



Banksia
Palliative Care Service

Information Booklet





Non-English Speaking Clients

If you do not speak English, or English is not your preferred language, please arrange for a trusted family member or friend to contact Banksia on your behalf, if possible.

Alternatively, you can use the Multilingual Telephone Service. This is a free, confidential and professional phone interpreter for you, your family and/or your carer to use to communicate with us.

Multilingual Telephone Service

(This is a free service)

خدمة الهاتف 9679 9871

电话服务 (广东人) 9679 9876

Telefonska služba 9679 9872

Τηλεφωνική Υπηρεσία 9679 9873

Servizio telefonico 9679 9874

Телефонска служба 9679 9875

电话服务 (普通话) 9679 9857

Telefon servisi 9679 9877

Dịch vụ Thông dịch 9679 9878

Telephone services in other languages -
9679 9879



Hearing Impaired Clients

Support can be obtained through the Intake Worker at www.vicdeaf.com.au

Banksia is contactable 24 hours a day, 7 days a week.



Office hours

Monday - Friday
8:30am - 5:00pm

please call

9455 0822

During this time, we are available to help with any issues, including:

- if you have a health-related enquiry or concern;
- if you are concerned about a family member or friend who is a client of Banksia, or who you think would benefit from our support;
- to reschedule an appointment or visit;
- to speak with a Banksia staff member, and
- for general information.



After hours

After 5:00pm and before 8:30am
Monday - Friday.

Note: This includes support all day on
public holidays and weekends

please call

9483 7940

Please note this number is a paging service

In the after-hours period you will speak with our partner service who are experts, and will offer initial help and advice on our behalf. If additional support is needed, you will be put in touch with one of our nurses who is on call for the night.

Our on-call nurse is available to offer support and advice throughout this after-hours period and will only visit the home under URGENT circumstances, such as a sudden deterioration in your condition or an increase in your symptoms that you and your carer are unable to manage without support.

We will always prioritise anyone with issues overnight for a visit the following morning if required.

Please Note: Occasionally due to environmental issues, such as electrical interference, we may not have received the message you sent to our pager system. If you have left an urgent message and do not hear back from us within 15 minutes, please call again.

**If you do not receive a response within 30 minutes of the second call,
please contact your GP or 000 for immediate assistance.**

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Banksia Palliative Care Service (Banksia) is a not-for-profit organisation and the sole, state government funded community palliative care service for the three local government areas of Banyule, Nillumbik and Whittlesea. We provide 24-hour palliative care services for a population of approximately 430,000 people over an area of approximately 1,000 square kilometres. For more than 30 years, Banksia has provided no-cost expertise and practical support to children and adults living with life limiting illnesses, supporting them in their homes, and decreasing the need for hospital visits.

Our Philosophy

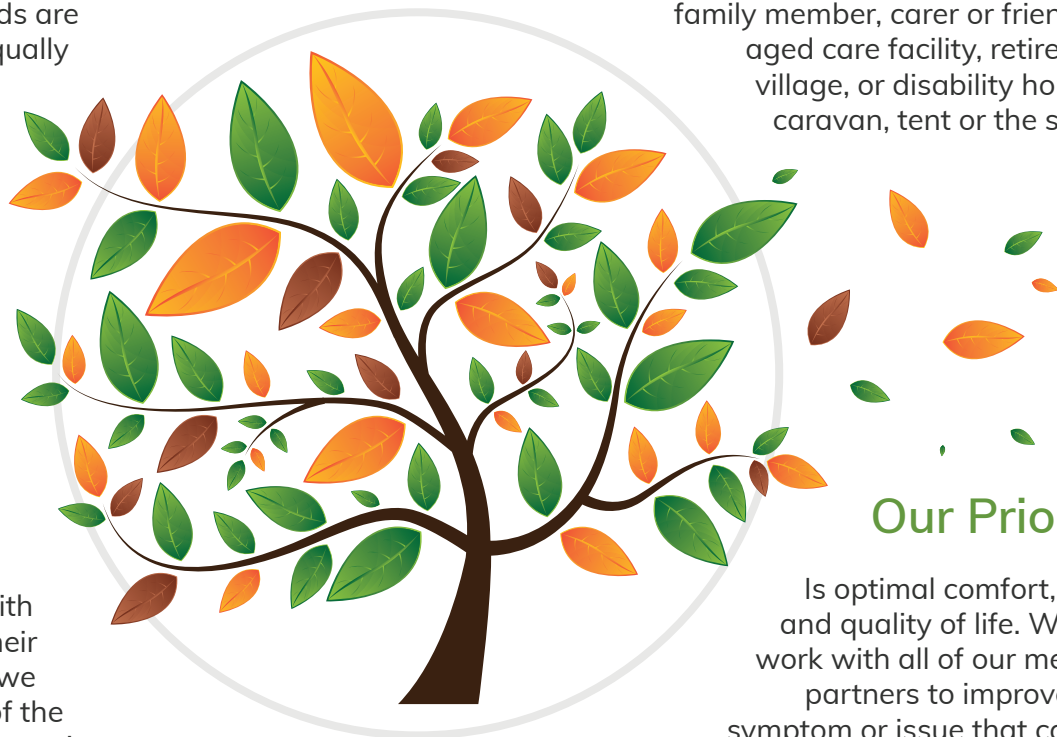
Banksia is based on a philosophy that sees the person as a 'whole' - mind and body are integrated and inseparable; physical, emotional, social, cultural and spiritual needs are determined as equally important.

Our Responsibility

We provide support and services for our clients in the place that they nominate as their preference for care – that may be their own house, unit, apartment; the home of a family member, carer or friend; an aged care facility, retirement village, or disability home; a caravan, tent or the street.

Our Focus

We provide person-centred care. We work with our clients and their carers to ensure we meet the needs of the individual. We determine those needs from conversation and exploration, working and partnering to achieve best outcomes. We encourage and promote active participation in care-planning and we aim to ensure that every client is in control of their own journey.



Our Priority

Is optimal comfort, care, and quality of life. We will work with all of our medical partners to improve any symptom or issue that causes discomfort or distress to our client, to enable maximum independence and we facilitate choice through the provision of options and information.



Banksia's Charter – Your Rights and Responsibilities

As a consumer of healthcare, you have rights and responsibilities related to your care. The Australian Charter of Healthcare Rights outlines your rights and how you can play a role in your health care. For more information, see Australian Commission on Safety and Quality in Health Care website (www.safetyandquality.gov.au).

Your Rights

You have the right to:

- access healthcare and treatments,
- access high quality care in a safe environment,
- be treated as an individual and shown respect, dignity and consideration,
- be informed in a clear and open way,
- be included in decisions and choices about care, and include others of your choice,
- have your privacy and confidentiality maintained,
- provide feedback about your care and have any concerns addressed.

Your Responsibilities

In addition to your rights, you have responsibilities to:

- be polite, respectful, open and honest in your communication,
- provide all requested/relevant information to our care team,
- inform staff if anything is making you uncomfortable, and raise your concerns in a timely manner,
- ask questions and be actively involved in care decisions,
- look after yourself and others to the best of your ability; support wellbeing and safety,
- provide a smoke free environment for staff and volunteers who are providing your care,
- ensure the absolute safety of Banksia staff and volunteers, and
- support service requests to ensure staff can practice safely in your home.

Our Services

24/7 Care

We provide 24-hour specialist palliative care services and support. Our expert staff work every day of the week and will provide advice over the phone or visit (in special circumstances) outside of normal business hours, including weekends and public holidays.



Palliative Care Doctors

We have our own team of expert Palliative Care Doctors, who specialise in palliative medicine, providing you with relief from any symptoms and stresses you may be experiencing as a result of your illness. Their overall goal is to improve the quality of life for you, your family and carers.

Our doctors will visit you at your place of residence to review any symptoms that may need additional support to be effectively managed. There may also be times that we suggest you come into our clinic, located at our office, to speak with our doctors.

Our doctors will work alongside your GP and communicate with your whole medical team. They will all work together to ensure there is continuity of care across the multidisciplinary fields that are managing your care.



Palliative Care Nurses

Our Palliative Care Nurses are specialist nurses with advanced skills and expertise to support your general wellbeing and symptom management, including pain, nausea, tiredness, changes in appetite or changes in mobility. They will assist you, your family and carers with any other concerns or issues that may arise.

Our nurses will regularly visit you at home to monitor and manage your condition and address anything that is causing concern. Their focus is to work with you and the people closest to you, to ensure that your care needs are met and overall comfort is achieved.



Social Work Team

All clients and families of Banksia are allocated a Support and Wellbeing Team member who will, with sensitivity to your cultural, personal and privacy requirements, assist with a variety of practical and emotional support issues, including:

- Provide counselling and emotional support for you and your family.
- Arranging home help and respite care.
- Assistance with any financial burdens or stresses.
- Navigating Centrelink.
- Liaising with workplaces or schools.
- Accessing *My Aged Care*, and if needed, transition to an Aged Care Facility.
- Advance Care Directives.
- Pastoral Care liaison.
- Arranging family meetings for optimal communication and transparency.



Grief and Bereavement Support

We recognise that grief can occur before the death, during all the caring phases and through the difficult period of end of life care and beyond and we're here to support you, your family and carers through it all.

Our grief and bereavement counselling is provided by specially trained and experienced counsellors who will provide support through all stages of the grieving process. .

We also provide support in bereavement through:

- Information and education about grief, loss and bereavement.
- Reflection and exploration of common thoughts, feelings, and reactions to loss.
- Finding strategies to manage the painful aspects of loss and uncertainty.
- Providing companionship and comfort during a personal time of transition and adjustment.
- Supporting you to take care of yourself and your loved ones.

Massage Therapy

Our Massage Therapists offer gentle, nurturing massage, using light strokes to encourage relaxation, stress relief and symptom management.

Our massage therapy sessions are flexible and tailored to each person's individual needs and wishes.



Occupational Therapy

Our Occupational Therapist will visit you at home to make suggestions and arrange any modifications to your environment to maximise independence and safety. They will also help support you to obtain any necessary equipment needed for your home to ensure your safety and help with your comfort.



Advance Care Planning

We will support Advance Care Planning (ACP) discussions to ensure that your wishes and preferences are known should the situation arise when you are unable to speak for yourself.

Advance Care Planning is particularly important for people who are older and are frail, or people who have a chronic illness, multiple diseases, an early cognitive impairment, or are approaching their end of life.

An Advance Care Plan may involve appointing a Medical Treatment Decision Maker and completing an Advance Care Directive (ACD). This process helps give you the reassurance that, should the situation arise, your loved one will know your wishes and how to speak and act on your behalf.



Music Therapy

For many people, music is an important part of life. Our Music Therapists develop a personalised relationship with you through the diverse use of music to increase your, your family and carers health and wellbeing. Music is used to relieve pain, anxiety and stress, and to provide independence and quality of life. It has many benefits, including:

- Alleviating pain and promoting physical comfort.
- Achieving feelings of relaxation and peace.
- Management of anxiety and mood.
- Positive engagement opportunities for families, resulting in life-long memories.
- Improved quality of life.
- Emotional wellbeing through difficult times.
- Provision of legacies.
- Coping mechanisms to assist with grief and loss.



Client & Carer Support Team

Our Client and Carer Support (CCSP) Team provide in-home education and training related to managing your care needs as your condition changes. They will show you, your family and carers how to move you safely, how to wash you, and how provide basic care, on days where you may be feeling tired. Their support and guidance will decrease anxiety and increase confidence, allowing you and your family and/or carers to feel empowered to address your care needs in the home.

Respite can also be provided, through our CCSP Team. This gives you an opportunity for some companionship as well as giving your family and/or carer some time to recharge, or run some errands.

Your family and carers are invited to remain in the home during respite if they wish to do some gardening, take a bath, take a nap, read a book or have the opportunity to leave the house for the duration of the respite.



Volunteer Support

Our Volunteer team work alongside our multidisciplinary team to provide holistic palliative care to you, your family and/or carer.

All our volunteers have unique skill sets that we pair alongside palliative care training to ensure they are well equipped to provide you, your family and carers support. We work hard to link like-minded people. Our Volunteer Coordinator will visit your home to meet with you prior to arranging visits. This allows us to determine your interests, hobbies or background, so we can link you with a volunteer who is similar so that an enjoyable relationship can be formed.

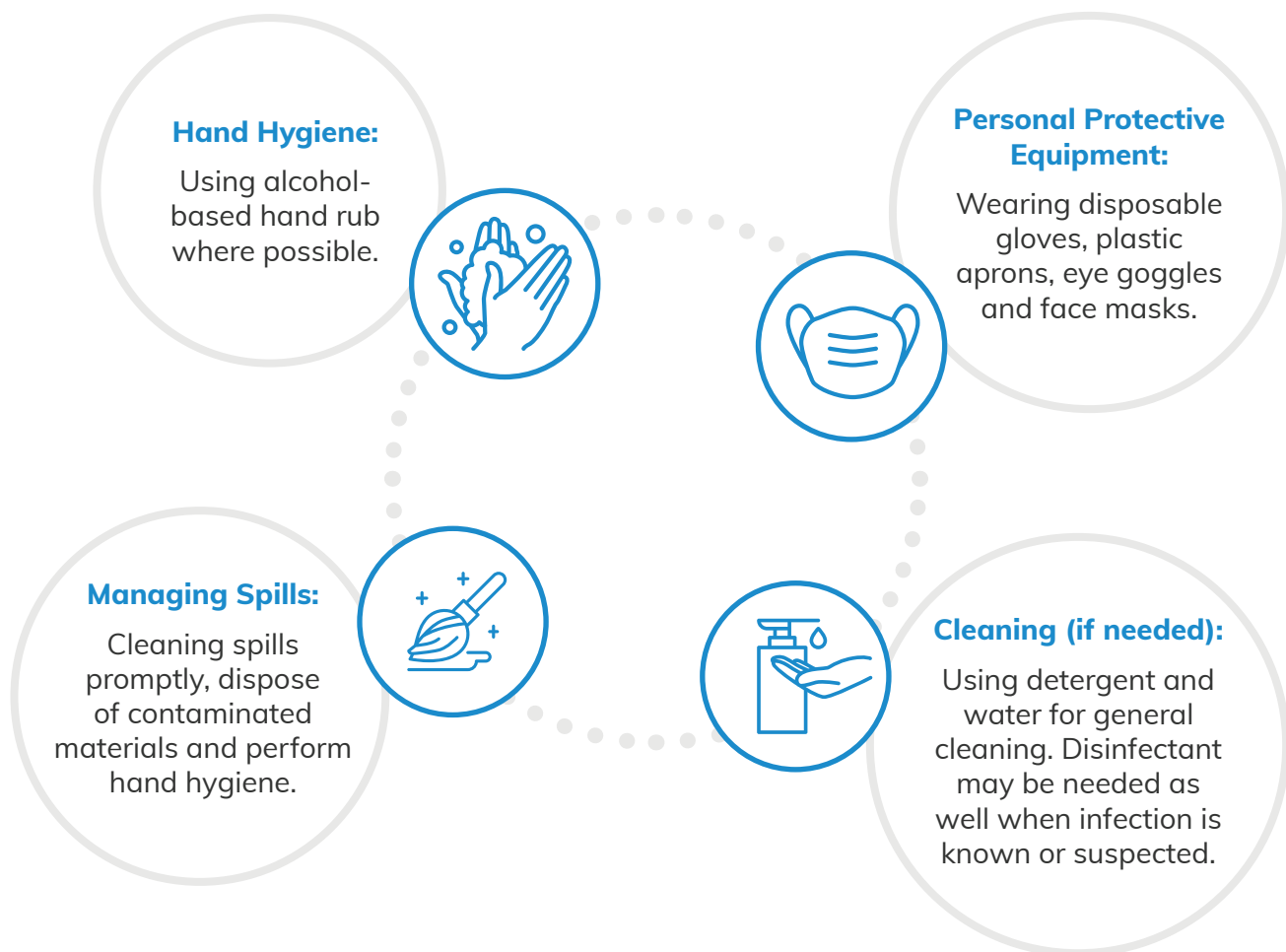
Our volunteers will come to your home during the hours of 9am-4:00pm Monday-Friday, and will stay for between 1 to 3 hours – this can be arranged on a regular basis - weekly, fortnightly or monthly.



Infection Control in the home

Banksia has a strong stance on infection prevention and control. It is essential that we provide care to a high standard whilst functioning within the organisation's Infection Prevention and Control Guidelines. These guidelines have been developed, in accordance with the Australian Guidelines for the Prevention and Control of Infection in Healthcare (NHMRC, 2010).

If risks are identified (examples below), we will be required to use universal precautions which may include some or all of the following, to ensure that you and we are minimising the spread of infection:



Risks which require additional measures include, but are not limited to:

- Presence of community-acquired infections.
- Immuno-suppression resulting in the potential for further compromised health.
- Presence of hospital-based bacterial infections.
- Chronic illnesses or infections unrelated to your diagnosis.
- Some treatments or small procedures.
- Other situations that require an individual review and risk assessment to determine appropriate infection control prevention and strategies.

Managing your symptoms

Each time one of our team members speaks with you, whether it be on the phone or face-to-face, we will ask you how you are feeling and what we can do for you so that we can provide you with appropriate and responsive care. It is beneficial for you to share any existing or new physical, emotional or social issues that you are experiencing with us so we can explore options to manage and control your concerns to improve your quality of life.



Client Self-Assessment tool

During our visits we use an assessment tool known as Symptom Assessment Scale which we have further developed into a Client Self-Assessment Tool (Appendix 1). This helps us to determine whether our responses and actions are effective in addressing your care needs.

We encourage you to use this tool to identify any symptoms or concerns you might be experiencing, and decide where they fit on the tool. There is a copy of this tool in the back of this booklet for you to use to monitor your symptoms and give us further insight and knowledge about how we can best manage your symptoms and concerns.

On the next few pages you'll find a list of common symptoms and helpful suggestions that might assist you in managing care at home. Please note that these are to be used as a guide only, and if you have any concerns you should contact us as soon as possible.



Pain

Pain is generally a distressing symptom, that can be both physical or psychological in nature. It can have a significant impact on a persons' quality of a life.

Pain can be subjective, meaning people often do not experience the same type of pain. An individual's personal beliefs, personality traits and social factors can also influence their experience of pain. What is tolerable for one person may not be for another. Our team are specialists in pain management and will work with you to ensure your pain, if present, is well controlled, so you are as comfortable as possible.

It is for this reason that during each visit/contact the Banksia clinical team will ask about your pain, including if you have any new pain issues, so we can alter your care plan accordingly. We focus on prevention and early intervention as the best way to manage your pain so it is important to always tell us, your GP or someone from your medical team about your pain.

Pain Suggestions:

It is very helpful to keep a record describing the pain, including:

- Where it is.
- What time it occurs.
- The type of pain (sharp, dull, muscular, cramping, constant).
- Trying to rate the pain as a figure out of 10 (using the Client Self-Assessment Tool at the back of this booklet).
- Noting the effect of any pain medication taken.

Please Note:

Pain medication should be taken at regular intervals to prevent pain from developing, rather than waiting for pain to occur.

If you have been prescribed new pain medication one of our nurses and/or your GP will discuss how and when to use the medication and any potential side effects that can occur.

We may suggest other therapies or activities that support medications, such as massage, music therapy and relaxation activities, all of which can be very effective depending on the circumstance.

Interesting facts about pain relief medications:

- Some pain medications are described as “short-acting” and they provide relief for short periods of time, up to 4 hours, whilst others are described as “long-acting” and may last for 12 hours. You may be prescribed both long and short acting pain medication to ensure you are comfortable at all times.
- Pain medications can be taken orally, injected under your skin or into a muscle, or applied to the skin in the form of a patch.
- Morphine, as prescribed by your GP or Specialist to manage your pain is not addictive.
- Sometimes your body can build up a tolerance to some pain relief medications and they might not work as well as they once did – it is very important you share this detail with our nurses, your doctor or someone on your medical team, so appropriate adjustments can be made so that you are comfortable.

Remember there are no ‘silly’ questions. Please discuss any concerns or questions in regards to any of your medications with your GP, Specialist or a Banksia nurse and/or doctor.

Breathlessness

Breathlessness refers to a regular feeling of shortness of breath or difficulty breathing. It is an extremely common symptom in palliative care clients, and is normally controllable and treatable with specialist advice and, in some cases, medications and/or oxygen may be used. Untreated breathlessness can be uncomfortable, distressing or frightening. It may be associated with your illness or related to other conditions, such as anxiety. It often becomes worse with exertion (movement) or exercise.

Breathlessness Suggestions:

- A fan or open window with a breeze gently sweeping across your face may help to relieve symptoms.
- A calm environment will be helpful in allowing you to relax and breathe easier.
- Avoid very warm air, or very cold air when possible if breathless.
- Positions that might help ease any difficulty you have breathing include:
 - Sitting upright;
 - Sitting at a table with your arms raised on pillows;
 - Sitting in a chair with your arms well supported and your legs elevated;
 - Being well supported by pillows or a backrest while in bed.
- Limiting or reducing some activity will help with breathlessness, and when you are active, take some time to relax and catch your breath.
- Talking can increase breathing difficulty. Limit conversations where you are expected to do a great deal of talking.
- Wearing loose clothing, especially around your waist, chest and neck.
- When showering, avoid the water flowing directly onto your face and, if possible, try to limit the steam in the bathroom. Also, where possible, have someone help you to dry and dress.

Nausea and Vomiting

Nausea and vomiting may occur intermittently due to your illness or medications, or may represent a new physical or emotional issue. It is important that you are aware of anything that makes you nauseous. Some factors such as eating too quickly, eating large amounts in one sitting, certain smells or odours, pain, disease progression or continuous coughing can increase the feeling of nausea and may make you vomit. There are several medications that will assist you if these issues occur. Your GP or one of our nurses will be able to recommend the correct medication to help you with this.

Nausea and Vomiting Suggestions:

For nausea:

- Avoid fatty, spicy and overly sweet foods. These have been known to contribute to people feeling unwell.
- Keep the house well ventilated when cooking. Some people find food smells make them feel unwell.
- Eat smaller meals, more frequently and slowly.
- If swallowing tablets causes nausea, we may suggest medications that are available in a liquid form.
- Relaxation and breathing exercises may relieve the unpleasant wave-like sensation of nausea.
- Clean your teeth or rinse your mouth before and after eating.
- Prevent constipation if possible.
- Avoid lying down immediately after eating.
- Suck on ice, icy poles or sip flat carbonated drinks.

For vomiting:

- If you vomit more than once a day, please contact Banksia as soon as you can.
- Anti-nausea medication can be prescribed to help manage your vomiting.
- Once you have finished vomiting, rinse your mouth, clean your teeth and/or suck on ice.
- Take regular sips of water or flat soft drinks.
- Re-introduce food slowly.

Loss of appetite

Losing your appetite, and not wanting to drink are common symptoms and occur for different reasons. Pain, constipation, nausea and vomiting can have an effect on your appetite, as well as the side-effects of medications. Some treatments such as chemotherapy and radiotherapy can contribute to a loss of interest in eating and drinking and can cause additional concerns, such as a sore mouth, persistent diarrhoea or changes to your sense of taste.

Loss of Appetite Suggestions:

- Dehydration is a complication of loss of appetite, so it is important to ensure adequate fluid intake. Fluids can be in the form of drinks, or fluid-based “foods” such as ice-cream, custard or jelly.
- Try eating several small meals throughout the day.
- Avoid fatty, heavy foods.
- Try eating small tubs of mousse, yoghurt, ready to use custard, jelly or smoothies which provide fluids as well as energy so will assist with hydration.
- Try having finger-food accessible, as “grazing” (eating small amounts all day) will help.
- High calorie protein supplements such as Sustagen, Ensure or Resource (if able to tolerate) are easy to consume and beneficial.
- Ensure good ventilation when preparing foods as some smells can negatively affect your interest in food.
- Consider both cold food and hot food options.
- Let your family and carer know what foods you prefer – your taste may have changed recently.

Constipation

Constipation is a reduction in the frequency of bowel motions or increased difficulty in passing stools and is very common in palliative care clients. Numerous factors can lead to constipation, such as changes in your diet, inadequate amount of fluids, stress, reduced activity and the use of some medications. Even though your body may seem different, it is important that your bowels work regularly. Constipation, if untreated, can lead to hospitalisation.

Constipation Suggestions:

- Introduce a fibre supplement into your diet, or eat high-fibre foods if your condition will allow.
- Try to increase the amount of water you drink. This keeps you hydrated which helps with constipation.
- Medications or enemas can be used to manage constipation if needed. Please speak with our nurses about these as options.
- Gentle activity daily may help.

Although it can feel embarrassing, we recommend you record the details of your bowel movements. It is important that you let us know how your bowels are going so we can help you manage this.

Anxiety

Everyone feels anxious, nervous, sad and stressed from time to time, but repetitive feelings of anxiety may be difficult to manage and control. Anxiety can be influenced by many factors, physical and emotional. People experiencing anxiety may have intense feelings of fear (panic attacks), shortness of breath, uncontrollable shaking, dry mouth, headache, irregular heart rate, feel a thumping pulse, or even chest pain.

Anxiety Suggestions:

- Try deep, slow and calm breathing techniques – calming sounds, and slow breaths in and out for 2-3 full minutes.
- Sharing your thoughts and concerns with people who care, including our team.
- Sitting quietly with soothing background sounds or music may help you feel calmer.

Contact us. We have a Support and Wellbeing Team who are experts in helping to manage these feelings they will assist you. Alternatively, we can assist you accessing other support if needed.



Oral Symptoms

A sore or dry mouth, lips and/or gums; a coated tongue, or pain when eating and swallowing, are uncomfortable. It is important to report any oral discomfort to your palliative care nurse or your GP immediately as these symptoms are often treatable.

Oral Symptoms Suggestions:

Uncomfortable Mouth:

- Maintain good fluid intake. If you are unable to drink normally, try small frequent sips of water or suck on ice chips or icy poles.
- Use a lip balm to keep your lips moist.
- Sucking ice cubes, lollies, or chilled pineapple may increase saliva production in a dry mouth.
- Rinse your mouth (with 1 teaspoon salt dissolved in 600mls of warm water) after meals to remove any food that may cause irritation.
- Swabs may be used to keep the mouth moist. Our nurses will teach you how to use swabs safely.

Ulcers, pain or bleeding gums:

- Remove dentures if painful or irritating.
- Clean teeth and gums with a soft toothbrush and a mild toothpaste. Use water if toothpaste irritates.
- Use analgesic mouthwashes and gels for ulcers - these are available from your pharmacy, and the pharmacists will assist you in choosing what is best for you.
- Avoid mouthwashes that contain alcohol, as they have a drying effect and can cause pain and inflammation.
- Eat soft, moist food where a minimum of chewing required.

Bad Breath:

- Try to maintain a moist mouth (see above).
- Clean teeth and gums with a soft toothbrush and a mild toothpaste. Use water if toothpaste irritates.
- Use sugar free chewing gum (this can also stimulate the production of saliva).

Falls risk

We screen all our clients to ensure they are safe and steady on their feet, and are not at an increased risk of falling due to illness. We use an assessment tool known as a FRAT (Falls Risk Assessment Tool) to identify potential issues, which allows us to tailor your care to your individual needs. There are various elements that can affect a person's ability to function that may increase their risk of falling. These include, but are not limited to:

- A history of falls.
- General weakness and frailty.
- Cognitive impairment (mild confusion).
- Visual impairment.
- Side-effect of some medications.
- Pain.
- Dehydration.
- Feeling tired and unwell.

We will help you to reduce your risks of falls and provide recommendations for equipment that will make your environment safer.

Falls Risk Suggestions:

- Always wear 'sensible shoes' that are well-fitted with good grip and a flat, broad heel. A podiatrist may be helpful to identify the shoes that are best for you.
- Ensure your home/room is well lit and avoid glare. Sensor lights and night lights are helpful.
- Fall-proof your home. Consider changes such as a seat or a handrail in the shower, handrails near steps, removal of rugs, tidying cords and ensuring pets are at a safe distance when moving in the house.
- Make things easier! Keep your commonly-used items within easy reach to prevent losing your balance when reaching.
- Consider walking aids, such as walking frames and walking sticks for support, and to assist with balance.
- Avoid hazards outside your home that may cause you to trip, for example, cracked concrete, uneven ground, plants on pathways, etc.
- If medications are responsible for dizziness or drowsiness, discuss with one of our nurses, your GP, or someone from your medical team.

Fatigue

Fatigue is one of the most common symptoms for palliative care patients and is identified as a feeling of overwhelming tiredness or a persistent lack of energy that is unrelieved by rest. This often happens with some of the medical treatments you may be having, but is usually the body's response to being unwell.

Fatigue Suggestions:

- Try alternating busy days (e.g. hospital appointments) with quieter, restful days so you can recharge your energy levels.
- It may be helpful to limit or control visitors by:
 - Suggesting that everyone except immediate family or close friends phone prior to visiting;
 - Keeping friends and family informed of how you are going through regular emails, calls or text messages, or through changing the message on your answering machine and inviting people to leave a message that you can return when you are able;
 - Leave a notice and a note pad at the front door when you are resting, so visitors can leave a note.
- Using mobility aids (e.g. walker or frame) to conserve energy and strength when you want to be more active.
- Maintain a healthy diet including fresh fruit and vegetables.
- Ask friends and family to help with shopping, cleaning and other household jobs.

Don't be afraid to tell us if you are feeling fatigued. There are a number of options available to support you.

Sleeping

Sometimes a person's sleep pattern changes considerably when they are unwell or their routine changes. Irregular sleeping patterns are not unusual, you may find that you sleep for a large part of the day, take frequent naps, or may have trouble sleeping.

Sleeping Suggestions:

- Making sure to get out of bed each day is helpful – this can assist in using energy and can support achieving sleep.
- Try to have some quiet time prior to going to bed. Relaxing music or a period of reading may assist.

If irregular sleeping patterns are a problem for you, please let us know and we will work with you and your GP to manage this.



Skin Care

Maintaining healthy skin, and avoiding pressure injuries or pressure sores is very important for your comfort. This can be difficult with people who sit or lie in the same place for a long period of time without moving, if skin is consistently moist, if circulation or sensation is altered, or if you are bed bound or inactive. Pressure injuries or pressure sores are areas of damaged skin and tissue, caused by constant pressure or friction. They usually occur on bony parts of the body (elbows, tail bone, shoulders and heels), but can occur in other places. If left untreated, these injuries can become quite serious and possibly become infected.

Skin Care Suggestions:

- Where possible, change position every half hour to hour.
- Keep active – stand or walk every hour if you are able.
- Eat a variety of foods daily from each of the five food groups.
- Drink plenty of fluids to keep hydrated.
- Avoid smoking as it reduces blood flow to the skin.
- Avoid firm massage, especially over bony areas. A gentle massage of “sore” or red areas can be beneficial to improve circulation in the area.

Caring for your skin:

- Use a mild cleanser when washing, and dry your skin gently.
- If shaving, electric razors are often safer than those with blades.
- Use moisturisers if your skin is dry, flaky or cracks easily.
- Use barrier creams between skin folds.
- Use warm, but not hot or cold water in baths and showers.

If you have any skin pain or a burning feeling, tell one of our team, or call us.

When you are in bed:

- Where possible, change position every half hour.
- Lie on your side to relieve the pressure on your bottom and heels. You may also like to place a thin pillow between your knees for support and comfort.
- Avoid tight, wrinkled or damp clothes and bedding.
- Sliding down the bed can cause friction and injury to your heels, bottom or elbows. To avoid this:
 - bend your knees up and place a pillow underneath them, or raise the foot of the bed slightly (where possible).
 - if sitting up in bed, arrange pillows like an armchair that allows you to maintain your position.
- The use of special mattresses or medical sheepskins may help reduce pressure areas developing – we can help you access these should you wish to.

When you are sitting in a chair:

- Change position at least every half hour. If you can, stand and walk around every hour.
- If standing is difficult, lean forward or move from side-to-side (left and right) to take the pressure off your bottom and hips.
- It is important to avoid sliding down in the chair – this can cause skin injuries and can result in additional discomfort from muscle stiffness.

Advance Care Plans

Our Support & Wellbeing Team can assist you to develop an Advance Care Plan which is a document that gives a clear description of your wishes and preferences, should the situation arise where you are unable to speak or make those decisions for yourself.

Completing this process gives you the reassurance that your loved-ones and your medical providers will know your wishes and will make treatment decisions that are based on the direction that you have given in your personal Advance Care Plan.

There is no way or us to predict what is going to happen or when, so having plans in place is helpful for everyone involved.



Caring at the end

We will stay involved in your care, and will provide whatever supports needed, for as long as we are needed. We will visit more regularly and will put additional services in place, based on your needs and the needs of your family and/or carers. When things change and when things become more difficult, we will be there. There is no need for people to go to hospital at the end of their lives – with the support of your family/carers, we can help you to stay home, should that be your wish.

We will be able to provide guidance as things change. We will often see signs of deterioration that due to our experience and expertise, will alert us that the end of life may be coming. Some changes that may happen include, but are not limited to:

- Drowsiness that does not pass;
- Decreased energy and difficulty/disinterest in moving;
- Decreased interest in food and water;
- Confusion and/or disorientation;
- Difficulty swallowing*;
- Skin may become pale or flushed;
- Breathing may become slower and/or deeper;
- Incontinence.

Not all symptoms mentioned here will happen in every person, and they do not appear in any particular sequence - these may begin only hours before a rapid decline, or in the days prior.

NOTE: If your wishes are to receive end of life care in a hospital, we will support your transition and handover your care to the hospital staff.

*If the ability to swallow becomes difficult, we will consult with you and your GP, and we will change your medications from oral to injectable, to ensure we maintain your comfort and needs.

Appendix 1

Client Self-Assessment Tool

This Client Self-Assessment Tool is designed for you to assess the degree of concern any issues or symptoms you may be experiencing, are causing you.

We may use the tool with you to ensure we are addressing all of your concerns, and adapting your care plan to meet all of your needs.

How to use the tool.

Score each symptom listed between 0 and 10, using the numbered scale, the faces, colour and/or word to help you identify the level of your symptom experience.

1. Write the day or date in the first row.
2. Use the scale to choose a number between 0 and 10 that shows the level of distress or concern you are feeling.
3. Add any other issue or symptom not listed in the blank boxes at the bottom of the list, and score as above.

What do the scores mean?

0 means you are experiencing no distress or concern for that particular symptom, or the symptom is absent.

1 means you are experience slight distress or concern for that particular symptom.

10 means you are experiencing the worst possible distress or concern for that particular symptom.

Score Guide:

1-3 (Green) Please advise our staff of this symptom next time we make contact with you.

4-7 (yellow) Please call us immediately for support.

8-9 (orange) Please call us immediately for attention.

10 (red) Please call us immediately for attention.

Remember we are available 24/7 to support you.

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