Symptom Management Guidebook

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Contents

Introduction

Living with an advanced illness can produce unpleasant symptoms. This booklet contains information to help you and has been developed to provide clients and carers with useful information to help prevent, manage and resolve common symptoms that you may experience.

EPC acknowledges that this can be an emotional and confronting time. We offer, and can provide, ongoing support from our interdisciplinary teams as required.

This booklet is a guide only.
Contact your palliative care nurse or GP if symptoms continue or worsen.

Pain Management

One of the greatest fears of clients and caregivers is severe and uncontrolled pain, although not everyone with a progressive or life-threatening disease experiences this.

- Pain is an individual experience, it is your description of the pain that guides health professionals to determine the best treatment approach.
- Pain can almost always be effectively managed. It is generally easier to do so early, before the pain becomes prolonged or severe. It is helpful to the team if you are honest about the extent and nature of your pain.
- Untreated pain can cause increased fatigue, depression, anxiety, anger, poor appetite, difficulty with sleeping and stress.
- Pain medications are the foundation for controlling physical pain, but these medications can be used in combination with non-drug treatments, such as heat/cold packs, massage, relaxation and spiritual/psychosocial support.
- Pain medication is generally prescribed on a regular basis and is usually long-acting to prevent pain. Sometimes, however, you may experience ‘breakthrough’ pain for which your doctor may have prescribed a fast-acting medication. It is helpful to keep a record of the amount of fast-acting or ‘breakthrough’ medication you are using. That way your palliative care team can determine if your long-acting medication dose is adequate to manage your pain. If you feel that your pain is poorly controlled, please inform your palliative care nurse and/or your medical team.
- Painkillers range from paracetamol/aspirin, to codeine, morphine or other opiates, such as Oxycodone or Durogesic patches. The palliative care team has the expertise to determine the right mix.
- Morphine and Oxycodone are the most commonly used opiates for moderate to severe pain because of the effectiveness, availability and cost of these medications.

Sometimes there are anxieties and myths surrounding the use of opioids (like morphine), including the following:

Addiction - People with pain have a physical need for medication. This can neutralise the ‘euphoria’ effects which occurs in people with a psychological dependence.

Tolerance - Research has shown that developing a tolerance is unlikely in palliative care.

Respiratory Depression - Opiates do not cause respiratory depression when the correct doses are used. In fact opiates can be used in low doses to ease difficult breathing and suppress coughs.

Need to ‘save’ morphine for when pain gets really bad - There is no ceiling dose above which the medicine stops working. It is far better for you to have good pain control to optimise your quality of life. If the pain gets worse, the dose can easily be adjusted or another drug can be used.

What are the side effects of opiates? Ongoing constipation, which is controlled with laxatives, is a common side effect of some pain medication. **[Refer to the Bowel Care section on Page 6 for more information].**

- Some people experience short-term nausea, sleepiness or confusion - these symptoms usually settle within 48-72 hours of commencing the medication. Sometimes symptoms may persist for up to a week. Speak to your palliative care nurse for further information.

Take an active role in helping to control and treat your pain by talking with your palliative care team. If you are experiencing any pain, try to remember where you have pain and what it feels like. Write it down if this helps. The team will review your pain and the many management options available.

Bowel Care

Constipation is a very common and uncomfortable problem in people with significant illness.

Some causes of constipation include:

- changes in how much and the types of food you eat;
- drinking less fluid;
- reduced physical activity; and
- some medications.

Certain medications, such as morphine and other medications, can be constipating. Do not stop taking these medications. An increased awareness of preventing and treating the constipation is required.

Be aware of your normal bowel pattern when discussing bowel issues with your GP or visiting palliative care nurse.

Constipation occurs when at least two of the following problems are present:

- Less than 3 bowel actions per week
- Hard and lumpy stools that are difficult to pass
- Needing to strain to pass a stool (even if it is soft) or needing to sit on the toilet for much longer than usual
- Feeling like the rectum hasn't fully emptied after a bowel action
- Bloating, abdominal cramping
- Very watery diarrhoea with no formed stool

Management of Constipation:

The best form of constipation management is prevention. Staying hydrated, taking regular laxatives and engaging in gentle activity can help prevent constipation. Prune or pear juice can be helpful.

Using the toilet after breakfast can make the most of the natural cycle of movement in the intestines.

Managing symptoms such as pain or breathlessness is important so you are able to get to the toilet as needed.

Keep a record of your bowel movements, you can use a calendar or a note book. There is a bowel chart in your EPC folder or even apps for your phone. Aim for regular daily or 2nd daily bowel actions that are passed easily. If your bowels have not opened for three days, inform your palliative care nurse.

If constipation persists despite regular laxatives, the dose of the laxatives can be adjusted, or anenema or a suppository may be necessary.

For people taking regular morphine, or other pain medications, a regular laxative should be taken to help with the constipating effect of these medications.

The most common laxatives are:

- Coloxyl with senna;
- Movicol; and
- Lactulose/Duphalac (often used in conjunction with Coloxyl with senna).

Other helpful hints to manage constipation include the following.

- Increase your fluid intake if possible.
- A small footstool (or a couple of telephone directories for you to place your feet on) may help with the pushing down action.
- Hugging a fat pillow resting on the thighs may have the same effect;
- Light massage in a clockwise direction over the abdomen, using warm oil, may help to stimulate the bowel muscle (Do not do this if an abdominal tumour is present).
- Discuss with your palliative care team if a commode or an over-toilet seat may be helpful.

Management of Diarrhoea:

Diarrhoea is an increase in the fluidity and frequency of stools. Reasons for this occurring include the following:

- Medications/Treatments; (eg. Chemotherapy/ Radiotherapy or antibiotics)
- Diet; and
- Disease related.

If there is a cause that is able to be identified, the diarrhoea could be resolved. If the cause is not an issue that can be resolved, then you may be prescribed some medication to help manage the diarrhoea.

Some helpful hints to improve comfort if you are experiencing diarrhoea include the following.

- Discuss the issue with your palliative care nurse or your GP.
- Increase fluid intake.
- Use electrolyte replacement fluids (eg. Gastrolyte/ Hydralyte).
- Rest the gut for 24-48 hours by avoiding solid food.
- Ensure washing of hands and good hygiene practices following each bowel action.
- Soft toilet paper and/or moist wipes can be soothing.
- Barrier creams to the anal area may be beneficial.

Nausea and Vomiting

Nausea and vomiting are unpleasant and distressing symptoms which can occur intermittently. Each can exist independently, or can occur with the other, so nausea and vomiting are assessed separately.

There are many possible causes for Nausea and Vomiting. Within the body, nausea and vomiting are controlled by an area of the brain (vomiting centre) which can be triggered by the following;

- Particular smells, sights, tastes or movements.
- Some medications or treatments (chemotherapy, radiotherapy) or body imbalances like dehydration, constipation, obstruction to the bowel, or a change in the level of certain chemicals in the blood.
- Emotional factors like anxiety and anticipatory nausea.
- Continuous coughing.
- Disease progression.
- Pain.

Nausea - *what can you do?*

- Prevent constipation if possible and treat constipation early if it occurs.
- Take anti-nausea medications regularly as prescribed by your doctor.
- Keep a record of symptoms and what caused them.
- Keep the room well ventilated and free from unpleasant smells.
- Ask your GP or palliative care team to review medications and eliminate unnecessary drugs or review the timing of taking medications.
- Avoid lying down immediately after eating.
- Clean your teeth or rinse mouth before and after eating.
- Try eating small amounts of your favourite foods 5-6 times per day and avoid an empty stomach which can trigger nausea.
- If the smell of hot food makes you feel nauseated, eat cold or warm food.
- Try relaxation activities, music therapy, deep breathing exercises, meditation or simply being involved in an activity.
- Try sucking on ice, icy poles and sipping flat carbonated drinks such as flat lemonade.
- Eat or drink ginger products such as dry ginger ale/beer, ginger biscuits or ginger tea.

Vomiting - *what can you do?*

- If you experience vomiting, especially for more than one day, contact your palliative care nurse. They will identify any immediate treatable causes.
- Injectable anti-nausea medication may help to control vomiting.
- When vomiting stops, rinse mouth, clean teeth and suck on ice or take small sips of water.
- When possible, take regular sips of water, soda water, ginger ale, lemonade or energy drinks. Experiment with temperatures.
- Gradually introduce a greater variety of drinks and a small amount of plain food (eg. slice of dry toast).
- Re-introduce food slowly.

Nutrition

Loss of appetite and weight are common symptoms that may be experienced when you are unwell. It is a good idea to allow yourself control over the size and time of your meals or whether you have a meal at all. Deciding what to eat can often be an added burden, therefore it may be easier if someone else makes these decisions for you.

The following are suggestions that may assist in maintaining comfort in the area of nutrition.

- Decrease the amount of fluids taken just before or with meals as they can fill you up.
- Try serving meals on smaller plates so it is not overwhelming.
- Drink from a glass that is half full as it is more satisfying to finish this than to half finish a full glass.
- Timing of meals is important. By the time evening comes you may be tired, earlier in the day may be better for 'main' meals.
- Eat small frequent meals throughout the day, instead of three main meals.
- Make meal times a social occasion.
- Avoid foods that carry heavy aromas. (eg. cauliflower)
- Avoid fatty foods.
- Eat food slowly and relax after meals.
- A referral to a dietician may be beneficial.

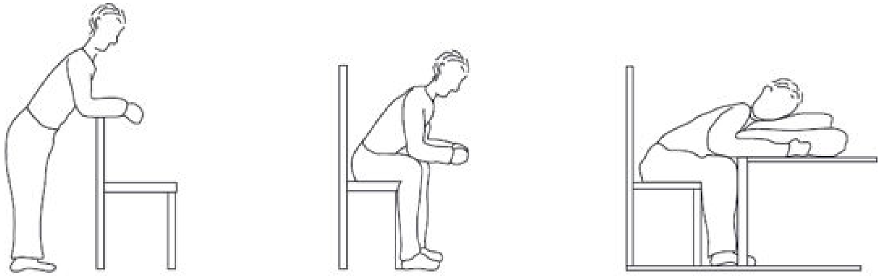
You may experience changes in taste and may need to experiment with different ways of making food taste 'right'.

- Reduce 'bitter' taste by reducing red meat.
- Try more chicken, fish and dairy products.
- Try foods at different temperatures.
- Try adding extra flavour to foods. (eg. salt, pepper, sugar/ sweetener, stock, sauces)
- Make sure you are comfortable when sitting up to eat. If in bed a triangular pillow may be of use.
- Nausea, vomiting and constipation can affect appetite. [**Refer to these sections in this booklet for further information].**
- A dry and sore mouth may affect nutrition. [**Refer to the Mouth Care section on Page 15 for further information].**
- "It's all too much effort...''. Use convenience foods as these cut down on preparation time and food wastage.
- Supplement drinks such as Sustagen, Resource, Proform, etc. can be used to improve intake. High protein powders can be used in recipes such as puddings and egg flips. These are purchased from chemists or online.
- Try small tubs of mousse, yoghurt and ready to use custard, ice cream, jellies, smoothies and soups.
- Try baby foods.
- Enrich milk drinks with full cream milk powder.
- Increase calories in diet by adding eggs and cheese to food.

Shortness of Breath

Shortness of breath in palliative care clients is common. People who are experiencing shortness of breath feel that they cannot get enough air and breathing may be faster or slower than usual. Breathlessness in itself is not damaging, however, it can be distressing. There are many helpful interventions, and ways to adjust your lifestyle, to reduce breathlessness and maintain a sense of control.

- Maintain a calm and unhurried approach to activities, attempting only what can be comfortably tolerated. Rest between activities.
- Avoid situations that make you anxious and increase your shortness of breath. Try to remain calm at all times.
- Keep your immediate environment as uncluttered as possible. Place essential items within easy reach.
- Positions that might ease breathing difficulty, include:
  - sitting upright;
  - sitting at a table with arms raised on pillows;
  - in a bed supported by pillows or backrest; and
  - in a chair with arms well supported and legs elevated.
- Ensure you have loose clothing around the waist, chest and neck as this can promote comfort.
- Use of equipment can assist to reduce breathlessness (eg. commode, wheelchair, raised toilet seat and strategically placed chairs). Ask your palliative care team for information on hiring/purchasing equipment.



These positions aim to enable patients to relax their shoulders and upper chest so that the diaphragm expands.

- A fan (either a pedestal or hand-held) is useful to circulate air, as is an open window or door, or sitting outside.
- There are some breathing techniques which might help, discuss these with your palliative care team.
- Pace your day to day activities and ask for help if required.
- There are some medications commonly used in palliative care to control breathlessness.
- Medications such as morphine syrup and anti-anxiety medications are used individually and in combination to assist in controlling this symptom. Please speak with your palliative care nurse or GP about these medications.
- Many of our clients benefit from a shortness of breath ‘action plan’. This is created in consultation with your palliative care team and is regularly reviewed and updated as necessary.

  This includes easy steps for you to follow to take control of your breathlessness. Please contact an EPC nurse if you are unsure about the management of this symptom.

Oxygen Therapy

Use of Oxygen Therapy is not considered the first choice in the management of shortness of breath. Oxygen Therapy should only be used if ordered by your doctor. Oxygen concentrator units are available for continuous oxygen use in the home.

- **Do not** smoke where oxygen is used.
- **Do not** expose oxygen to areas where open fireplaces or gas cookers are being used.
- Portable oxygen can be arranged for outings.
- Education and support will be provided if oxygen therapy is recommended by your treating doctor.

No Smoking, Matches or Open Flames near the oxygen concentrator or persons using concentrator.

Notify your doctor or palliative care nurse if you are having sudden episodes of shortness of breath, as your treatment plan and medications may need to be adjusted. Your palliative care nurse can advise an action plan for you to manage these acute episodes. Keep this plan in an easy to find place.

Fatigue

Fatigue is a very common and distressing symptom for people with advanced diseases. This type of fatigue is described as a feeling of overwhelming tiredness, weakness or a lack of energy, which is not relieved by sleep or rest.

Fatigue is thought to be caused by a number of different factors. Common causes include some cancer treatments, pain, shortness of breath, anaemia, infection, dehydration, poor diet, depression or disease progression. Depending on the cause of your fatigue, there are many interventions to help manage this often distressing symptom.

- Let your palliative care nurse or doctor know if you have uncontrolled symptoms such as pain, shortness of breath, depression or insomnia. Treating these symptoms can assist in improving your fatigue.
- Maintain a healthy diet including fruit and vegetables. Dietary supplements or drinks can also assist in increasing energy levels.
- Planning your day and pacing or adjusting your activities to happen at times when your energy levels are at their best.
- Research into fatigue has shown that gentle exercise including stretching and keeping active can actually help improve energy levels and maintain muscle strength.
- Regular rest periods during the day and the use of equipment can also decrease fatigue (eg. wheelchair for outings, raised toilet seat, shower seat).
- Asking people for help with shopping, cleaning and other household jobs will allow you to conserve your energy for important activities such as spending time with family and friends.

  Please discuss with your visiting palliative care nurse or palliative support clinician if you are interested in being referred.
- Reorganising your environment may also decrease your levels of fatigue (eg. rearranging your bed so it's closer to the bathroom).
- Some medications can increase the level of fatigue that you may experience. Please discuss with your palliative care nurse or your GP who can review your current medications.

Mouth Care & Oral Problems

Mouth and oral problems may be experienced as a result of particular treatments and/or medications you are taking. These problems can include a dry mouth, coated tongue, bad breath, infections, oral thrush and ulcers. To reduce discomfort it is important to be vigilant in maintaining good oral hygiene.

Inform your doctor and palliative care nurse of any signs of mouth and/or throat soreness. There are a number of possible reasons why the mouth is painful and the cause needs to be identified so that the appropriate treatment can be given.

Dry Mouth - Frequent mouth rinses may be useful. Avoid commercial mouthwashes that contain alcohol as these have a drying effect on the mucous membrane of the mouth.

A simple plain water or salt water rinse (1 teaspoon of salt in 600mls water) 3-4 times a day, after meals is recommended.

Other effective suggestions for care of a dry mouth are as follows.

- Pineapple/watermelon wedges to refresh the mouth (fresh or frozen).
- Chips of boiled lollies.
- Ice chips or icy-poles made with frozen tonic water, coke/lemonade or lemon/orange juice.
- Sugarless gum may help to stimulate saliva. Saliva substitutes can be purchased from your local chemist.
- Keep lips moistened with lip balm, lanolin or pawpaw ointment.

Coated Tongue - Clean the teeth and tongue with a soft toothbrush. Or, mix sodium bicarbonate with some water to form a paste, brush mouth and tongue using the paste with a soft toothbrush. Fresh pineapple or unsweetened tinned fruit or fruit tingles may assist with a coated tongue.

Inform your doctor or palliative care nurse who will examine the mouth for signs of infection.

Ulcers/Pain/Bleeding - For maximum comfort, adhere to regular mouth rinses with salt water. Avoid heavily seasoned/acidic foods and irritants such as caffeine, alcohol or tobacco. Bonjela, Dentamed or Difflam mouth rinse may be useful if mouth soreness is present.

Oral Thrush - A solution called Nilstat or other anti-fungal products may be recommended by your palliative care nurse or doctor. It is important to adhere to the following instructions for best results.

- Rinse mouth and clean dentures if being worn.
- Place 1ml Nilstat in the mouth.
- Swish, gargle and hold in the mouth for a short time.

Swallow the solution. Do not eat or drink anything for 30 minutes after this routine to allow the solution maximum effect. If this is ineffective, discuss alternatives with the palliative care team.

Halitosis (Bad Breath)

- Routine mouth care
- Maintain a moist mouth
- Treat any underlying infections as advised
- Chewing gum
- Peppermint water gargled or used on moist swabs
- Chewing mint or parsley
- Apple cider vinegar gargle 1 tsp to 1 cup warm water

Dentures - Dentures may not fit properly if a person experiences rapid weight loss.

Refitting by a dentist or the use of denture pads may be necessary to provide comfort.

If ulcers are present, removal of dentures will help promote comfort and healing.

Soak your dentures twice weekly in one part white vinegar and 20 parts water.

Skin Care

Your skin may be at risk of infection or pressure sores due to immobility, incontinence, some treatments and medications, and decreased nutritional intake. The palliative care nurses will assess your risk when they visit and explain precautions you can take.

The following suggestions will assist in maintaining comfort and decreasing the risk of infections and skin breakdown.

- Protect yourself from cuts/scratches where possible.
- Thoroughly clean any cuts or scratches that have visible debris. Tell the visiting palliative care nurse if any cut or break in the skin becomes painful, red or hot to touch, or if you have any swelling of the skin as this increases the risk of skin breakdown.
- Electric razors are often safer than blade type razors.
- Use sun block/protective clothing to prevent excessive exposure to sun.
- Avoid clothing that is too tight.
- Bony prominences (eg. buttocks, heels, elbows, shoulder-blades and hips), should be examined for redness.
- Regular position changes, if unable to move freely or independently, is essential to prevent skin damage, especially when in bed.
- Pillows can be used to reduce contact between bony prominences and surfaces (eg. between knees when lying in bed).
- The use of special mattresses or sheepskins can help reduce pressure.
- Care for your skin by washing it gently and patting it dry when exposed to bodily fluids. Apply moisturiser to dry skin (eg. sorbolene or barrier creams).
- If you are having radiotherapy treatment, refer to the skin care guidelines provided by the treating hospital or clinic.

Itchy Skin - This can be caused by various factors (eg. dry skin, your disease or medication).

The following suggestions may improve comfort:

- If your skin is dry, use a moisturiser such as a water based cream twice a day (store it in the fridge so it will feel cool on the skin).
- Discuss with your doctor any medications which may help relieve the itch.
- Protect your skin from damage that could be caused by scratching - keep nails short, rub rather than scratch.
- Avoid irritants to the skin (eg. washing powders, perfumes, scented soaps, hot water).
- Avoid overheating.

Sweating - Sometimes people with advanced disease can experience episodes of sweating. This can cause discomfort and affect activities like sleeping. Your doctor will be able to advise you on the best treatment depending on the cause.

The following suggestions may improve comfort.

- Wear layers of light, non-synthetic clothing e.g. cotton, bamboo.
- Keep room cool and well ventilated.
- Use light bedding. Layering bedding can decrease disruptions in the night if a change is necessary by removing the top layer leaving a fresh sheet underneath.

Anxiety and Depression

Anxiety is a natural response to stresses in our lives and is common in people living with a life threatening illness. Anxiety is a feeling of worry or fear. In some people, anxiety can cause physical and emotional symptoms and reduce their quality of life.

Anxiety can be expressed in different ways, but symptoms you may experience can include:

- A churning feeling in the stomach
- Restlessness and irritability
- Feeling tired
- Lack of concentration
- Muscle tension or pain
- Disturbed sleep.

Some people may have panic or anxiety attacks, where they feel intense or overwhelming fear and discomfort. Attacks can come on suddenly with no warning and can last up to 30 minutes. They may cause physical symptoms such as chest pain, a pounding heart, dizziness, breathlessness, sweating or shaking.

Depression is often misunderstood with “feeling sad”. Depression and feeling depressed is more than just sadness, it’s a combination of how we think, feel and behave. It may be triggered by things such as uncertainty about the future, uncontrolled physical symptoms such as pain, medications and worry about side effects, the end of treatment or family and money worries.

The worry about when and how death will occur is a common concern in those receiving palliative care. Fears about what death will look like and feel like and what events may lead up to it can cause suffering, can affect mental health and quality of life.

Many of the symptoms you may be already experiencing such as fatigue, weight loss or insomnia are common in palliative care and don’t necessarily indicate depression. But if you have persistent low mood, loss of interest in everyday activities, loss of interest in engaging with family and friends and feelings of hopelessness and helplessness you should let the team know or make an appointment with your GP.

It is important to get depression diagnosed, or to let us know if you have an existing anxiety and/or depression diagnosis. If someone’s anxiety and /or depression is severe and is affecting their wellbeing, their GP may prescribe medication and/or refer you for psychological support.

Things you can do to help:

Talking to someone you trust such as family, your GP or a Palliative Support Clinician.

Telling us if you have uncontrolled or new symptoms, such as pain and breathlessness.

If medications have been prescribed for anxiety and depression ensure you follow the directions, don’t stop them abruptly and talk to the nurses or GP if you have any concerns.

Regular physical activity can help support the management of anxiety and depression. People may have good days and bad days, so they may need to vary how much activity they do. You can go for short walks or do gentle exercises in bed.

Practical help – for example, help with developing advance care plans, housing or finances.

Seek spiritual care – this is supporting people to feel a sense of meaning, comfort, strength and connection in their life.

Psychological therapies can often help. But they can take a few weeks to have an effect and so people need enough energy to keep going with the therapy. You can talk to your GP or the team about this.

Complimentary therapies may help with emotional and spiritual expression, promote relaxation, pain control and a sense of wellbeing and improvement in mood. Let the team know if you feel you need further support and they may be able to help.

Participate in other activities that are meaningful and enjoyable such as:

- Time with family and friends
- Hobbies if possible
- Reflection and Meditation
- Reflecting through completion of a Biography

Recognising Deterioration

Are you concerned that the person receiving palliative care is deteriorating? Listed below are some signs of deterioration that you may notice;

- Activities such as walking, eating, breathing, sleeping, going to the bathroom, may eventually become difficult
- A person's body may have changed in appearance due to issues such as fluid retention, muscle waste, hair loss, pallor (pale appearance) or jaundice (yellowing of the skin and whites of eyes)
- Need for more frequent interventions (e.g more nursing input)
- Increased inability to heal or recover from wounds or infections
- Increased swelling (oedema) - extremities or entire body
- Profound weakness, fatigue - increasingly bedbound
- Sleeping longer – difficulty waking up
- Withdrawal
- Becoming confused as body chemistry changes
- Restlessness
- Loss of appetite / weight loss
- Swallowing difficulty or forgetting to swallow

If you have concerns that the person receiving palliative care is experiencing any of these signs or symptoms, please discuss your concerns with the palliative care team.

Preparing for Death

You might find some things in the following section difficult, so please speak to your Palliative Care Nurse or Palliative Support Clinician for further understanding or support.

Preparing for Death

The last few days of a person's life are very different, and may be viewed with apprehension by all concerned if you are not prepared. EPC is available to provide support, help and understanding during this time.

Not all the symptoms discussed will occur in every person, nor will they occur in any particular sequence.

They may begin only hours before death or a few days prior. These symptoms indicate that the body is preparing itself for the final stages of life.

Food and Fluid - There will be a decreased desire for food and drink as the body will naturally begin to conserve energy. This is a natural process, and attempting to feed a person who is unable to swallow at this time may cause distress. Moist swabs or tiny amounts of crushed ice will help relieve a dry mouth or feelings of thirst.

Sleeping - The person will gradually spend more time sleeping during the day and, at times, will be difficult to rouse. Increased sleeping is a result of a change in the body's metabolism.

The best time to communicate with the person is when they seem most alert.

Restlessness/Agitation - This may occur at the end-of-life. This may be due to decreased circulation in the brain or a build up of toxins in the body.

Do not try to restrain motions, but make the environment safe. Try things such as massaging hands, reading to the person, or playing soft and familiar music. Medications are also available to assist with the restlessness.

Decreased Communication - The person may make a seemingly out of character or non-sensical statement, gesture or request. This may indicate he/she is ready to say goodbye and is testing you to see if you are ready to let him/her go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever needs to be said.

Confusion - The person may become increasingly confused about time and place and the identity of the family who are normally familiar to them. Talk calmly with the confused person to reassure them. Identify yourself by name which may help lessen the confusion. The use of a night light may also help.

Physical Changes - The hands, arms and legs may become discoloured, cold or hot. The colour of the skin may change as the circulation of blood lessens. This may not happen until the end of life. Dark skin, that can look like bruising, can sometimes be seen at the base of the spine or on the back as circulation of blood decreases. This is a normal part of the dying process.

Changes in body temperature may occur. Keep the person warm if they appear cold and remove covers or use a light sheet if the person is hot to touch.

Urine output - This decreases and can become concentrated. This can be a result of decreased fluid intake.

Incontinence - Loss of control of urine or bowel movements may occur when the person is very close to death. Use incontinence pads and sheets to protect the person's skin and bedding. This will help maintain comfort and cleanliness.

Noisy breathing - Saliva and mucous may increase and pool in the back of the throat, as the person's cough or ability to swallow diminishes. This sometimes causes a noise known as the 'death rattle', which is unpleasant for the carers, but is usually not distressing for the client. Elevating the head of the bed with pillows, and turning from side to side, may relieve the noises. Medications to dry up secretions may also be appropriate.

Breathing patterns - This may change. You may notice that breathing becomes irregular, with ten seconds to several minutes where no breathing occurs. This indicates a decrease in blood circulation.

The person may give out several exhales as their body shuts down. This is a normal part of the dying process.

Withdrawal - The person you are caring for may seem unresponsive, withdrawn or in a comatose like state. This may indicate that death is imminent.

The person may be detaching from their surroundings and close relationships. This may indicate that they are ready to go. Hearing is thought to be the last sense to leave the body during the dying process. Speak to the person in a normal tone of voice, identify yourself by name, hold his/her hand and say what you need to say.

Odour - The shutting down of the dying person's system and the changes in metabolism can create a distinctive odour. Speak with the palliative care nurse who can offer some advice about managing the odour.

Saying Goodbye - A family's ability to reassure and give the person 'permission to die' can help the person let go. Saying goodbye is personal and can be said and done in individual ways.

It may include lying in bed with the person, holding their hand or saying whatever you need to say. Tears are a natural part of the grieving process and should not be hidden or apologised for.

Vision-like experiences - The person who is dying may speak or claim to have spoken to persons who have already died; this does not necessarily mean that they are hallucinating.

Spiritual and Religious needs - Consider the spiritual and religious needs of the person who is dying. If appropriate, organise a visit from someone involved in meeting the spiritual or religious needs of the person i.e. priest, pastoral care worker, pastor or other religious/ spiritual person to visit at this time.

How will you know that death has occurred? Breathing and heartbeat stops. The person cannot be roused.

Their eyelids may be partially open with the eyes in a fixed state, their mouth may fall open as the muscles around the jaw relax. The person has no pulses and there is sometimes a release of bowel or bladder contents as the body relaxes.

What do you do next? The palliative care nurse can be called and can attend the home if required after death. You do not have to contact anyone immediately unless you feel you need to.

If you are usually alone with the person, plan to have a close friend or relative available at short notice to be with you at this time. Do not contact the police or call an ambulance. The body may remain at home for several hours and you may like other close friends and relatives to be able to say goodbye.

You may wish to call a funeral director at this time to advise of the death.

EPC can provide bereavement support for up to 13 months after the death of a person on our program. The team will be in touch to offer support.

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