



**Banksia**  
Palliative Care Service

## **Carer Information Booklet**

*This handbook is designed especially for Carers.*



# 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 loved one's condition or an increase in their symptoms that you 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.**

Emergency or  
Urgent Help  
Needed:

**CALL BANKSIA  
FIRST**

**DAY:  
9455 0822**

**AFTER HOURS AND  
WEEKENDS:  
9483 7940**

If you require an interpreter, contact the Translating and Interpreting Service (TIS National)



**13 14 50**



**tisnational.gov.au**

If you have a hearing or speech impairment, contact the National Relay Service. 24 hour relay call numbers:



**TTY/voice calls 133 677**  
**Speak and Listen 1300 555 727**  
**SMS Relay 0423 677 767**



**relayservice.gov.au**



## 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](http://www.vicdeaf.com.au)

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## About Us

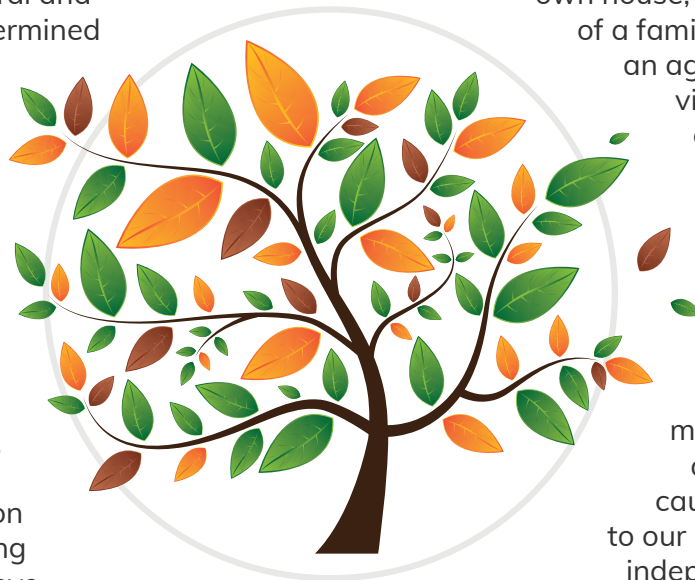
Banksia Palliative Care Service (Banksia) is a not-for-profit organisation and the sole, state Government funded community palliative care service for Banyule, Nillumbik and Whittlesea. Since 1989, Banksia has provided expertise and practical support at no cost, to children and adults living with life-limiting illnesses, supporting them in their homes, wherever that may be.

## 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 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 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 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.

## Our Vision

Every person accesses and receive exceptional, personalised palliative care support at the right time and in the right place.

## Our Mission

To provide exceptional palliative services that assure quality in life, in death and death and support in bereavement.

## Our Values

Excellence; Respect; Integrity; Collaboration

We strive for **excellence** in everything that we do. We act with **integrity**, **respect** others always and our **collaborations** make us stronger and better... and we never lose sight of what's important.

# Our Services

- Support, advice and care, 24hrs/day, 7 days/week.
- Specialist Palliative Care Doctors.
- Palliative Care Nurses – Registered and Enrolled.
- Support and Wellbeing Team, which has specially-trained experts in the fields of:
  - Social Work.
  - Massage Therapy.
  - Occupational Therapy.
  - Music Therapy.
  - Grief and Bereavement Counsellors and services.
- Volunteer support.

*(Note – for more details, please see our Information Booklet)*

## What we don't do ...

- What is done in hospital.
- Take blood pressures, pulse, temperatures or monitor blood-sugar levels as a regular service.
- Take blood or other pathology samples, arrange oxygen cylinders or give medications or fluids through a drip (intravenously).
- Provide active CPR (resuscitation) for our clients under any circumstances.
- Shower our clients, or attend to complicated wounds or dressings.
- Housework, gardening, transport or cooking.

We do not tolerate aggression, abuse or any type of behaviour that makes any of our team feel uncomfortable or unsafe during the visit.



## What we do ...

- **We recognise that this is VERY hard, and we encourage you to look after yourself.**
- We work with our clients and carers to enable people to stay at home, avoid hospital stays and minimise the need for visits to Emergency Departments.
- We will come to the home of our client, or be on the end of the phone, to monitor, treat, advise, support, encourage, educate, guide, and assist as needed, 24 hours a day, 7 days a week.
- We will closely monitor our client and help to manage all symptoms and issues, arrange medications, equipment, and supplies and assist with ensuring all physical requirements are met.
- We will work very closely with the GP and Specialists, hospitals and other services to ensure support comes from a number of places, and make links and referrals as needed, including assisting in admissions to hospital palliative care units, when possible and appropriate.
- We will provide our carers with information, training, respite and practical supports (related to hygiene, diet, movement, etc.), and we will assist with hygiene in hospital beds in the home, or simple washes for freshness.
- We will visit the client regularly, with that regularity increasing or decreasing as our client's needs change.
- We will assist with other agencies, including My Aged Care, NDIS, HCP where required. We can assist with information, filling in paperwork and explain the process to the family.
- Counselling.
- Assist with Advanced Care Planning to ensure wishes are known and understood.
- We will remember that we are guests in your home.
- We will ensure every person knows that we are there for our client, and also for our carers.

We will be there at the beginning and until the end, whatever the end may be...and then we will still be there for YOU.

# PALLIATIVE CARE

## What is Palliative Care?

The World Health Organisation defines palliative care as:

“An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

*We believe palliative care is much more...we believe palliative care enhances each day for each person; it considers each person as an individual, so beliefs and wishes are at the forefront of planning, ensuring people can live the life that is best aligned to their individual situation and preferences. Palliative care provides compassion, advice, expertise and support at the time it is needed, and wherever possible, in the place of choice. It acknowledges that all situations are unique, and allows us to tailor our services accordingly.*

## What Palliative Care is not...

Palliative care does **NOT** mean *terminal* care, though we do provide both. We will provide support and care every day that the client is with Banksia, and that will include terminal care as required.

A common misconception about palliative care is that a person is going to die soon, or very quickly – this is often **NOT** the case. Many illnesses take many months, even years to reach the terminal phase – the timeline depends on how advanced the illness is when the diagnosis is made. Please see the following table:

	Palliative Care	Terminal Care
<b>Definition</b>	When a person has a life-limiting illness, that is not likely to be cured, and which is expected to cause death.	End of life, when a person is irreversibly dying.
<b>Timeline</b>	Generally, several weeks or months, and even years, <b>however</b> complications of illness may result in people dying more quickly than anticipated.	Usually days to weeks. Note: In some very unusual situations, this may be only hours, if sudden deterioration occurs.
<b>Medical treatments</b>	Many people continue having treatments, such as radiotherapy, for symptom management whilst being palliative.	Generally, when a person is dying, only comfort measures (including medications) are implemented.
<b>Medications used will shorten life</b>	<b>Incorrect</b> – all medication doses are carefully calculated by specialists to ensure safety - no medications will ever shorten a life.	

**Our whole team sees dying as a normal process, and we strongly believe that every person who has a life-limiting illness benefits from specialist palliative care. We will never hasten nor postpone death, however we will ensure optimal comfort for every client, and provide much-needed help to our carers throughout the duration of the illness, and into bereavement.**



# PROVIDING CARE AT HOME

## The role of a Carer

Sometimes people do not identify themselves as carers, even when they are filling this role. Most people see themselves as a spouse, a partner, a parent, a child, a sibling, friend or neighbour. If you are providing assistance and care to the person who is our client, then you are a carer... and we recognise that this can be both rewarding and challenging, and that you need support.

## How we help you...

From the beginning, our carers are part of our focus. During the admission process, members of our team who have a specific role in caring for carers, make contact so we can talk to you about how we can best support you. You and your family will be given information so you feel empowered to make informed decisions.

Throughout the time our client is on our program, carers can access (at no cost):

- Counselling in your home or at the Banksia office.
- Telephone or video counselling, advice, information and support.
- Carer Education sessions. These provide information as to what you might expect in your caring role, how you can access extra support services, and information about self-care.
- Assistance with Centrelink, NDIS, My Aged Care, access to council and other community support services.



### Carer Support Needs Assessment Tool

This easy and clear assessment tool, is used to help identify areas where you might need additional support. We may use this assessment to adjust our services to meet your individual needs, or you may choose to complete the assessment yourself at any time, so that you can see if there are areas that we may be able to provide you with further support.



### Client and Carer Support Team

Our Client and Carer Support Team (CCST) consists of specially trained nurses and care attendants whose role is to support carers to monitor and maintain their own health and well-being. They will assist and support them to continue in the carer role.

They provide individualised information and education to carers in the home, to increase knowledge and confidence, and reduce anxiety related to providing care for their loved one at home.

They will teach:

- Basic safe manual handling and utilisation of equipment, such as hospital beds and slide sheets.
- General hygiene support, mostly in the form of bed based care, including bed washes and general hygiene, linen changes, etc. **Please note:** full hygiene support can only be provided if there is a hospital bed in the home. We do not provide assistance with showering, however we can show carers how to shower a person in the home, if safe to do so.
- General care of a person who is not moving, including assistance in standing and sitting, pressure care, tips on diet and mouth care.



## Respite

We recognise that caring for your loved one can be stressful, and at times you might need to recharge so you can continue to provide care. We will provide respite in the home, so you can attend to other duties or get some much needed rest, knowing that your loved one is in safe hands.

Respite options available in the home include:

- Our Volunteers who can provide respite for a few hours each week. (Note: this is available for clients who are mobile and mostly able to care for themselves).
- Our Client and Carer Support Team, who can be booked to come to the home for a set period of time during the day.
- Overnight nurses (when available). This option requires planning and is generally possible for each client three times, and under very particular circumstances – please ask our team about this option.

Alternatively, we can help organise other respite options, such as temporary accommodation in a hospital or aged care facility (subject to availability). This is generally for a period of 1-2 weeks.



## Equipment in the home

From time to time, equipment may assist in the care of our client as their condition changes, eg. a hospital bed, a recliner chair, a shower chair or a walking frame. We are able to provide you with a range of equipment at no cost for a period of six weeks, after which time some hire charges will apply.

Our Occupational Therapist may come to the home to assess equipment needs, if required. Our team will suggest this if they see a need.

We will also help with applications for more specialised equipment, or funding for equipment if needed.



## Specific, practical support

Your family will be allocated a Social Worker, who, with sensitivity to cultural, personal and privacy requirements, can assist with a variety of practical and emotional support issues, including:

- Counselling and emotional support for you and your family.
- Arranging home help and respite care.
- Assistance with financial concerns.
- Navigating Centrelink, My Aged Care, transition to an Aged Care Facility (if needed).
- Liaison with workplaces or schools.
- Assisting with Advance Care Directives.
- Arranging family meetings for optimal communication and transparency.



## Preparing the home

There may be a need to change the home environment, and rearrange some rooms when there is someone in the house who is very unwell. As that person's conditions changes, we may suggest to you that equipment be arranged to ensure everyone's safety and to help with mobility and the provision of care such as hygiene. We may suggest that a person moves from upstairs to a lower floor for ease, and that furniture be moved from room to room. For example, you may wish to move a recliner or comfortable chair to a central room in the house for the person who needs care, and place furniture, such as chairs or beds for carers, and small tables for meals nearby. A small bell or a baby monitor may give you peace of mind, when you are not nearby. Our team will be able to advise and support you in these decisions.

## Providing Personal and Practical Care

There are many things that can happen to a person as the illness progresses and their condition changes – they will deteriorate mentally or physically or possibly both, and their ability to care for themselves will also decrease.

Their symptoms, or the issues that they have, will generally depend on their illness. There are many symptoms that may present. For information related to those symptoms, please see the “Information Booklet” or visit our website – <https://banksiapalliative.com.au/client-booklet>.

As a person’s condition changes, they will need some help with their normal daily activities, including personal care, movement and eating and drinking. Our team will identify this and will start a conversation with you and our client in relation to how we can help this very important care and support to be provided. We recognise that this may be new for you, so we will be available to guide you, and help you to gain the knowledge and confidence to be able to help ensure the highest level of comfort and well-being...for you both.

Personal and practical care is a very important part of helping to ensure safety, comfort and that a person does not have unexpected complications, such as falls, pressure areas, mouth infections and itchy skin, etc. Please see the following:

- **Washing, showering or bathing and clothing** - People may not need, nor wish to shower/bath daily, however it is important when movement decreases, that some care is provided. A daily wash of hands and face and other areas where there may be some perspiration can provide comfort and a feeling of freshness, with more extensive hygiene provided every 2-3 days, depending on the wishes and condition of the person. Our team will help when this is required.  
It is important that clothes are comfortable, soft, and if possible, made of stretch fabrics for ease when changing and moving. Changing clothes daily can provide a feeling of freshness, and gives a chance for a quick wash, and any other appearance or hygiene-related habits that may be important to the individual, such as deodorant, perfume, make-up, etc.
- **Skincare** - Sometimes, people will develop dry or itchy skin on various parts of their body, including their face and hands. This may occur due to medical treatments, changes in their normal hygiene routines, decrease oral intake, sitting or being in bed for long periods. This is very easily fixed! Gently applying a moisturising lotion (preferably something that they have used in the past) once or twice each day to any dry areas will provide comfort, while addressing the dryness.  
Applying a facial moisturiser is also a nice way to make a person feel comfortable and fresh.
- **Mouth care** - Keeping the mouth clean is very important, especially if they are not eating or drinking properly. To prevent oral infections, sore throats and possibly mouth ulcers (which can occur with general deterioration, or rubbing from loose dentures), it is important that the mouth and teeth are cleaned gently at least daily, with a soft toothbrush or a mouth swab. Lips can often become dry – applying lip balm regularly will prevent this from occurring...or even lipstick if that is something that was important to your person, before they became unwell.
- **Hair and nails** - Having hair brushed every day is very comforting. If washing hair is difficult, dry shampoo can be used, and will help to keep the scalp clean.  
It is also helpful to keep finger and toes nails cut and filed for comfort and to prevent possible damage to skin from scratches. If it was normal for nails to be painted with polish, it is nice to keep the polish fresh, if that was important to the person when they were well.
- **Pressure areas** – these can develop when there is decreased blood circulation to an area of the body that a person sits, rests or lays on extended period of time. They can occur on bony areas, or any part of the body that has pressure on it, for example, elbows, heels, hips, shoulders and bottom. They start as red area, then progress to becoming sore areas and can increase to being open sores. These can be prevented. Gentle rubbing or massage of these areas, with some lotion or cream will help prevent these. It is important to keep an eye out for any pressure areas, so that pressure sores can be avoided.

- **General body soreness/stiffness** – decreased movement will often result in stiffness, as will sitting or lying in one spot for a long period. Shoulders and necks may become sore, and if there is a history of arthritis or joint conditions, this may become more of an issue as movement and the ability to care for the symptoms themselves decreases.

Gentle massage is recommended to help with this discomfort. Gently rubbing the shoulders or neck with long strokes can provide great comfort. Gently rubbing hands and feet with a moisturiser can also help with stiffness and discomfort, and can be a way to manage anxiety or stress that may be present.

- **Moving and lifting** - If the person you are caring for needs assistance to move in any way, we will show you how to do this safely and will suggest the correct equipment. It is important that we work together to make sure both of you avoid being injured.
- **Emotions and affection** - It is important to recognise that when someone is very unwell, they still experience feelings and emotions, as they did before they became unwell. They feel love, happiness, contentment, and pleasure...but they may also feel pain, sadness, frustration, fear and stress. These feelings may affect their behaviours, and this can be particularly difficult for the people closest to them, who are enduring their own challenges and managing their own emotions.

Being physically close and touching another human being is a basic need which may become even stronger during the last weeks and days of life – it provides comfort and feelings of love and caring. People may have an increased need for physical intimacy with a partner, or may seek additional time with children, parents and other loved ones, including pets. At this time, often relationships, affection and connection become a very strong priority – people may wish to be held, to feel touch, or in some cases, insist on having pets near at all times.

It helps to understand these needs and behaviours. It will also be helpful for you as the carer, after the death, as the affection will provide memories.

- **Managing changes in appetite and taste** - It is important to understand that nutritional needs of a person with a life-limiting illness will change over time, and their appetite will lessen as their illness progresses. They might become more particular about their food, and wish to eat smaller portions or not want to eat at times – this is not unusual, and it is important not to force them to eat and drink, or to become disheartened if they do not – as their condition changes, they need less.

The best way to manage eating and drinking is to be guided by personal preferences and physical capability. The preference may be for smaller meals or snacks more regularly, or only one or two meals each day. Taste may change, so requests may be for food that is less spicy or sweet than previously enjoyed. There may be difficulty chewing or swallowing so soft foods or thick fluids may be the best options, and in some cases, sense of smell may alter, so strong cooking smells, or strong-smelling foods may decrease their interest in eating or drinking.

*Again, our team will be readily available to guide and advise you in relation to managing oral intake, and how to manage these changes.*





## Managing Medications

A person living with a life-limiting illness will often take multiple medications to manage their symptoms, provide them with the greatest level of comfort, and to allow them to feel their best. They may also have medications that they have been taking for a long time for other conditions that are not related to their illness – it is important to have knowledge of the medications, what they do, and why they are being used.

All medications should be stored safely, and as directed by the manufacturer. It is also very important that Banksia staff know about all of the medications that are being used - that will help us provide the best care and advice. There are many medications that are used in palliative care, and they are used for many reasons, and to manage many different symptoms or issues that person may be experiencing – they may also be used to prevent an issue arising, which can be equally as important.

It can be beneficial to have long-term medications reviewed by your doctor regularly. Your loved one may be taking several medications each day, and you may not think that some of the medications they have been taking for a long time are still needed, as their use will not affect their long-term health (eg cholesterol tablets). It is always valuable to discuss the benefits of medications with your doctor, and if the benefit is considered to be low, it is OK to discuss stopping those medications, and keeping only what is needed for comfort.

Medications can be given in a number of ways – it will depend on the medication required, however in palliative care, the most regular ways for someone to take their drugs are orally (by mouth) and subcutaneously (through a very small tube that is inserted just under the skin, that allows the medication to be injected). When the subcutaneous method is required, which is usually when a person has deteriorated, or is unable to swallow safely, the nurses will prepare the medications in the syringes. They will teach you all need to know - our team are experts at teaching people about medications, including how to give them in this way.

**NOTE:** Many medications have side effects – some of the medications are quite strong and may make a person tired and unable to be left at home alone, or do other activities, such as drive. As the need to change medications arises, we will work very closely with your doctor/s to ensure that we have all of the medications available that we may need to use if things change quickly. We will communicate with you as the carer, and our client throughout this entire process, and will welcome and answer any questions that you may have – your understanding of the medications that are being used, is important.

The following table shows some medications that are commonly used in palliative care. Note: these are the most common, but not the only medications that we may suggest. These may be given orally, or if a person is having difficulty swallowing, or is very unwell, they may be used in Syringe Drivers and given under the skin (as mentioned above).

Medication name:	Names for the medications when given by mouth:	Names for the medications when given subcutaneously (SC) or under the skin:	Uses:
Morphine	Ordine MS Contin Sevredol	Morphine (sulfate or hydrochloride) injection	Pain relief. Shortness of breath or difficulty taking a breath.
Hydromorphone	Dilaudid	Hydromorphone injection	
Fentanyl	Fentanyl Lozenges Actiq	Fentanyl citrate injection	
Lorazepam	Ativan	N/A	Restlessness
Clonazepam	Rivotril	Clonazepam injection	Agitation Seizures
Midazolam	Midazolam (pediatric use only)	Midazolam injection	Anxiety
Hyoscine	Buscopan	Hyoscine butylbromide injection	Crampy pain Noisy or 'rattily' breathing. Decrease secretions.
Haloperidol	Haloperidol	Haloperidol injection	Nausea Vomiting Agitation Restlessness
Metoclopramide	Maxalon Pramin	Metoclopramide injection	Nausea Vomiting

# SELF-CARE

## Looking after yourself is imperative

Looking after your physical and mental health is important, so be sure to make this a priority. There is no need to feel guilty about caring for you. Many people receiving care feel better if they know their carers are taking time to enjoy themselves and rest. Here are some ideas that may work for you:

- **Get some exercise.** Doing something physical will help you remain fit and well and maintain your energy. Try an exercise that you enjoy and can fit easily into your routine. Walking, swimming and daily stretching are good examples.
- **Get enough sleep.** Lack of sleep can become a problem for carers as the person they care for becomes increasingly unwell. Often stress and a busy mind can keep you awake. Limit coffee and alcohol intake, especially in the latter part of the day. Try relaxing with a warm bath or herbal tea before bedtime. Sometimes listening to soothing music or reading a book can help you unwind. If you find sleeping difficult on a regular basis, see your nurse or doctor. Importantly, try to avoid driving or making important decisions if you are overtired.
- **Maintain a healthy diet.** Try to maintain a well-balanced diet and stay hydrated. Factors such as stress or a disrupted routine may affect your appetite. If your appetite decreases and becomes a matter of concern, seek advice from your doctor.
- **Be social.** Try to maintain social contact with friends, other family members and usual social groups. Keep up your usual activities as much as possible.
- **Practise your own spirituality or religion.** Whether it be meditation, yoga, prayer or discussion with a pastoral worker, maintaining religious or spiritual practice will help you to stay well.
- **Do something for yourself every day.** Consider activities to help clear your mind including walking, gardening, meditation or listening to music. Take a break. List the things you enjoy that would give you a short break and renew your energy. Try to do one of these things each day.

## Tuning in to feelings and emotions

It is normal for carers to experience a range of feelings and emotions, including fear and resentment. You may fear the unknown, or worry you won't be present when the person you are caring for dies. There are also times when you will see the funny side of things. It's okay to maintain a sense of humour and enjoy a good laugh along the way.

Being aware of your feelings and emotions will help you to cope with the grief, anxiety, and sadness that are a natural part of being with someone as they approach the end of life. Recognise your physical and emotional limits.

Sometimes you may not feel that you are able to continue being a carer. Even though you really want to, sometimes, it may not be possible. You may feel distress or guilt at having to say that you are unable to continue. You may find it hard to hand over to someone else. You may also feel a sense of relief. There is no right or wrong way to feel about stepping back. You may find you can be involved with the care, but in a different way.



## Asking for help and accepting it

Sometimes carers find it hard to acknowledge that they need help, fearing it is a sign of weakness or that they are not coping. Often carers do not seek help for themselves because they consider their needs less important than those of the person they are caring for.

Do not be afraid to ask for help. Your well-being is vital to your role as a carer. Try to share the load so you don't become overwhelmed and exhausted.

Providing palliative care at home is a big commitment that requires the help of family, friends and others close to the person. Often family and friends would like to help but are unsure what to do. Practical assistance like making a meal, walking the dog, buying groceries and hanging out the washing can make a big difference to your load.

### Consider:

- Making a list of family and friends who could provide practical support. Invite them to choose from a list of tasks so you can lessen your workload.
- Asking a friend or family member to stay overnight, so you can get a good night's sleep.
- Setting up a roster if more than one person is providing care.
- Talk to our social workers to find out what services you may be entitled to receive or access, or if there are community groups or support programs that you may find beneficial.
- Talk to our team about accessing the Banksia Volunteer program to arrange a volunteer to provide some in-home respite for short periods.



## Involving children

Children and young people often manage stressful or difficult situations better, if they are told the truth about the situation in a way that reflects their level of understanding. They can become distressed if they see, or know adults are upset and are not given an honest explanation of what is happening, or if their questions are dismissed or not answered truthfully. Find a way that suits you and them to encourage them to ask questions and gain knowledge and reassurance. If this is not something you feel you are able to do yourself, that is ok – let our team know and we will support you in these discussions. Alternatively, a close family member, friend or even your GP may be able to assist you with these conversations. There are a number of ways that this information can be shared including face-to-face conversations, drawing pictures, making cards, using photos, messages or letters.

Another consideration is communicating with schools, sporting clubs, and any other activity providers that the child may attend regularly. It is often helpful if some of the school community such as the teacher, principal, parents of close friends etc, sporting coaches or other pertinent people are aware of the situation, as they will be able to provide support when needed in different environments. Our team can help with these conversations, or can make contact directly with schools or groups to discuss the situation.

It can be helpful if children are able to maintain routines as much as possible and in some cases, offered the chance to help with caring. This will vary from child to child, however if you are having any difficulty in meeting these needs, or having these conversations, please inform our team – they will be able to provide you with support and assistance.





## HELPFUL THINGS TO KNOW

We recognise that there is a huge amount of information being provided to you almost daily – information that is probably new to you. The following is to give you some ideas and starting points. If you need any further information about anything below, please speak with one of our team, who will ensure you are provided the guidance and support you need.

### Medical and Legal planning

#### Advance Care Planning

Advance care planning is planning for future health care. It enables people to make decisions about the health care they would, or would not like to receive if they were unable to communicate their preferences or make treatment decisions for themselves. It gives the opportunity to think about, discuss and record preferences for the care people would like to receive and the outcomes they would consider acceptable for them. Advance care planning ensures loved ones and health providers know what matters most to an individual, and that their preferences are respected. Planning is not just for people who are palliative – it is recommended for all adults, so there is clarity about what would be acceptable to each individual person in the case of unexpected illness or injury. Ideally, these preferences will be have been discussed with a *medical treatment decision maker*, and documented in an *Advanced Care Directive* (see following).

#### Advanced Care Directive

An *Advance Care Directive* (ACD) records specific preferences for future health care. This includes treatments for a person with a life-threatening illness or severe injury. An ACD is only used when a person does not have the capacity or ability to make decisions for themselves or is unable to communicate their preferences. (In Victoria, it may include one or both, a values directive and an instructional directive).

An ACD can include information such as whether the person who is very unwell (or severely injured) would like measures such as a machine to help them breathe and cardiopulmonary resuscitation. It can also be used to refuse treatment, including food and fluid, under specific circumstances. The forms are a legally binding document that have specific instructions for completion that need to be followed. After completion, they need to be witnessed by a medical practitioner and another adult, and should be shared with the

medical treatment decision maker and doctors, so the wishes documented in the ACD can be followed.

Our team would be happy to assist you with ACDs.

All ACD's must be written in English. For more information and all appropriate forms, see the *Advanced Care Planning Australia* website - [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

### Medical Treatment Decisions Maker

A medical treatment decision maker is a trusted relative or friend who assists in the management of health care. This person becomes the substitute decision-maker, appointed to act when on behalf of another, when they are no longer able to make decisions.

The medical treatment decision maker can consent to or refuse treatment. They must act in accordance with any lawful limitations or conditions and they must make the decision they believe the person they are acting on behalf of would make if they could make their own decision. For this reason, it is helpful to speak openly about preferences and limitations, and to have an ACD in place.

### Enduring Power of Attorney

In Victoria, an enduring power of attorney (also known as an attorney) is a person legally appointed to make personal or financial decisions on behalf of someone else. It is important that the person appointed to this position is someone of trust as they will be making important decisions. A person can choose to appoint more than one attorney, limit the power to cover specific matters and choose when the powers start.

### Making a will


A will is a written, legal document that sets out how a person would like their assets and belongings distributed upon their death. A valid will ensures property and any belongings are distributed exactly as the person wishes. New wills should be made when circumstances change, eg. divorce, separation, new partner, new children, new step-children or new grandchildren. A person must be able to make clear decisions when they make a will.

### Organ and Tissue donation

Being an organ donor can be a little complicated, but it can be possible for some organs, regardless of where and why death occurs. It is important to have a conversation related to organ donation, and that doctors, family and people closest to the donor know that being an organ and tissue donor is important to them. Relatives will be asked to give consent before the donation can occur and they can overturn the decision of a registered donor.

### Body donation

Some people choose to donate their body "to science" after they die. *The University of Melbourne* coordinates a Body Donor Program for Victoria and uses these donated bodies for teaching, study, examination and investigation of real human anatomy. Bodies may be kept for up to three years before being cremated, the ashes may then be retrieved by family.



*"I was so glad mum shared her wishes with us while she could. When the time came to make decisions, we knew exactly what she wanted."*

Bereaved Carer

## Relationship-related

### Family Communication

Living with a life-limiting illness has a major impact on everyone involved, and the physical and mental exhaustion of caring for someone takes a toll. Communication is essential, even though talking about illness and dying may be difficult.

It will be useful to have regular conversations with the person you are caring for, so you are able to convey their wishes to relevant others so everyone knows what is happening and what to expect as the illness progresses. Sometimes, in these challenging circumstances, there may be conflict, distress, and friction including with people not directly involved. It is important for everyone to know that the person with the illness has the right to make decisions about all aspects of their treatment and end-of-life care if they have the capacity to do so.

If communication becomes a problem, consider speaking with our team, who will arrange a family meeting where all concerns can be shared, so problems can be solved and support provided.

### Managing visitors

You have the right to manage visiting times so that you and the person you are caring for, have time to rest and attend to tasks. We suggest you decide the best time for visitors to come to the house, for instance, only late morning or mid-afternoon. Ask that all visitors contact you or a family member before visiting, and that you agree to the length of the visit during that contact. We suggest a nicely worded sign at the front door stating a visit is not convenient might help to let people know if a visit is no longer possible, and to minimise poorly-timed, unexpected visits. A roster system may also be useful.

### Spiritual and religious beliefs

Spirituality means different things to different people and with impending death, belief systems often become more important.

People will follow their own paths and seek spiritual support from their preferred religious leader. Others find comfort in meditation or prayer and the knowledge that others are praying for them. Others may find their illness or condition has challenged their beliefs and need to talk this through with family, friends or pastoral care worker. Those with a personal philosophy on life may wish to share this through conversation, by writing their thoughts down or recording them in another way.

We have staff who will be able to assist in supporting spirituality, whether for the person who is unwell, or for the carers and family. If you would like some assistance in accessing support, please let our team know.



## Preparing for End of Life

We recognise it might be difficult to have conversations with the person you are caring for about their illness, deterioration, death and preferences related to all of these things, however there are benefits in doing this. Open communication can support everyone to share their thoughts and feelings, resulting in clarity and understanding. These conversations may also provide lovely memories.

*Please know, there is no way to predict exactly what is going to happen or when, so sometimes, even the best laid plans change.*

## Preferred place of death

Knowing the preferred place to die is helpful. If we know where you and your loved one have decided that their end-of-life will be, at home or in an inpatient unit (a palliative care ward or hospital), we will help you to achieve that goal.

If the preference is to be at home in a familiar and comfortable environment, our team will continue to visit regularly, up to daily, or even multiple times in a day, if needed. We will be constantly monitoring and assessing you and our client, and will be sure to put every support service in place that we can, to ensure your preference is met.

Alternatively, if you and your loved one's preference is to be admitted to an inpatient unit, we will help with the admission process where we can, and the hospital staff will take the responsibility for care, from that point.

## Funeral conversations

Conversations with the person you are caring for regarding funeral arrangements can be helpful, and can provide comfort. It may also be useful to include key members of the family and important friends in the discussion.

A funeral director can guide you through the planning process and explain your options. They are very good at conducting these conversations, and will provide you with all of the information that you require, including what happens after death. We can assist you in accessing a local funeral director, if you would like us to.

# END OF LIFE

**Please note:** you may find some of the information in this section difficult, however the more you are able to understand death and know what may happen, the better prepared you may be ... although even the best information may not be able to prepare you or your family for the reality of dying, and death.

We have included this section for you to access if you choose to. The following information is designed to provide a guide for you so you have an idea of what is happening as deterioration progresses. The dying and death process is rarely identical from one person to the next, however this information will provide you with the ability to have an understanding of what may happen, and what it may look like.

**If the following information causes you any concern or you would like more information or support, please do not hesitate to contact us on 9455 0822.**





## END OF LIFE

### Progression toward the end of life – what may happen?

The last phase of life, when a person begins deteriorating toward their final breath, can start weeks or months before someone dies. An increase in symptoms that do not improve or resolve, despite medical treatment can be the earliest signs that the dying process is beginning. Simple actions, such as going from a bed to a chair, can become exhausting. A dying person often starts to withdraw from the news, activities and other people; they may talk less or have trouble with conversation, and sleep more.

This all ties in with a drop in energy levels caused by a deterioration in the body's brain function and body processes. They may also start to consider end-of-life issues, so may start to feel anxious, frustrated and helpless. **Though all of this is difficult, it is not unusual.**

### Days and weeks leading up to death

Predicting exactly when a person will die is nearly impossible and depends on many factors ranging from the illness or condition they have, to whether there have been medical interventions. You may need to prepare yourself for the person you are caring for dying earlier or later than you expected.

*Some indications that death is approaching are listed below, but not everybody experiences these changes and they do not occur in any particular order.*

**NOTE:** Our team will guide you through all of the changes below, and provide you with information related to the cause of the change and ways to provide care and support for each change.

- **Sleeping more** - The person you are caring for may sleep a lot more – this is normal and is ok. During these days, it is important to move their position in bed so they do not become uncomfortable and sore from lying in the same spot.
- **Moving less** - People often lose the ability to move safely as their condition deteriorates. They may no longer have the energy or strength to move themselves, or wash and dress themselves. It may become unsafe for them to try to move from the bed or chair, or to take even a few steps, as they may fall and injure themselves. Decreased movement and a lack of energy is a normal part of the process.



- **Drinking and eating less** - Inactivity reduces the need for food and fluid, so eating or drinking will slow and eventually stop altogether. This is a normal part of the body's preparation for death so the person will often not feel hungry or thirsty, however they may have a dry mouth. Gargling and cleaning teeth will help ease this discomfort.
  - **Becoming vague, confused or restless** - Sometimes people become quite restless in the days or weeks before they die. Explaining who you are, speaking calmly, softening lighting, having pleasant fragrances in the area and playing their favourite music can provide calmness and give reassurance.
  - **Changes in vision and hearing** - Clouded vision, a faraway look in the eyes, or inability to focus on anything or anyone may occur. Hearing may become affected, although this is thought to be the last sense to be affected. Though they may not be responsive to conversation, they may find familiar voices and sounds reassuring and calming.
  - **Incontinence** - Loss of bladder and bowel control often occurs as the body slows and the person loses the strength to be able to move to access a toilet. The reduced food and fluid intake will have an impact on the amount of waste the body excretes. Incontinence pads are very useful to maintain comfort and hygiene.
  - **Breathing** - When someone is deteriorating, they may become short of breath easily, or find it difficult to take a deep breath. Sometimes elevating or repositioning their head can help, or a doctor may prescribe medications to ease the discomfort and concern this may cause.
  - **Changes in colour and temperature** - As blood circulation changes, people's colour may also change – they may become pale or flushed; they may develop dark areas on their bodies from pressure, eg. the hips or heels. They may also, depending on their illness, appear jaundiced (have a yellow tinge) – all of this is normal.
- The body's ability to regulate temperature may also change, meaning they may feel very hot, or become quite cold. Adjusting bedding should be sufficient to make them comfortable, but this needs to be monitored as they may not be able to communicate that they are feeling too hot or cold.

## Final days

As deterioration occurs and death approaches, you may experience a range of emotions including anger, fear, sadness, frustration, worry, loneliness, grief and perhaps some relief that the situation and suffering will soon be over. This can be a very difficult time for you and people close to you. It is helpful to acknowledge your feelings and your place in this process – this is a very difficult experience and you may need some support during this time.

Often during the final days of life, people may:

- **Sleep more** than they are awake, meaning they may only wake for minutes at a time, and then they will return to sleeping. Their sleep also becomes heavier and it is normal for them to become difficult to wake at all when spoken to, or touched.
- **Become confused** due to reduced blood flow or chemical imbalances in their brains that can cause them to be disorientated and confused about simple things such as where they are, or the year they are in – they may even forget names, or not recognise people close to them.
- **Have visions or hallucinations** of unexpected things or people. They may see items, or pets, or loved ones who are not actually in the room, or even people who have perhaps died many years before. Though it may feel distressing for you, these visions can be comforting to them, especially if they are seeing loved ones.
- **Refuse, or be unable to take any food or fluids at all** as their bodies simply no longer want or require food. Their sense of taste and smell may alter, so they no longer wish to take anything orally. It can also become dangerous to place anything in the mouth if they are too sleepy or physically unable to swallow.
- **Feel hot or cold to touch** due to the slowing of their circulation. Body temperature can fluctuate, so a person can be cool to the touch at one point and then hot later on.
- **Breathe differently** – they may breathe faster or slower, have noisy breathing or very soft and shallow breathing.
- **General appearance may change.** In the days leading up to the death, some people start to look a little different – they may appear to lose weight, so their cheek bones may appear more prominent, or their eyes may appear to be deeper or larger. If present, their dentures may no longer seem to be a comfortable fit within their mouth.

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## Saying goodbye

Caring for someone with a life-limiting illness allows time to say goodbye in ways that feel most meaningful to you. This may take the form of an intimate conversation with them, telling them how important they are to you, letting them know their impact on your life...saying all of the things that you may not usually say to someone.

Saying goodbye is an intensely personal experience so do what feels most appropriate for you – it may be talking, sharing music together, looking at photos together to re-live happy memories, or even playing a game. It can be very difficult talking about death and dying, especially when there is so much emotion involved, however saying words and sharing feelings and experiences may provide comfort and remove or decrease regret after the death.

There is no right or wrong time to have these conversations or experiences – they should be done when it feels right.





**If the person who is dying is unable to talk or respond, feel comfortable talking to them and telling stories – tell them what they mean to you, and encourage family to do the same. It is important not to be afraid - sit next to them, hold their hands, stroke their forehead, talk to them about their garden and pets and assume they are listening - hearing is the last sense to fade so keep talking calmly and reassuringly to a dying person.**

## Relatives and visitors

Some people feel awkward about what to say or do when visiting someone who is dying, so it might help to encourage them to:

- Focus on listening rather than talking.
- Encourage the person to talk about their life, as talking about memories may be pleasant for them.
- Ask gentle questions that may encourage sharing e.g. is there something you would like to talk about?
- Try to converse as normally as possible by sharing what is happening in their life.
- Watch television, listen to music, or just sit comfortably in silence. Company may be just as soothing as talking.

**NOTE:** It is important to ensure children are given a choice about visiting the person who is dying, and options for their involvement and interaction.

## Death is hours or minutes away...

### The information below may be confronting.

Death is a process that profoundly affects the body and its functions. It can be unpredictable – it may be evident that death is near, as described below, or it may occur very quickly, with little or no warning.

If you think information may cause you distress, please consider reading the following information with a loved one, or when support is available.

Remember, Banksia staff will be able to answer any questions that you may have.

### How long does dying take?

It is very difficult to know how long it will take for the body to shut down completely and for death to occur. The process can take weeks, days or hours. In some cases, where there may be a very sudden and unexpected complication, death occurs very quickly. Even in people with the same disease, the rate that deterioration and death occurs will often vary.

Sometimes, people appear to be waiting for an event to occur, such as a baby's birth, or a person to arrive from overseas. Though it is difficult to understand how this occurs, it appears that people will wait for the moment which allows them to feel like they can let go ... In other circumstances, they will wait until they are alone and someone has left the room to take their last breath.

For this reason, we will not be able to tell you "how long" – all we know is that they are going to die soon.

### Is death painful?

Dying and death are not thought to be painful, however the symptoms of the disease or condition that the person has been experiencing

often remain, and will cause the same discomfort that they did prior to deterioration. Along with these, a person will feel discomfort from not being able to move themselves, along with other discomfort which may be present, such as having a dry mouth or throat, stiffness of limbs, feeling hot or cold, or altered breathing.

### What to expect from Banksia at this time

As the person may not be able to communicate their discomfort, Banksia staff will use their expertise and experience to ensure people are as comfortable as they can be during this time. The staff will visit regularly and will always suggest and arrange any treatments or services that will manage any discomfort that may be present, including the use of a wide range of medications such as morphine, which do not interfere with, or speed-up the dying process. If they are unable to swallow, these medications will be injectable.

On these visits, please raise any concerns you may have with the nurse. They are there to answer any questions and address your concerns.



**When death is very close, the person will usually be deeply unconscious – they will not be rousable at all. They are unaware of the changes to their bodies, and therefore not feeling distress, even though some of the changes to their body may appear to be causing distress or discomfort.**

It is very common for a person's **breathing** to change again at this stage, sometimes slowing, other times speeding up – it may become noisy, soft, uneven or shallow. Some people will make a gurgle-like sound with each breath – this is sometimes referred to as the “death rattle”. This sound is caused by secretions (fluids) sitting in the back of the throat which the person can no longer shift. There may also be an irregular breathing pattern where there are long gaps between breaths (so long, that you may think they are not going to breathe again), followed by a number of quick breaths – this is known as Cheyne-Stokes breathing.

This irregular breathing may happen for minutes or hours. These changes occur as blood flow slows, and the body starts to close down. The changes in breathing can be very distressing for those in the room, however it does not cause the person any pain or discomfort.

**Circulation** changes also mean a person's heartbeat may be very fast or very slow, and will become fainter. Skin can become flushed, mottled or pale grey-blue, particularly on the knees, feet and hands. They may feel very cold to touch in places, such as the cheekbones, nose, forehead, fingers and feet; there may be perspiration or clamminess present.

The **eyes** may begin to water, appear glazed over, or a slightly different colour. The eyelids may not stay fully closed, even though the person is not awake.

The **mouth** may stay open and the lips and tongue may appear to be either darker, or become very pale.

### What is the moment of death?

The moment of death is when the body ceases to take a breath and a heartbeat (or pulse) is absent. This can occur in either order. It is usually extremely difficult to know exactly when this will occur – people may have taken very few breathes for several minutes, or may have been breathing regularly, then suddenly stop...

When they do stop breathing, and there is no longer a pulse, the person has died because of their disease or medical condition – their body has stopped functioning, and life for this person is no longer possible. At this point, there is nothing further that can be done to keep them alive.

The following signs typically indicate that death has occurred:

- Breathing ceases and there is no heartbeat.
- No response to loud talking or movement.
- Eyes are fixed, pupils dilated, eyes may be open.
- The person may be incontinent.

Death may happen when the room is full of people, or it may happen when a carer leaves the room briefly. Most loved ones want to be present at the time of death, however sometimes this simply does not happen. It is very important not to feel guilty or sad about this – what is much more important to remember is the time leading up to the death...



### After death has occurred

If your loved one dies at home, please remember it is an expected death and not an emergency so **you do not need to contact an ambulance or the police.**

There is no rush to move a person when they have died, so take the time you and your family need with them.

When you are ready, please call Banksia on the numbers provided and we will arrange for one of our nurses to come to you and give you support and help with the next steps.

Our nurse will examine your loved one and complete a "Verification of Death" document (this is a normal process). This verification allows the funeral director to collect your loved one from your home when you are ready.

Their body can remain at home for several hours to allow time for family and friends to say goodbye. Ideally, the person should be positioned so that they are lying on their back with their head and chest very slightly elevated on pillows with their hands on their chest. It is natural for their jaw to drop, and eyes to stay slightly open. The nurse who visits your home to verify the death can assist with positioning, some basic hygiene or tidying of bedclothes as required.

We will contact your GP to inform them of your loved ones passing so the "Certification of Death" can be completed, informing The Registry of Births, Deaths and Marriages - Victoria.

**NOTE: If your loved one dies in hospital, the staff there will support you and explain the processes.**





# Grief and Bereavement

## Caring for yourself

Our time with you does not end when our client dies. We are here for you and your family, and have a variety of ways that we can support you during this time. Please be sure to make contact with us at any time after the death, if you feel that you need some help.

It can be a time of great change, emotion and challenge for you when the person you love, or have been caring for dies. Grief is a natural response to the loss of someone special and can affect every part of your life, including your thoughts, behaviour, beliefs, emotions, physical health and relationships with others.

There is no way for you to know how you will be affected by the death – there is no way to predict the impact. You may have mixed reactions including anger, anxiety, depression, disbelief, relief, guilt or numbness. These reactions can be unsettling, particularly if they are not expected. Not everyone will experience these emotional responses and there is no set order for those who do. The effect of the death, the feeling of loss and the length of time the grieving process takes will vary from person to person.

It is very important for your well-being and your general health, that you acknowledge your grief, remembering that there is no right or wrong way to do this. You may need support during this time (remembering that this may be days, weeks, months or years) from family, friends, a religious figure or a professional bereavement counsellor. A social worker may also be able to help guide and support you with practical tasks and questions after death.

The Banksia Bereavement Team will be in contact with you after the death. In the weeks following the death, you will be sent information about our services, which are available to you and your family. These include:

- Bereavement Counselling
- Information sessions
- Support groups
- Walking groups
- Remembrance Services

***These are all free services to carers and families of Banksia clients. If you would like to contact our Bereavement Team, please contact us on 03 9455 0822.***

# Notes

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This book would not have been possible without the dedicated input of our Consumer Advisory Panel, all of whom were carers of Banksia clients. This group has been instrumental in bringing this book to fruition and for that we are immeasurably grateful.

Thank you to Jo Manoussakis, loving daughter of Voula Vlahopoulos;  
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Voula Vlahopoulos



Eddie Keir



Sofia Pastrana Martinez

