

Nursing for Caregivers



DOVER PARK HOSPICE
Every Moment Matters



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Introduction

As you provide dedicated care for your loved one in their final journeys, you will need to carry out nursing care to ensure their dignity and comfort.

This guide is intended for Dover Park patients at home. It introduces common scenarios that you may encounter, and the care interventions and/or actions you can perform at home.

It is intended to empower you, as a caregiver, to respond in an informed, confident manner to likely care needs, even while receiving support from our clinical team.

This guide is to be used as a reference for information and is not a substitute for training. Unless explicitly advised to do so by the clinical team, do not attempt any intervention on your own. Where in doubt, approach our clinical team for clarification or further training.

Care of Infusion Pumps

Your loved one may be fairly symptomatic and require medications at a regular dose via a subcutaneous port inserted by the Home Care team. These medication(s) will be delivered by a small electronic pump that is loaned out to you.



The Home Care team will instruct you to send a photo by 10am the following day to the Primary Nurse or On-Call number (Public Holidays/Weekends). This is to ensure the pump is running smoothly. Please ensure the syringe and pump are visible.



Press the “INFO” button to access battery level and the screen shown here

“YES” & “NO” buttons will start and stop the infusion respectively. Please do not press without guidance from Home Care team

All other buttons are **LOCKED** for safety

Things to note:

- In the event of an alarm, please contact Home Care team – our team will guide you on troubleshooting.
- Alarms can be caused by various issues such as blockages (i.e twisted tubing), low battery.
- **DO NOT** dispose of infusion pump.
- Infusion Pump has to be returned to Dover Park Hospice.

Managing Breathlessness

Breathlessness is the uncomfortable awareness of breathing. It can be a sensation felt by the patient without appearing obviously breathless. Patients may describe it as “trying to catch a breath”. It can occur for various reasons including lung cancer, chest infection, pleural effusion (water in the lung), chronic lung disorder, anxiety, heart disease, anaemia and side effect of chemotherapy or radiation therapy.

How do you count breathing rate?

- Act of breathing in + Act of exhaling out = 1 breath
- Usually counted as number of breaths per minute

What to look out for?

- Chest pain
- Fingers and lips turning blue
- Cold, clammy skin
- Wheezing and noisy breathing
- Laboured breathing
- Fast breathing (>20 breaths per minute)

What to do?

- Reassure patient
- Prop patient up with pillows at 45°
- Open the windows
- Turn on a fan to blow gently at patient's face
- Loosen tight clothing
- Use medications prescribed for breathlessness
- Attempt pursed-lip breathing.
Deeply inhale through nose then exhale gently via pursed lips for twice as long as it took to inhale
- If still breathless, sit up at edge of bed/chair and bend over, resting arm on a table and tilt head forward

Some patients may feel embarrassed and frustrated that their activities are limited due to breathlessness. Allowing these patients to do simple tasks themselves gives them some sense of satisfaction. Provide help only in more complicated tasks.

Remind the patient to pace himself/herself and get adequate breaks in between activities. Small adjustments to tasks can help enormously, e.g., sitting down while dressing or showering, placing a commode chair near the bed, holding onto the banister while walking up the stairs.

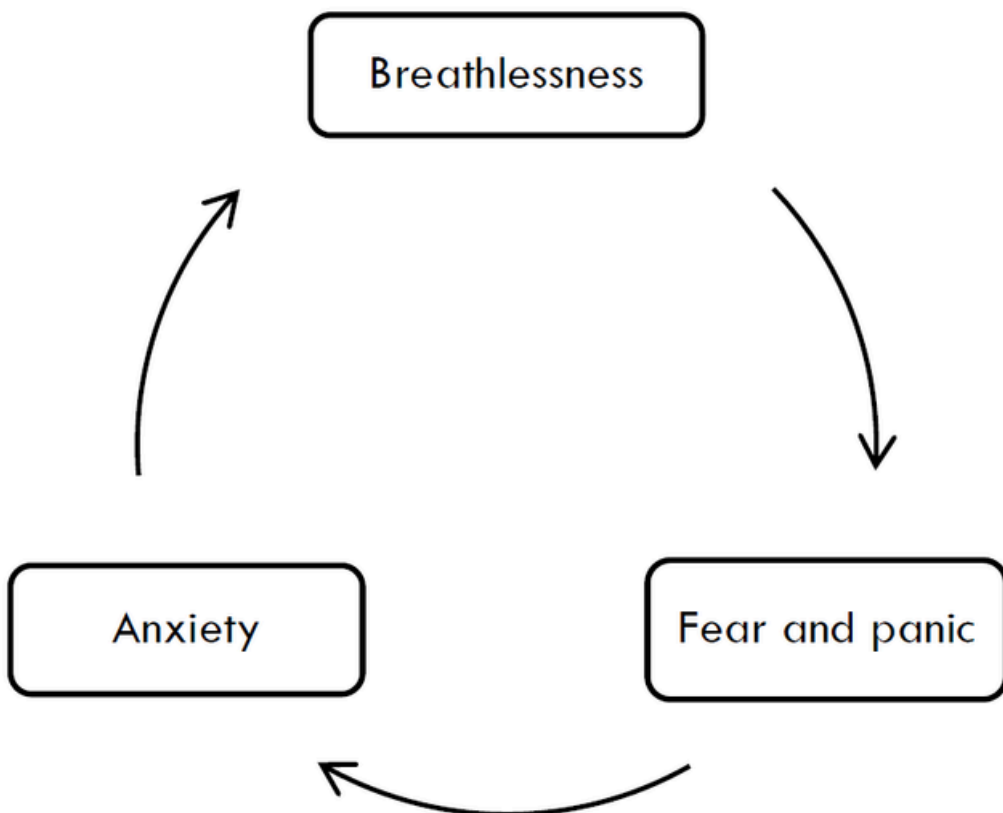
When to call for help?

- New onset breathlessness with chest pain
- Fever and thick yellow phlegm
- Lips or fingers turning blue
- Confusion or restlessness
- New onset wheeze or noisy breathing
- Facial swelling, difficulty swallowing

Note

If patient is known to have chronic obstructive lung disease (COPD), do not increase the oxygen setting of the oxygen concentrator without first consulting the hospice care team.

Anxiety is known to worsen breathlessness. Hence, there is a role for reassurance, relaxation and, at times, anti-anxiety medications.



Managing Constipation

Constipation refers to infrequent bowel movements that is less than your usual habit or passing out very hard stools. It is common among patients who are bedbound or lack activities, weak, frequently ignore urge to move bowels, poor fluid intake and on long term pain medication e.g., Morphine.

What to look out for?

- Stomach pain or cramps
- Small, hard stools
- Passing gas or belching frequently
- Tummy looks distended, patient feels full or uncomfortable
- Vomiting or nausea
- Leakage or passing very soft, liquid stools (similar to diarrhea-like stools)
- No bowel movement in last 3 days

What to do?

- Increase fluid intake if possible
- Hot or warm fluids in the morning
- Avoid foods and drinks that cause gas, e.g., carbonated drinks, cabbage
- Encourage light exercise
- Go to the bathroom as soon as there is an urge to move bowels
- Regular laxatives as prescribed
- Suppository laxative (if instructed by the home care team)

When to call for help?

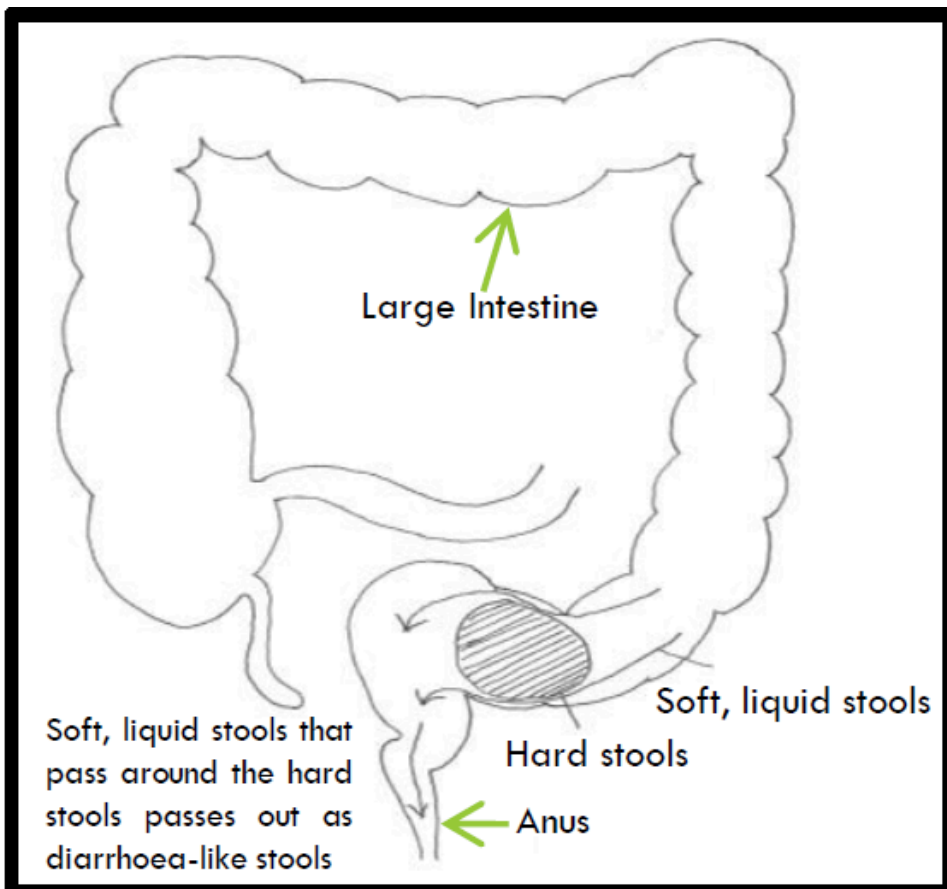
- No stools passed despite suppository laxatives
- Blood at the anus or in stools
- Severe abdominal cramps/pain or vomiting
- Not passing flatus

Common Laxatives

- *Lactulose (Lantus)*
 - Sweet, clear yellow syrup.
 - Acts by absorbing water from the gut.
 - Can cause abdominal cramps or bloat.
- *Senna*
 - Small, brownish pill
 - Acts as a stimulant
- *Macrogol (Forlax)*
 - Powder form, to be mixed with water. Acts similarly to lactulose but causes less bloat.
- *Suppository Bisacodyl (Dulcolax)*
 - Small, white bullet-like pill
 - Acts as a rectal stimulant
 - To be inserted via the anus and should be placed in direct contact with the rectal wall

Note

- Stools are still formed even in patients who do not eat anything as the body still forms wastes that need to be removed. Hence, they too can get abdominal discomfort from constipation.
- If there are multiple bowel movements a day and passing large amounts of watery stools (not the normal routine), try reducing the laxatives by one dose. If the patient becomes very tired, is not eating or drinking much, or the frequency and stool consistency does not improve after a day, please inform the home care team.



- If the patient is passing small amounts of semi-formed stools a few times a day, and still feels abdominal discomfort, he or she may be constipated. It is very commonly mistaken as diarrhea. This occurs when there are impacted hard stools near the rectum and the softer, more liquid stools pass round the hard stools and is passed out as diarrhea-like stools. You can insert a Dulcolax Suppository to attempt to clear the impacted stools. Otherwise, inform the home care team, who will then do a rectal digital examination and give an enema as appropriate.

Managing Seizures

Commonly occurs in patients especially when there is involvement of the brain, from a primary brain cancer or a cancer spread. Other causes of seizures in cancer patients include high fevers, head injury, infections involving the brain or the fluid surrounding the brain and spine, certain medications or an imbalance in the body chemistry.

What to look out for?

- Patient may moan or let out a cry then lose consciousness
- Twitching or jerking movements, especially of the arms and legs
- Eyes staring blankly or rolls back
- May affect the whole body or just one part
- May suddenly lose control of urine and bowels

Seizures usually stop on its own after a few seconds or minutes. It can be frightening, especially if you have never seen one before

What can you do?

- Stay calm and stay with the patient
- Keep the patient safe
- If the seizure starts while the patient is in bed or on a chair, cradle the patient in your arms to prevent him or her from falling to the floor
- Move patient only if the vicinity is unsafe (near glass doors, stairways or other hazards)
- If patient falls to the floor, place a padding (rolled-up clothes or towels, pillow) under the head
- Try to gently turn the patient to the side, while supporting the head, to allow saliva to flow out of the mouth
- Remove his or her glasses and loosen any tight clothing
- **Do not try to restrain** the movements. Allow the seizure to happen
- **Do not insert any object** into the patient's mouth.
 - Many do this to prevent tongue biting or to keep the mouth open. Instead, it may cause damage to the teeth or gums.
 - Patient may break the object and cause choking

Try to take note of:

- Duration of seizure
- Type of movement occurring
- Parts of the body involved

After the seizure

When the seizure stops, patients are usually very drowsy.

- They may be confused or frightened and unable to recall the seizure.
- Speak gently and reassure the patient.
- Keep the patient on their side and allow them to rest in that position till more awake.

Wait until the patient is fully conscious before giving any food, drink or medications.

If there is a possibility of a seizure, medication to stop a seizure would have been given as stand-by. This medication is called *Stesolid* and is given via the rectum.

When to call for help?

- Seizure lasts for more than 5 minutes
- Patient does not regain consciousness after seizure has stopped
- First episode of seizure

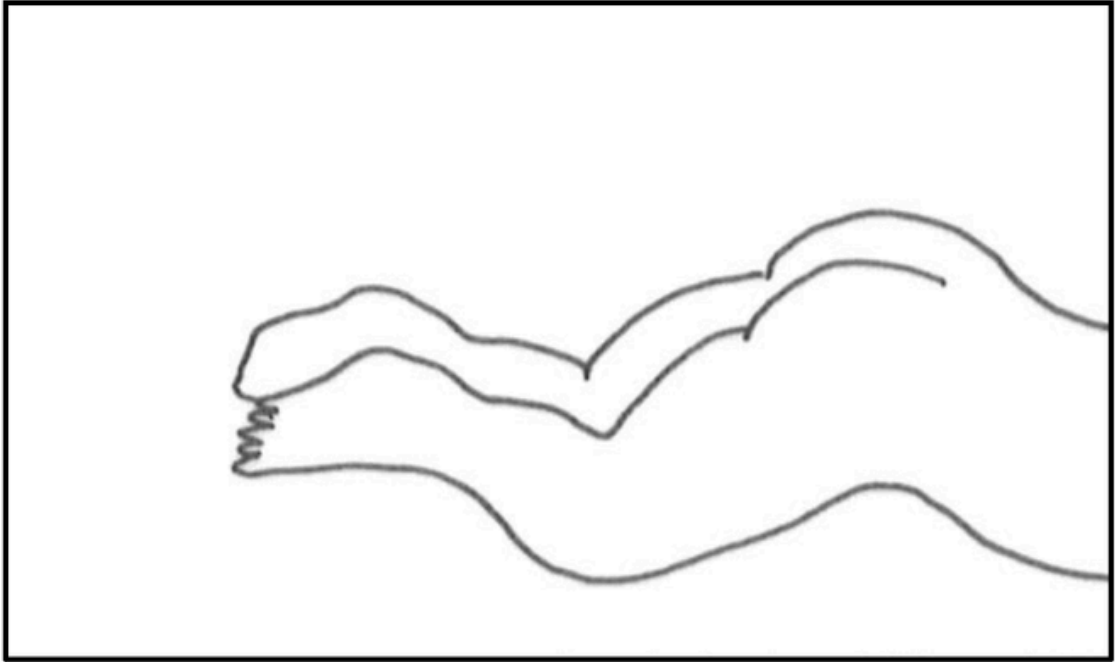
Call for help only after the seizure has stopped or if another person is available to make the call. ***Never leave a patient having seizures unattended.***

Precautions

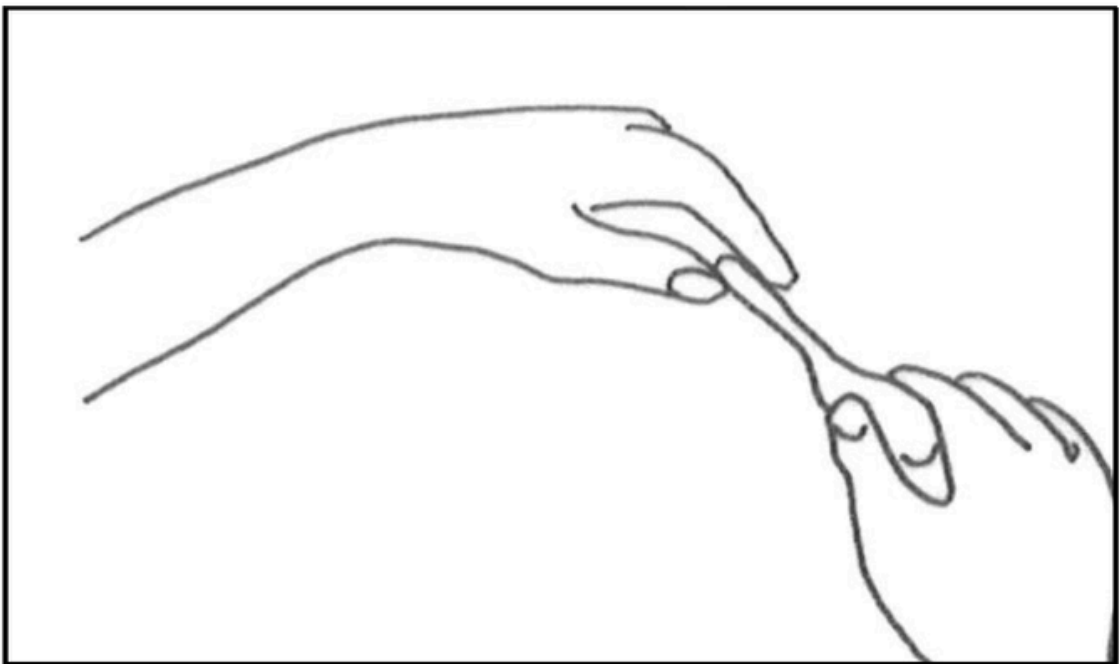
- Ensure there is always standby Stesolid available in the refrigerator
- Anti-seizure medications are served regularly to prevent a seizure
- Use side-rails and paddings at side of bed to prevent injuries. Ensure patient is always accompanied when he or she is walking or sitting on a chair

How to administer Stesolid?

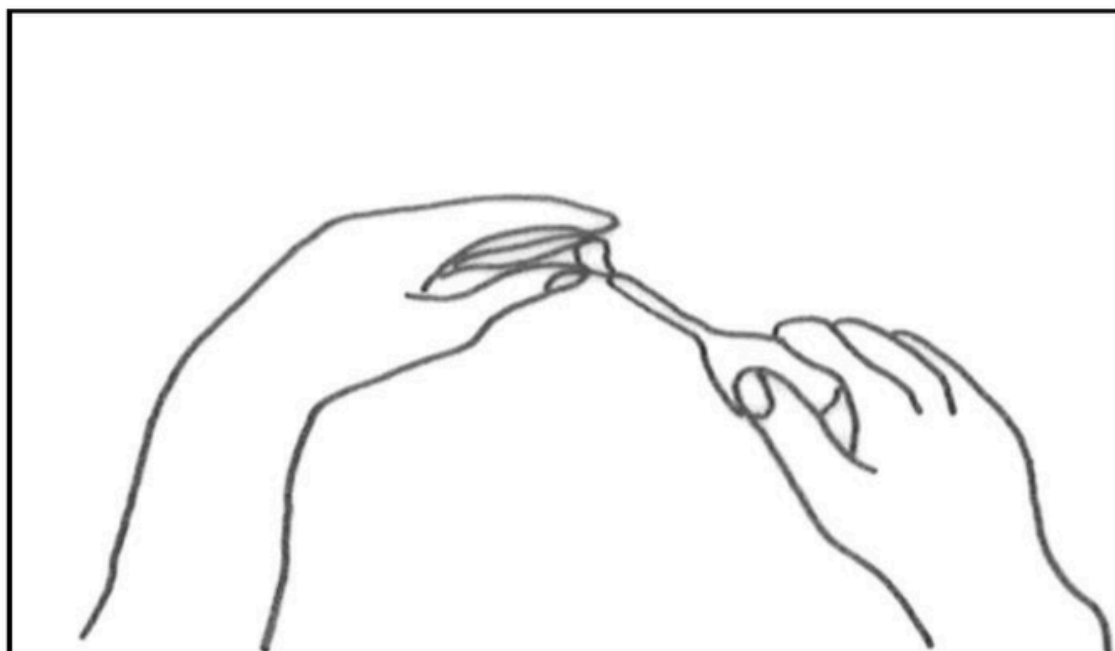
Adapted from the Actavis Stesolid Diazepam Information Sheet



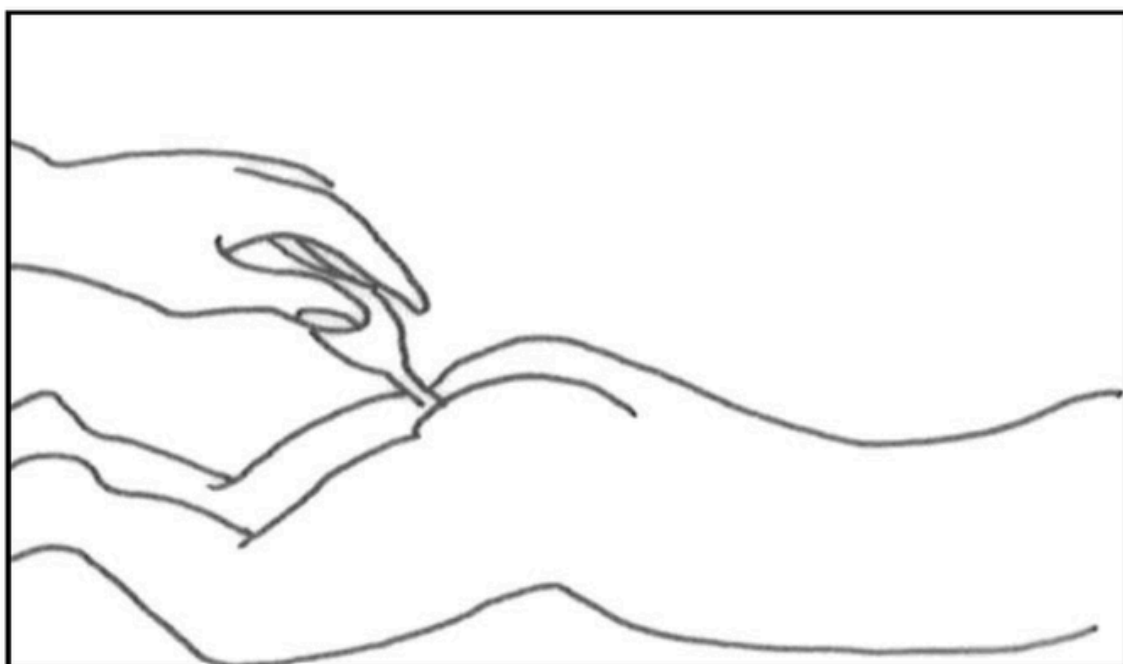
- a) Child : place across your knee with buttocks raised
Adult : lay patient on his/her side with buttocks facing you



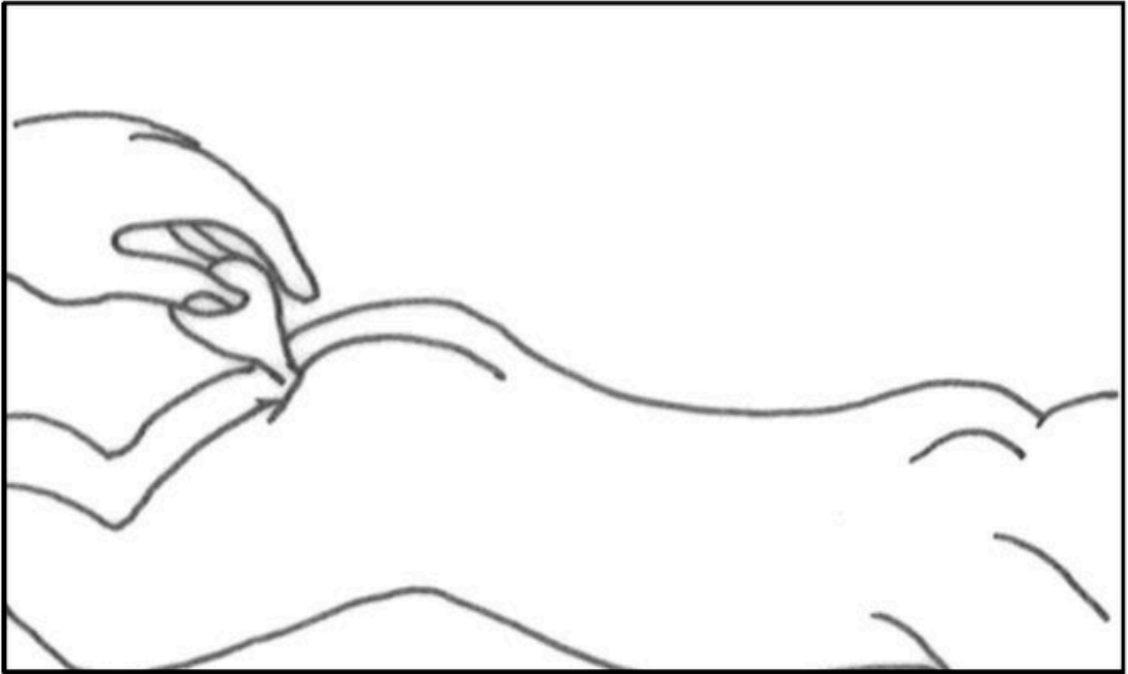
- b) Remove the tube cap and seal



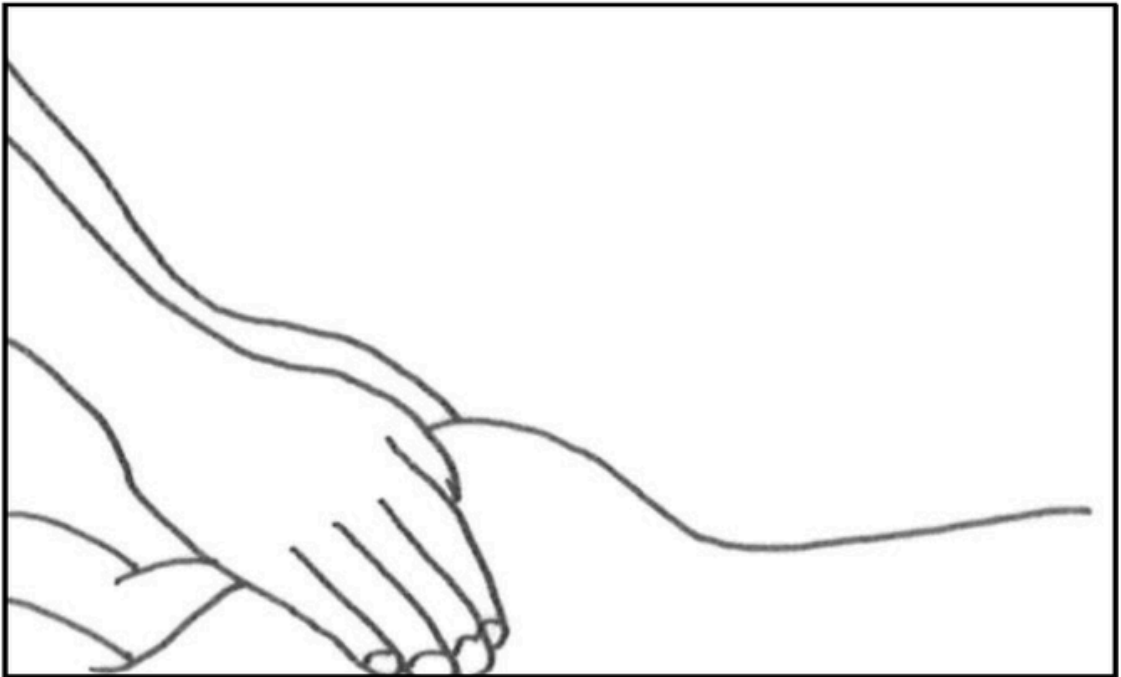
- c) Smear some lubricant gel on the end of the nozzle



- d) Insert the entire length of the nozzle into the anus (about 5cm)



- e) In releasing the contents of the tube, the position of the tube must be straight down



- f) Once the tube is emptied, it must be kept in pressed position till pulled out. Keep patient in the same position and press together the buttocks to avoid seepage

About Pain

Many associate cancer with a painful dying process. This need not be true. Good pain control can be achieved if the patient, family and the medical team are able to work together to find the best combination of pain medication that works for you.

Some common issues about pain are explored below.

Does everyone with cancer have pain?

No. Some patients remain pain-free till the very end.

What causes the pain?

Pain is usually caused by tumour pressing on the surrounding structures. Frequently, it may press on and irritate nerves which cause pain in a location away from the tumour. Other causes of pain in cancer include effects of radiation to surrounding healthy tissue.

Do keep in mind that a person with cancer can also have pain from common conditions unrelated to the cancer, e.g., headaches, arthritic pain.

What does it mean when asked to describe the pain?

Pain from different causes manifests differently. By describing the type and character of pain, you guide us in prescribing the most appropriate medication to deal with that particular type of pain.

Pain descriptions include the following:

Character	Aching, sharp, electric shock-like, throbbing, poking, burning
Onset	Sudden; gradual
Frequency	Lasts all day long; on and off
Severity	Mild, moderate, severe, minimal
What makes it worse?	Movement, coughing, breathing, walking

Pain builds character. I prefer not to take pain medication.

Taking pain medication is an individual's choice. The meaning of pain and the pain threshold of each individual is different. It is important to understand that there are options available to help control your pain if you are open to it.

This will **not** prolong life but it can **improve your quality of life** and allow you to enjoy your time with family or participate in activities that interest you. If chronic cancer pain is left untreated, it will get worse as the nerves are trained to deliver the pain signals more effectively and the brain becomes more sensitive to these signals. This happens even if the injury or illness remains the same.

Only injection pain killers are effective.

Pain killers are available in different forms – oral tablets, capsules, syrup, injection, suppositories, patches, gel. The method of administration is influenced by a few factors including ease of administration, duration of action, patient's comfort and monitoring facilities. A painkiller in other forms is just as effective as injection painkillers in providing pain relief and spares the patient from a needle injection.

Thinking about the pain makes me more depressed.

Severe chronic pain is usually accompanied by emotions of anxiety, depression, fear, poor appetite and poor sleep. All these add on to the pain experience and cause more distress in perceived and anticipatory fear of more pain. This can be avoided most times if the pain was well controlled from the start. Sometimes, we may need to treat the depression and anxiety to improve the pain.

About Morphine

Morphine is an opioid type painkiller. Other painkillers from the same family include fentanyl, oxycodone and oxycontin.

Many have reservations about using morphine. However, morphine is good and effective in controlling severe pain. Some concerns regarding morphine are discussed below.

Morphine is only given to dying patients

This is not true. Morphine is given according to a patient's needs.

Morphine is usually prescribed if pain is severe or not well-controlled by simple painkillers like Panadol[®], Ponstan[®] and naproxen.

I will be addicted to Morphine

Addiction refers to the misuse of drugs, despite harmful effects, in the absence of a medical reason for use.

Patients started on morphine do not seek or crave more morphine once their symptoms are controlled.

Addiction should not be confused with tolerance. Tolerance refers to the need for higher doses of medication (e.g., Morphine) to achieve the same effect as the body has adapted to the medication. This occurs in all patients who take morphine.

What are the side effects of morphine?

Common side effects include:

- Constipation
 - It is important to take regular laxatives as advised by your home care team
- Drowsiness
- Nausea
- Dry mouth

Most patients develop tolerance to nausea and drowsiness after a few days of taking morphine.

People tell me the pain will get worse later. If I use morphine now, I will not have any painkiller to use later

Pain is more easily controlled in the beginning. Uncontrolled, severe pain at a later stage is not only difficult to control but also greatly affects patient's ability to spend valuable time with family.

There is no maximum dose of morphine. Instead, the dose is usually safely increased according to patient's requirements.

Sometimes a combination of painkillers is required to control pain. This does not mean that morphine is no longer working, but instead, some pain requires other medications or procedures done to improve it.

Morphine affects breathing, it may hasten death

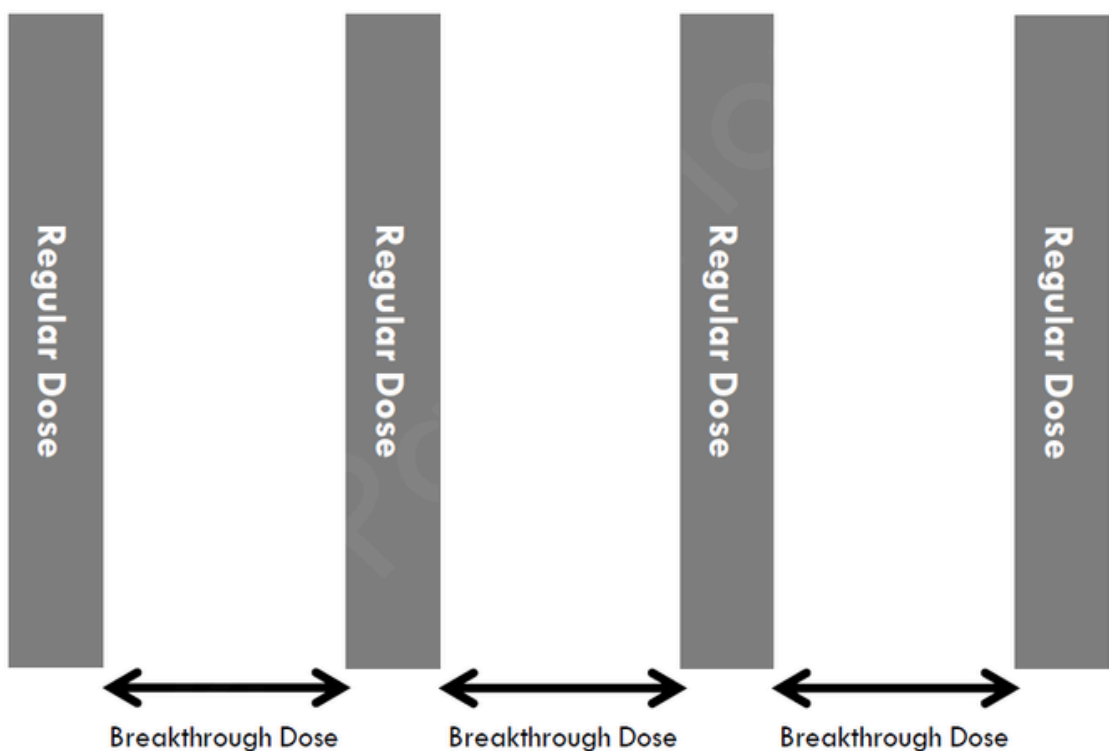
Morphine rarely causes a patient to stop breathing unless given in very large doses or dose is increased very rapidly.

Morphine's effect on breathing is used in breathless patients to allow them to breathe more comfortably and effectively.

Larger doses of morphine may be required towards the end of life to ensure patient's comfort. This should only be done at the advice of the homecare team.

About Breakthrough Medication

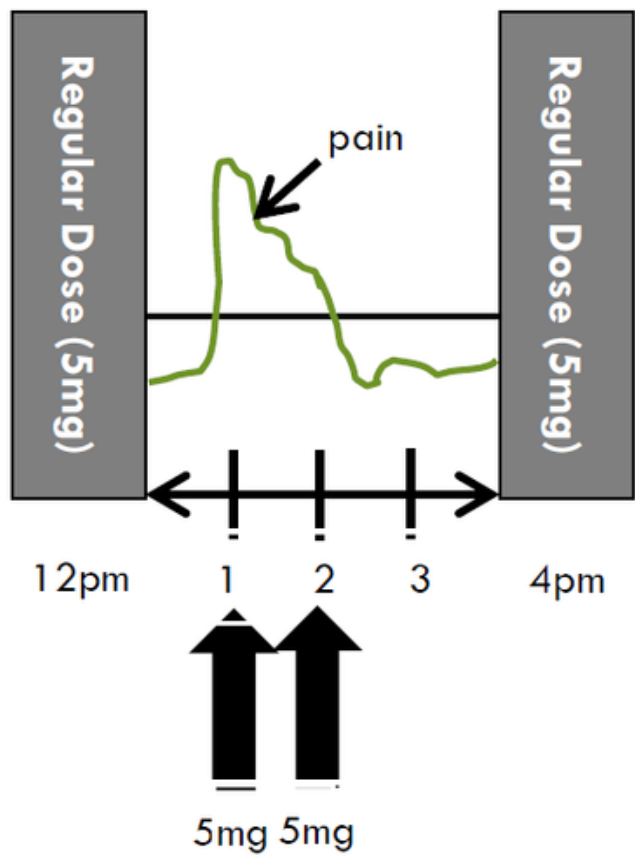
When you were prescribed pain medications, you would have been told about additional doses which you may take in the event you have pain despite taking your regular doses of painkillers. This is what we call breakthrough medication.



Example

Regular dose	5mg every 4 hours
Breakthrough dose	5mg up to every hour

12pm	Regular dose taken
1pm	Severe pain 1 breakthrough dose taken
2pm	Pain improving but still not comfortable; 2nd breakthrough dose taken
3pm	Comfortable
4pm	Regular dose taken



Important

- Ensure you take all regular doses at the instructed times even if a breakthrough dose was given.
- Caregivers, please call the Home Care Team if (a) patient is still breathless or in pain after 2 breakthrough doses (b) patient is very drowsy.

Administering Breakthrough Medication

Your loved one may require additional doses of the medication (breakthrough doses) to control his or her symptoms. This is done via a subcutaneous needle inserted for you by the Home Care Team (Figure 1).

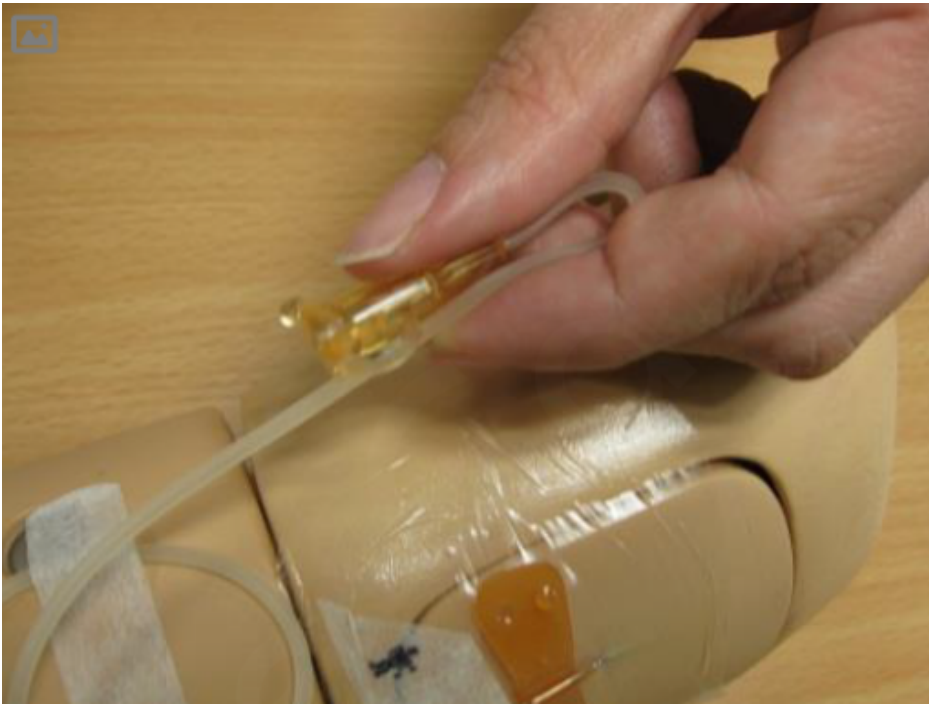
If he or she is prone to removing needles from their body, you may be required to administer the medication directly as illustrated in Figure 2.

Figure 1

a) Prepare the medications and 2 alcohol swabs.



b) Clamp the tubing then open the port.



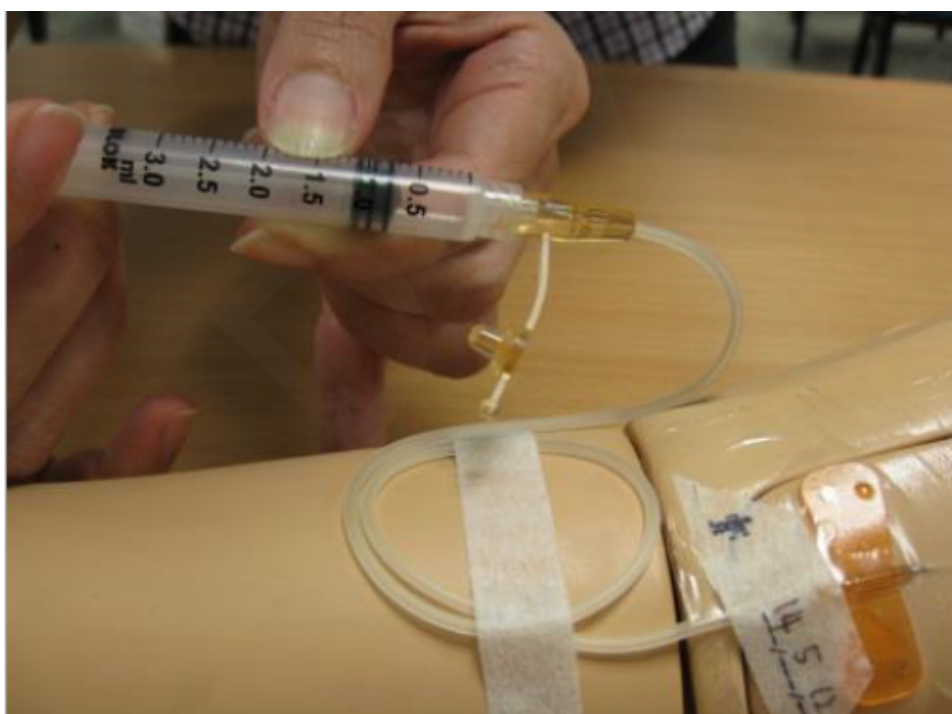
c) Clean port with alcohol swab.



d) Attach syringe with medication to the port.



e) Release the tubing and administer medication.



f) Repeat steps (b) to (e) to flush the tubing. Then, close the port.



g) Secure the port with a tape.



A 10ml syringe with saline is provided to flush the tubing (1ml saline) after administration of medication.

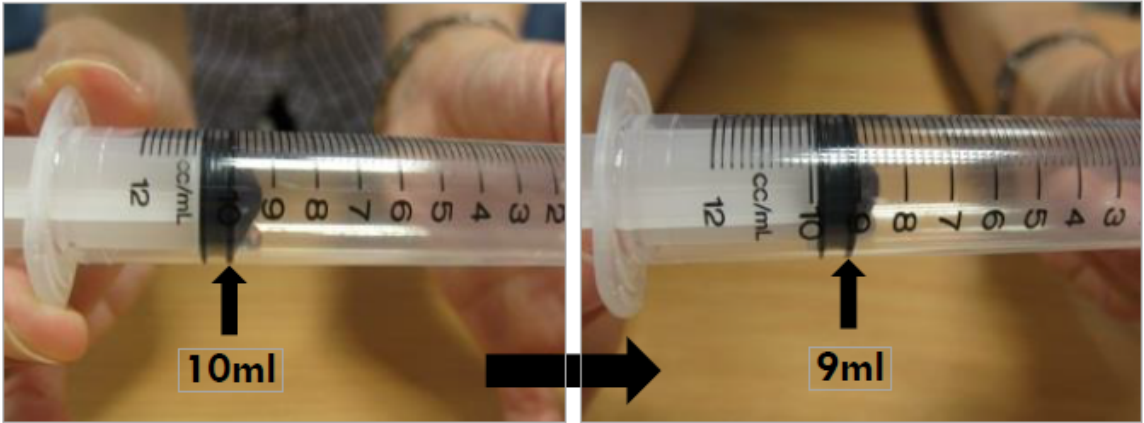


Figure 2

If your loved one is prone to removing needles, you may be required to administer the medication directly, as shown below.

a) Prepare the medication and an alcohol swab.



b) Clean the area with the alcohol swab.



c) Pinch the skin.



d) Insert the needle 45° angle, pull back the plunger to ensure no blood is seen then administer the medication.



plunger

