<tr>
<td>29/10/18</td>
<td>4.30am</td>
<td>Midazolam</td>
<td>2.5 mg</td>
<td>Anxiety</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

“I liked the diary because the nurses looked at it every day and used it as a tool to talk to us and tell us what was happening.”
Making sure there are enough medicines in the house

Prescriptions are needed for all subcutaneous medicines. It is recommended that enough medicine for at least three days is always available in the home.

In the one-on-one teaching session your nurse will advise you on the best way to make sure that you always have enough medicine in the house.

It may take a couple of days (especially in rural or remote locations) for the prescription medicine to arrive at the chemist. Check the amount of medicine each day and let your doctor/nurse practitioner and pharmacist know if stocks are running low.

If getting to the chemist is difficult, ask your pharmacist if medicines can be home-delivered.

Find out if your chemist has an after-hours service and how to access it if needed.

“Our pharmacist was very helpful. When I told her what was happening she was very prepared. We never ran out of medicines. But it was a bit stressful managing the flow of medicines and my son helped. He collected the medicine so I could stay at home with my wife.”
Safely storing and disposing of subcutaneous medicines

Medicines need to be stored safely and disposed of safely.

Your nurse will advise you on safely storing and disposing of subcutaneous medicines.

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 your fridge
• Store the sharps container out of reach of children

Disposal of unused medicine

• Return all unused medicines to your local chemist as soon as possible

If you are unsure or concerned, contact your nurse or doctor/nurse practitioner for further advice.

“We took our left-over medicines to our pharmacist. He was really helpful.”
Extra information

“I liked all the extra information. But I’m one of those people who likes to read.”
The subcutaneous cannula

What is a 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 health care team 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 a subcutaneous cannula inserted?

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

When will the subcutaneous cannula need to be replaced?

The nurse may change the subcutaneous cannula if:

- It is hard to push the medicine into the cannula
- The medicine leaks out of the insertion site
- The site is red and inflamed
- 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 health care team
More about common breakthrough symptoms

It usually takes adjustments to get the right type and dose of medicine to treat a particular symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>About the symptom</th>
<th>How can I help?</th>
</tr>
</thead>
</table>
| Pain                     | Pain is a complex personal sensation. It is as intense as the person says it is. Pain may occur in more than one location. Pain may be described differently depending on its location:  
  – Soft tissue, organ, and abdominal pain is often described as deep or cramping.  
  – Muscle or bone pain is often described as aching or throbbing.  
  – Nerve pain is often described as burning, tingling, shooting, stabbing, or as a numbed sensation. | • Some tips to help manage pain:  
  – Discuss non-medicine possibilities with your health care team because there are many things, apart from medicines, that may help to relieve pain  
  – If pain is worse when the person has to be moved, it is best to give pain medicine about 20-30 minutes before any necessary movement e.g. before bathing  
• Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s)                                                                                                                                                                                                                                                                                                                                                           |
| Shortness of breath      | Shortness of breath or breathlessness is an awareness of uncomfortable breathing. Shortness of breath may be due to the person’s disease process, anxiety, or a combination of both. It can be very distressing for the person experiencing it, as well as for yourself to see that distress. | • Some tips to help manage shortness of breath:  
  – Stay with the person, if possible  
  – Use a fan to circulate air around the person’s face  
  – Open a window to enable air flow in the room  
  – Suggest relaxation or breathing techniques, if appropriate  
  – Play music that you know the person finds relaxing  
  – Help the person into a more comfortable position e.g. sitting position, supported by pillows  
• Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s)                                                                                                                                                                                                                                                                                                                                                   |
| Noisy ‘rattly’ breathing | A person’s ability to cough, swallow, and clear secretions is limited at the end of life and noisy or ‘rattly’ breathing can result from these secretions pooling in the airways. The person who is being cared for is unlikely to be aware of, or distressed by, this noise when it occurs at the end of life. However, often carers can be quite distressed when they hear the sound, fearing that it must be uncomfortable for the person experiencing it. | • A tip to help manage noisy ‘rattly’ breathing:  
  – Reposition the person onto their side with their head slightly raised and well supported by pillows  
• Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s)                                                                                                                                                                                                                                                                                                                                                                                                 |

It is recommended to give subcutaneous medicine as soon as the noisy breathing is noticed.
<table>
<thead>
<tr>
<th>Symptom</th>
<th>About the symptom</th>
<th>How can I help?</th>
</tr>
</thead>
</table>
| Nausea and/or vomiting          | Nausea and/or vomiting can be caused by many disease processes and can also be a side effect of medicines. Nausea may be experienced with or without vomiting. Vomiting may occur with or without nausea. | • Some tips to help manage nausea and/or vomiting:  
  – Open a window or use a fan to help the person get fresh air  
  – Apply a cool face-washer or compress to the forehead or back of the neck  
  – Keep the person’s mouth clean  
  • Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s) |
| Restlessness/ agitation         | Restlessness or agitation is common as the end of life approaches. The causes are not well understood medically. | • Some tips to help manage restlessness/ agitation:  
  – Try to establish a quiet environment without too much stimulation  
  – Being present with the person may offer reassurance  
  – Speak in a calm, quiet voice  
  – Lightly massage the person’s hand or forehead  
  – Play music that you know calms them  
  – Notice if the person has pain and if so consider if this needs treatment  
  – Notice if the person is having trouble urinating and if so contact the health care team  
  • Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s) |
| Anxiety                         | People who are nearing the end of their life may experience anxiety. The causes for anxiety might be physical, emotional, spiritual, or a combination. Anxiety can increase other symptoms such as pain, nausea, and breathlessness. It may also cause sleep disturbance. | • Some tips to help manage anxiety:  
  – Being present with the person  
  – Reassure the person that they are safe  
  – Distract them, if appropriate  
  • Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s) |
| Muddled thinking or new confusion | New or worsening behaviours, not usual in the person, may be noticed:  
  – Inability to concentrate  
  – Confused conversation e.g. rambling, nonsensical, unconnected speech  
  – Talking to people who are not there  
  – Plucking at the air or the bed clothes  
  The person may appear anxious, restless or agitated, or behave in a way that is out of character. | • A tip to help manage muddled thinking/new confusion:  
  – Try to establish a quiet environment without too much stimulation  
  • Give subcutaneous medicine as per the doctor’s/nurse practitioner’s order(s) |
Common subcutaneous medicines and frequent side effects

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

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

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

If you have any concerns about medicines or distressing side effects, contact the appropriate person in your health care team.

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

* These 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 at the end of life. The person’s doctor/nurse practitioner may have prescribed other appropriate medicines, but not all can be listed here.