



*The Beginning of our Journey*

# Understanding the palliative care journey

A guide for individuals, carers, Communities and family. **2019 edition**

*VACCHO acknowledges the Aboriginal lands on which we live and work and pays respect to Traditional Owners, ancestors and Elders.*



**VACCHO**

Victorian Aboriginal Community Controlled Health Organisation Inc.  
*Vibrant, healthy, self-determining Aboriginal communities*



## Forward

This *Understanding the palliative care journey* guide has been designed as a companion guide to provide general information in assisting and gaining an understanding of what this palliative care 'journey' may hold for you, a loved one or someone you are taking care of.

This resource is also a contact guide for those who need to seek support or assistance during this journey. This can be through their Aboriginal health service, Aboriginal Health Worker, or Aboriginal Hospital Liaison Officer to link in with a palliative care service in your local region.

All Aboriginal people should be able to complete their journey in a culturally appropriate way, at peace with their family and ancestors and with the best medical and cultural care.

I hope this guide can help Aboriginal people, their families and services achieve the best possible care.

I would like to acknowledge everyone involved for their contribution and commitment to this important resource.

VACCHO would like to acknowledge and pay respect in honouring all Aboriginal people past and present who have experienced a journey that has taken them and their families, to a palliative approach.

**Jill Gallagher AO**  
Chief Executive Officer - VACCHO

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## What is palliative care?

Palliative care is care provided for a person who is living with a long term chronic disease or illness where there is no known cure. The main purpose of treatment for people who access palliative care is to ensure quality of life. Palliative care should have a holistic approach to caring and supports the spiritual, cultural, emotional, social, psychological and physical needs of the patient and the family.

Palliative care will be delivered to you by a range of different people who specialise in different areas as the patient and family needs them. This will be your care team. This team can include Aboriginal Health Workers, Aboriginal community controlled health organisations, case managers, Aboriginal Home and Community Care Workers and organisations which you request at any time of your treatment.

## What can palliative care help me with?

Palliative care services can provide specialist advice, support and effective care of symptoms to assist the family and person living with an illness that can't be cured.

Depending on what you and the family wants, the palliative care team provides:

- Resources e.g. equipment needed at home
- Assistance for families to come together to talk about sensitive issues
- Practical advice and support for the family and carers about making your loved one more comfortable
- Management of pain and other symptoms e.g. vomiting
- Links to other services e.g. for home help and financial support
- Support for people to meet their cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling when needed.

## Who is in the palliative care team?

Palliative care services vary in size and may include:

- GPs
- Nurses
- Social workers
- Bereavement counsellors
- Volunteer support workers

The palliative care team in your area can work together with your local Aboriginal Health Service, your Aboriginal Hospital Liaison Officer or your local GP/Medical service to meet your care needs.



## Different types of care

Within the palliative care system there are different types of care. You and your family need to consider which is the best care for you in providing support and giving you quality of life.

For example:

- At home
- In hospital
- In a hospice
- Residential health care facilities

Your wishes may be that you stay at home if a family member is able to take care of you. You may find that support is required and there are palliative care staff that come into the home to assist with your care.

You may be required to stay in hospital because they have the facilities or special equipment that is required to make you comfortable at that point in time.

## Getting the best care

An ideal approach to managing your health care when you are living with a terminal illness is to pursue the curative treatment that is available, and to consider palliative care support at the same time. This may help to achieve the best care for you and your family on your journey.

Hospitals and other services may also offer after hours services so find out what is available to you.

Crisis support and other resources will be available to you when you have been identified as needing palliative care services.

There are also additional pharmacy benefits and access to medications for people who identified as receiving a palliative care service, whether through your GP, health consultants, or a specialist palliative care service.

You should also discuss your pharmacy needs with your local Aboriginal Health Service as they may be able to assist you in ensuring you are receiving what you need.

If you are interested in finding out more about palliative care either in a hospital, aged care facility, disability centre or at home, discuss this with your GP or specialist care worker.

Other ways of getting the best health care include:

- Talking with your Aboriginal Health Worker, Aboriginal Hospital Liaison Officer, or your GP, as they can be of great support and it is important to discuss your concerns, ideas and your plans for your palliative journey.
- Being aware and talking to other health professionals that you have involved in your health care.
- Discussing your goals and preferences with people who are important to you and your health and wellbeing so that these can be acted on, especially if you are no longer able to communicate your wishes.
- Not being afraid to accept help from your community, family, or friends, as this is much easier when you support one another, it makes your journey a little more easier for you and your family.

It's also important to know what to do if you have a complaint or concern about your health care.

## Staying in hospital

You may at some point in your treatment be required to stay in hospital. If this is the case check to see if there is an Aboriginal Hospital Liaison Officer at the hospital.

They are able to assist you or your family to answer any questions. They will liaise with the hospital staff to make you as comfortable as possible and if you wish, they can be present when you speak to hospital staff.

It may cause you distress if at some point you need to move away from your family and community to see a specialist that may not be available in your area. Ask your family to speak with the specialist care team or Aboriginal Hospital Liaison Officer, Aboriginal Health Worker or your local Aboriginal health service for assistance, as they may be able to assist you or refer you to someone that can help in finding accommodation for your family if this is required.

## Role of an Aboriginal Hospital Liaison Officer

Aboriginal Hospital Liaison Officers are based in hospitals and within their roles they can assist in providing support and communication between you, the Aboriginal Health services, Aboriginal communities, mainstream communities and organisations whilst you are in hospital.

The Aboriginal Hospital Liaison Officer is there to try and assist you, your carer and your family in making things a little easier for you when dealing with the local hospital, staff and specialists.

Aboriginal Hospital Liaison Officers work with the local Aboriginal Health Service and Health Workers to coordinate follow-up appointments and special equipment etc. and to work with you and your family to better understand the situation.

The Aboriginal Hospital Liaison Officers are there to assist the hospital in understanding and respecting your needs and may also help the mainstream organisations have culturally appropriate practices.



**Note:** *If you don't have an Aboriginal Hospital Liaison Officer, and you would like to ensure you have someone involved that is of Aboriginal descent, let the hospital know of your local Aboriginal Health Service, this will then enable contact to an Aboriginal Health Worker.*

## Role of an Aboriginal Health Worker

Aboriginal Health Workers are of Aboriginal and/or Torres Strait Islander descent. They are based in Aboriginal Health Services within your local region. Aboriginal Health Workers provide health support to Aboriginal and/or Torres Strait Islander people when attending the local Aboriginal Health Service.

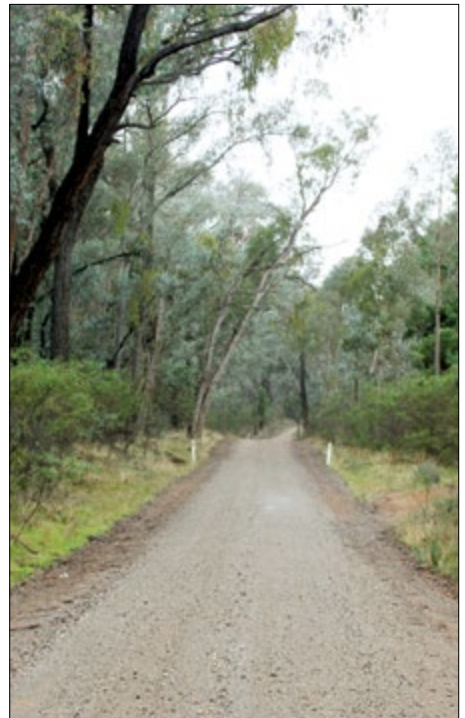
Aboriginal Health Workers are there to offer support to you and your family. They can assist in your care plan through the palliative care system.

If you are not sure how to access an Aboriginal Health Worker, call your local Aboriginal health service to ask where you can find them or ask the hospital you are attending to assist you to make contact.

## Support person

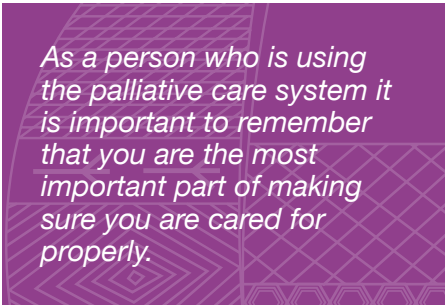
You are able to have a support person with you during the time of your care. This person is the person of your choice and may be the Aboriginal Hospital Liaison Officer or Aboriginal Health Worker.

The people/person you choose can help to ensure your needs are identified and that your cultural safety is supported. You may not feel confident in speaking with GPs or hospital staff alone and the support person may be able to clarify what is being said by GPs or hospital staff. They can ask the questions that you may be too shy to ask.



## Care plans

Care plans are designed for your health care and this will tell you and your family or health workers what treatments you have decided on and what your wishes are in regards to your treatment. This is to make you as comfortable as possible and have the quality of life that is right for you.



*As a person who is using the palliative care system it is important to remember that you are the most important part of making sure you are cared for properly.*

You should be made part of the process at all times in planning and managing your care. You may want to have an Aboriginal Health Worker or even a family member present when making decisions about your care. Let the specialist care team and your GP know this.

Care plans can include your cultural needs and ensure that they are being met at all times. For example you may want to include how your family and community are to be involved in your care and what your cultural preferences and requirements are.

Talk to your:

- GP
- Aboriginal Health Worker
- Aboriginal Hospital Liaison Officer
- and importantly, your specialist care team

## Seeking medical help or advice

If you are unwell please seek medical help by contacting your GP, Aboriginal Health Service or Aboriginal Health Worker.

You can request that a family member, carer, Aboriginal Hospital Liaison Officer or Aboriginal Health Worker be present with you or you may wish to take a member of your family or community.



*We understand that you and your family may have had some bad experiences with using health services in the past. We also understand the past policies and practices may act as a barrier for you in accessing services.*

## Cultural safety

Cultural safety is providing a safe environment that is respectful of an individual's culture and beliefs.

*You have the right for respect and support of cultural dignity on values, attitudes and beliefs.*

Whoever is caring for you, should be respectful and supporting of your and your carer's cultural identity and wellbeing.

If this is not happening and you are feeling unsafe then you do need to speak out or get your support person so they are able to advocate on your behalf. This could be an Aboriginal Health Worker, Aboriginal Hospital Liaison Officer or your nearest Aboriginal Health Service or a medical worker within the palliative care service.

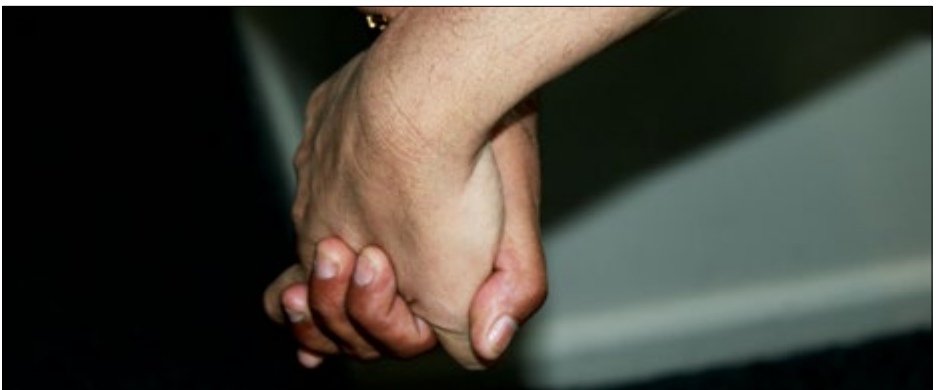
## Information gathering and forms

When you visit GPs or hospitals they will need to ask you lots of questions. This is quite normal for anyone seeing a GP or being admitted to hospital. This is where you may wish to have a professional support person with you as it may get confusing or you may feel you have already done this several times before.

Professional support people can be your local GP, Aboriginal Hospital Liaison Officer or Aboriginal Health Worker.

They may also ask you to fill in forms so they are able to speak with other people in regards to your care.

The reason they do this is so they all can communicate in regards to your care. It is to ensure that your cultural needs are also being met.



## Spiritual and emotional wellbeing

Spiritual care is acknowledging that there are varying spiritualities and supporting these can keep people well.

This can include connections with country, family and community, support groups, belonging to a church or a spiritual group.

It is also about having time to listen and support people with a chronic illness in any way that is necessary.

Talk with your local Aboriginal Social and Emotional Wellbeing Officer or chaplain for further support or information.

Spiritual care throughout the journey offers the individual, family and community the opportunity to reflect on personal and cultural beliefs.

Good relationships and life choices can provide you with:

- Guidance
- Support
- Comfort
- Strength
- And most importantly, hope.

## Aboriginal identity

You may also be asked if you are of Aboriginal and/or Torres Strait Islander descent. Please don't be offended by this question, as it is now hospital policy.

By asking this question the hospital is able to provide for all your needs and can assist you in linking with services that you require like an Aboriginal Hospital Liaison Officer, or Aboriginal Health Worker or services to assist with any special cultural needs.

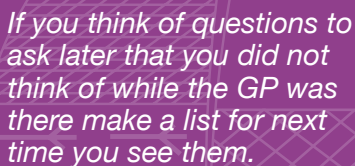


*You do not need to identify if you do not wish to.*

## Speaking the same language

We all know that sometimes when we go see the GP, we walk out not having any idea what he/she was saying. If you don't understand what is being said to you then you need to ask. Don't be too shamed to ask, or tell them you don't understand. If you would like to have your carer or family member, an Aboriginal Health Worker or Aboriginal Hospital Liaison Officer with you when you see the GP or nurses, they could ask questions for you.

It is good to ask lots of questions, particularly if you are not sure about what's going on. Asking questions helps you and your carer or family make informed decisions. You can only make informed decisions if you understand what's going on.



*If you think of questions to ask later that you did not think of while the GP was there make a list for next time you see them.*

You should receive information from the person treating you in regards to the nature of your illness, the diagnosis, and your care choices. If you do not receive this then ask for information. Make sure all decisions you make in regards to your treatment and care, are informed and suit your needs.

## Future decisions

When faced with the diagnosis of a terminal illness the more planning and preparation you put in place, the easier it may make the end of your life's journey and can provide comfort for those left behind. This will help reduce the load on family to clear up any outstanding matters such as family, financial and legal issues.

Preparing the journey for end of life doesn't mean giving up or taking to your bed and spending the rest of your time deep in despair. It's about accepting the limitations of your body and mind and finding the best 'quality of life' until the end.

Unfortunately due to your illness or disease there may come a point in time, when you will be unable to make decisions in regards to your future matters. Before this time you may like to think about appointing a person or people to make these decisions on your behalf. This person or people may be a trusted relative, friend, community member or professional. (See next page for examples)

## Your medical treatment

You have the right to make decisions about your current and future medical treatment.

You can appoint a support person to help you make your medical treatment decisions. Your support person can check that your decisions are followed.

You can take these steps in case you lose the ability to make or communicate your own decisions:

### Step 1. Appoint a Medical Treatment Decision Maker

You can appoint a Medical Treatment Decision Maker. This person will make decisions about your medical treatment if you are not able to. They can consent to treatment that they believe you would want. They can refuse treatment that they believe you would not want.

Choose a person who knows you well and who you can trust to make the decisions you would want.

You must use the Appointment of a Medical Treatment Decision Maker Form. This is available from the Office of the Public Advocate website: [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au).

### Step 2. Discuss your health care preferences

What matters most to you if you are seriously ill or dying? These are your 'advance care' preferences.

Discuss these preferences with your family, Medical Treatment Decision Maker and doctors. Do this often, including when your health care preferences or circumstances change.

### Step 3. Write an Advance Care Directive

Write down the things that would be important for your future health care decisions. You can do this by completing an Advance Care Directive form. This can include a Values Directive, or Instructional Directive, or both.

#### *Values Directive*

The values directive includes important things you want to guide decisions about your medical treatment, if you can no longer make decisions:

- What matters most to you.
- What worries you most about your future.
- The medical treatment results you want to avoid.
- The people you want involved in discussions about your care.
- What would be most important to you when you are dying.

Your Medical Treatment Decision Maker must consider your Values Directive when making decisions about your medical treatment.

## *Instructional Directive*

You can give specific instructions about your future medical treatment. These must be called an Instructional Directive and they must be written down.

This can include:

- Your consent to specific medical treatments in the future. You can specify the circumstances in which you would want this medical treatment. Health professionals must respect your consent when there is a good medical reason to provide this treatment.
- Your refusal of specific medical treatments. For example: being fed through a tube, having a machine breathe for you. You can specify the circumstances in which your refusal of specific medical treatments must apply. Health professionals must respect your decision to refuse specific medical treatment in relevant circumstances.

You cannot refuse reasonable medical treatments to relieve pain or suffering. You cannot refuse to be offered food and water but you are not required to accept it.

Your Medical Treatment Decision Maker will not make medical treatment decisions that are covered by your Instructional Directive.

## *Help and forms available*

Your doctor or palliative care team can help you to discuss your advance care preferences.

Guidance and forms for your Advance Care Directive are available from the Office of the Public Advocate and health services.

Keep your Advance Care Directive and give copies to your Medical Treatment Decision Makers, family, doctors and treating health services. Review it often and update it as necessary.

## **Financial and personal decisions**

You can appoint a person you trust to make financial, legal and personal decisions for you. This person is called an 'attorney'. Forms are available from the Office of the Public Advocate and lawyers.

You can decide what decisions your attorney can make for you. For example: paying bills, selling property, where you live, etc.

You can decide when your attorney can make decisions for you. For example, at a specific time or when you can no longer make your own decisions.

Your attorney must follow your instructions and make decisions they believe you would want.

## Andrew's story

Hi my name is Andrew Bamblett. I'm a proud Yorta Yorta/Kurnai man and I would like to share my story of two women that were a huge part of my life before they took their journey into the Dreamtime.

My two Aunties, Tahrina Cooper and Victoria 'Vicki' Bamblett were my rocks, my Aunties, my guardian angels and my best friends. They took their journeys into the Dreamtime surrounded by family support.

On the 9th of July 2000 my beautiful Auntie Tahrina entered the Dreamtime. I was only a young boy when she took her journey, but I sort of knew what was happening but didn't understand why or how. The thing I did know was that my Auntie Tahrina wasn't going to be around much longer. This took a little time to sink in and by that time it was later in her journey.

If you knew my Auntie Tahrina you knew she was a bubbly, energetic and strong woman that loved and cared for everyone that was a part of her life. She was one of those women who would like to play fun little games (pranks) on people just for laughs. "Love life and live it to the fullest", she never let anything or anyone bring her down. I later found out and had an understanding that bowel cancer was the cause of her journey.

On the 29th of July 2003 my equally beautiful Auntie Vicki had entered the Dreamtime. By this time I was a young teenager and found out from my mum that my Auntie Vicki was pretty crook, but I didn't know how crook. Like in the yarn about my Auntie Tahrina I

didn't really understand why or how. Same thing with my Auntie Vicki, is that I knew my Auntie wasn't going to be around much longer.

As before it took a little time to sink in but this time it was a much stronger feel as Auntie Vicki was like my second mother. If you knew my Auntie Vicki you would know she was a very strong independent person who had plenty of values. She loved and adored all her family, from mum and dad (my nans and pops), Elders, Aunties, Uncles, cousins, nieces, nephews and anyone else who was involved in her life. After a little while I was told that liver and bowel cancer was the cause of her journey.

As a young kid you don't understand these things even though they are explained to you. It is a little hard to understand.

Now, as a young Aboriginal man I understand how and why these things happen, but still don't understand why it happens to such beautiful people. These two women have shown me that even in the darkest times you can always have a positive outlook on life no matter what journey you take. They showed me that it is up to the individual how they want to take that journey. Because of my Aunties I learnt that family is everything. They're not just there for the good times but the hard times as well.

My hope is for other young Aboriginal people to understand why these things happen. That death is not the end of the road for someone as they live on in our thoughts and hearts.

*Thanks for reading my story.*

Andrew



## Coping with your diagnosis

Regardless of whether you have been ill for some time or feel well, the diagnosis of a terminal illness can be devastating. There is a huge and instant emotional, physical, spiritual and financial impact on your life and the lives of those around you. How can you begin to cope with the initial diagnosis?

- Accept that you are in shock and emotionally fragile. Don't try to disguise how you feel.
- Accept feelings as they happen. Talk about how you feel and encourage others to do so.
- If you are finding it difficult to talk to friends and family seek the help of others. This could be a GP, specialist counsellors or Elders within your community.
- Information can really help. Although it can be frightening, most people feel more in control with better knowledge of what they are facing, what to expect and what is likely to happen rather than fearing the unknown.
- Draw on the strength of people around you.
- Try not to worry about what you will not achieve, focus on what you have achieved in life so far.

## Sorting out the practicalities

As insignificant as it may seem, focussing on the day to day things such as sorting out bank accounts and showing your family where you keep special and important papers or items, can actually help you, your carer and family members.

As you move forward from your diagnosis try not to give up all your plans, but be sensitive to your self when knowing it to be realistic.



## Living with your illness

Although you may have a terminal illness, you could live with your illness for months or even years to come. You may start to focus on the end of your journey, or what might happen after your journey.

One of the hardest aspects of living with a terminal illness is trying to find ways to live each day of your life to the full rather than focussing on what comes at the end. You need to try and cope with the changes that living with illness brings and enjoy the time you have left?

***Note:** Discuss with your carer, family members, Aboriginal Health Worker or Aboriginal Hospital Liaison Officer, if you feel you would like to do some things that are important to you like for example; having days with your family and friends, or going home to country.*

Some of the things you might experience are:

### **Fatigue and exhaustion**

You need to remember that your body is using up lots of energy fighting the disease or illness. This may cause you to become tired. You may not be able to concentrate, might become irritable, easily upset and intolerant of others. This can be improved

after rest or a change in activity.

Your eating and sleeping habits may have changed and this can impact your day-to-day life.

### **Nausea and vomiting**

Being nauseous can be a very unpleasant feeling and hinder your quality of life. This can be experienced for sometime before actually vomiting. There may be a number of reasons as to why you may be feeling nauseous or vomiting but if you speak to your GP about this, there are some medications you can take to help ease these feelings to make you more comfortable.

### **Eating**

It can be hard to eat when you lose your appetite or feel nauseous. Medication, illness and stress can all cause appetite loss and nausea. However eating is the way we fuel our bodies - which gives us the strength to carry on with our daily lives and it is important to maintain your health for as long as possible. Eating little and often will help with nausea and keep your nutrient levels up. Find the times of day when you are most hungry and eat a good meal then.

### **Dehydration**

Drink up to six glasses of water a day, ice cubes or crushed ice is great.

Also try any foods that may assist with your fluid requirements.

If you are very dehydrated let your GP or specialist care team know.

### **Recipe for a hot soothing lemon drink**

#### **Ingredients**

- 1 cup lemon juice
- 2 cups water
- 1-2 teaspoons honey (to taste)
- Slice of ginger
- 1/4 teaspoon. cinnamon (optional)

#### **Instructions**

- Heat up water and lemon juice in a pan
- Add honey
- Add the slice of ginger
- Sprinkle in some cinnamon
- Bring to just below the boil

**Enjoy!**

## **Pain relief**

Some illnesses are very painful or can become painful, and sometimes people worry about this. GPs treating you will have pain treatment written into your care plan that is suitable to your needs. Sometimes people worry about this due to the side effects it may have.

Medication is most commonly used for pain relief. There is a range of pain relief medication available which can help you to control your pain. If the painkillers you have been prescribed are not working then discuss different options with your GP or specialist care team. There may certainly be an alternative that works for you.

**Note:** *Talk with your GP about this more to ensure you feel safe and comfortable about the medications you are taking.*

**Note:** *Talk to a dietician in regards to what would be suitable for you to eat during this time. Discuss with your GP or Aboriginal Health Service for a referral to a dietician.*

Relaxation is a very important aspect of pain relief. Relaxation floods your body with endorphins which are nature's pain relieving chemicals. Try to visualise breathing in calm warming waves to soothe the body part that needs special attention.

Pain is one of the most common symptoms in palliative care. Pain can be a much feared symptom which can contribute to its intensity.

The aim of palliative care is to allow you as a patient to be pain free or for your pain to be sufficiently controlled so that it does not interfere with your ability to function or detract from your quality of life.

Good pain control requires:

- Accurate and detailed assessment of each pain
- Knowledge of the different types of pain
- A different therapeutic approach to the chronic pain
- Knowledge of the actions and adverse effects that painkiller medications may have
- Multidisciplinary assessment of the treatment and other aspects of suffering that may aggravate pain which cause physical, psychological, social, cultural and spiritual wellbeing distress.

## Medications

The use of medications for the treatment of acute pain is the same for a non-palliative care patient. There are different approaches to chronic pain and you can discuss this with your GP or specialist care team.

## Physical changes

It is good to ask what physical effects may result from any treatment so that you are prepared and can manage the situation with full information. Some illnesses require surgery or treatments that may result in physical changes to your body which may be hard to accept. Most people come to terms with the situation if it means there is a chance of a prolonged life. However, some physical changes such as hair loss are difficult to deal with and can add to feelings of depression or despair.

Talk to friends and family about how you feel the changes have affected you and find simple ways to make yourself feel better such as massages, long baths, being with friends, family or community who make you happy.

**Note:** Talk with your GP, Carer or Aboriginal Health Worker to discuss some of the things that you may wish to do. They may be able to look at options available to you for self nurturing, care and spiritual and emotional wellbeing.

## Panic

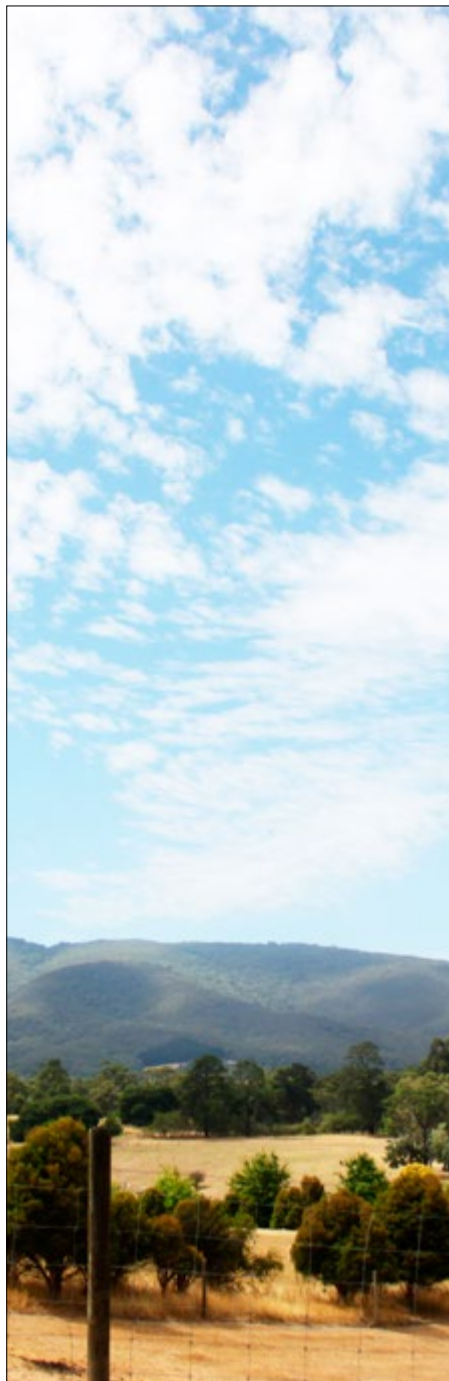
It is common to feel overwhelmed with negative feelings because of your illness and the thought of dying can lead to panic attacks. During a panic attack you may feel that you can't breathe and that this is it - the moment of death - this creates further panic.

Try to stop negative thoughts in their tracks and have a range of strategies ready to help you relax. If you know a certain situation will make you panic then either avoid it or have someone with you.

Panic can also be a side affect of your treatment.

Strategies could be as simple as taking deep slow breaths or even concentrating on your feet and wiggling your toes.

**Note:** *These are just some examples to help you, if this continues speak with your GP, Aboriginal Health Worker or care provider, they will be able to assist you in managing feelings of panic.*



## Grief/Sorry Business

Grieving is a very personal experience, with each person working through the stages of grief in their own way. Those who are having a difficult time coping with grief may benefit from debriefing or counselling.

### The stages of grief

While everyone embarks on their own journey through grief, there are many commonalities that those who are suffering share. There are five stages of grieving that many people work through, not everyone experiences all five stages, or goes through them in the same order.

#### Denial

Complete disbelief is a typical first reaction to a terminal diagnosis. “This can’t be happening”.

#### Anger

“Why me?” is a common feeling amongst the terminally ill and those who love them. Illness is never fair, so feeling angry about being one of the unlucky ones isn’t at all unreasonable.

#### Bargaining

Once the reality of the situation has been fully understood, many terminally ill patients begin to consider upcoming events that they fear they will not live to see. Hoping and praying for enough time to attend an important event is common.

## Depression

Extraordinary sadness is commonly the last step before acceptance. To a degree, allowing the sadness is a form of acceptance - no longer holding out hope that there has been a misdiagnosis or that the patient will beat the odds.

## Acceptance

While not everyone finds acceptance before death, those who are able to come to terms with their fates may have a greater sense of peace than those who continue to fight it.

It’s important to note that there is no ‘right’ way to grieve. Some people seem to cope better than others, but grieving can be a long and complicated process, with many people making progress, only to take a step back and regressing to a less comfortable place.

Reaching out for help from others can help for those who are having trouble managing their feelings.

Many people find that when they keep busy and redirect their focus to the needs of others, their own feelings of despair seem more manageable. Care must be taken however, to be sure that one doesn’t avoid dealing with their feelings - to do so simply postpones the grieving process, rather than avoid it.

## Financial assistance

A life threatening or terminal illness affects every aspect of life for you, your carer and family. The changes in turn can impact on your financial situation.

If this occurs you are able to discuss this with your specialist care team, Aboriginal Health Worker, Aboriginal health service or Social Worker. They may be able to assist you in seeking guidance in preparing a financial plan.

## Saying goodbye

For people who know they are facing the journey of end of life, there will come a time when you have to say goodbye. And saying a final goodbye is very painful for both the person on their journey and those being left behind. Expressing a goodbye can also be an opportunity to offer reassurance, affirm love and confirm closure.

Many people say that the grieving process is harder if they have not had the opportunity to say goodbye properly.

On your journey try to make sure things are not left unsaid as it is very important to allow those left behind to cope with their grief. Often saying goodbye is a process rather than a single event. You may have to say goodbye to many people and as we usually don't know the exact moment when we will die, you may repeat your goodbyes, and 'that's okay too'.

*For example: Saying goodbye is especially important if you are a parent who is leaving children behind. They can cope so much better if they understand what is going to happen. They will still be devastated, but this is better than you suddenly disappearing without an explanation.*

Saying goodbye is a chance to express your feelings openly and honestly and bring peace into the final days of your lives together. Saying goodbye is about making the end of your journey emotionally easier. "Like" and "love you" are the most important starting points for saying goodbye with complete closure.

This will be a very painful process, you will most likely feel and do many things like cry, get angry, be sad or feel lost. You may even struggle to know what to say. Speak from the heart and give yourself plenty of time. A goodbye doesn't have to be a solitary outpouring of emotions. It may be a more subtle letting go over time.

*If you are a friend or family member then part of your job is to give permission to die without guilt - you have to let go and allow them to do the same.*

This is a unique and special time in your life when you can ignore some of the social conventions that normally hold us back. Embrace the chance to say and do the things that you have always wanted to. You may also find this is a good opportunity to give something to those you are leaving behind rather than leave it to be divided in a will. You can then pass on the significance of the gift.

Give each other permission to express feelings freely. If you are the one on the journey, then give your family, friends and community permission to feel whatever emotion they experience.

You don't have to do something out of character. If you have always been a practical person then maybe that is the way you want to say goodbye - maybe you'd like a cultural ceremony to take place, have a party or just have personal time with each person.

*Do what feels right for you and those around you.*

Share your stories of your life journey. You may like to tell each other what you mean to each other, what significance you have played in each others lives and what you will remember and treasure. This is one of the most comforting things you can do in the last weeks and days for yourself and your family and those who hold a special place in your heart.

*Remember it is 'your journey' and 'your right' to choose what best suits you.*

*Never be afraid to let palliative care services know what is right for you culturally and spiritually.*



## Children and palliative care

When caring for a child with a life threatening illness, discuss with your GP, Aboriginal Health Worker or Aboriginal Health Service about paediatric palliative care and how to seek the services and assistance available to ensure your child is getting the best care in a palliative approach.

For further information please refer to organisations below.

### Very Special Kids

Very Special Kids is a unique Victorian organisation offering an extensive range of support to families of children with a life-threatening illness. It is offered free and without obligation by a team of professional family support workers. Family support workers when requested, link volunteers to families. The organisation also provides respite and palliative care at Very Special Kids' house.

**T** 03 9804 6222

**E** [mail@vsk.org.au](mailto:mail@vsk.org.au)

**www.**[vsk.org.au](http://vsk.org.au)

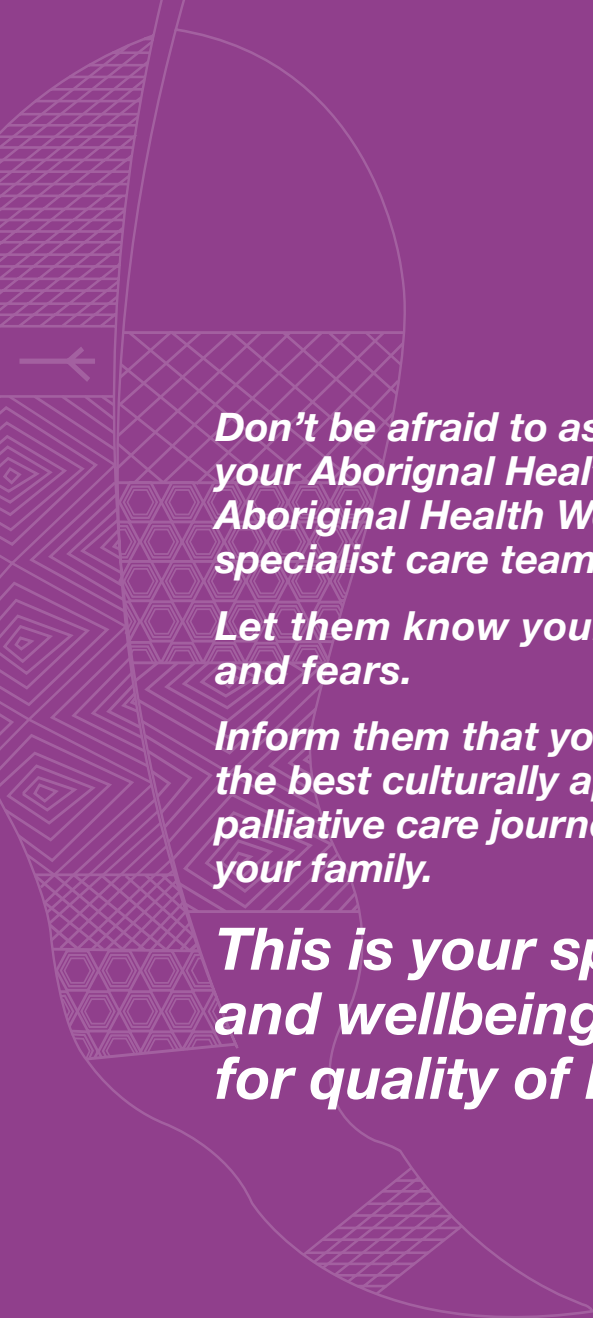
## Victorian Paediatric Palliative Care Program

The Victorian Paediatric Palliative Care Program (VPPCP) is a statewide program and supports any family of a child/young person with a life limiting illness who is treated in Victoria. It is a consultation-liaison program and will not take over from your child's treating team. Instead, it aims to enhance the care available to you and your child. The program is staffed by a consultant paediatrician, social worker and liaison nurses. They generally work behind the scenes with the health professionals looking after a child but they are also available to speak directly with families. Anyone can refer to the VPPCP for information or support.

3rd Floor, West Building  
Royal Children's Hospital  
Flemington Road  
Parkville, Victoria 3052

**T** 03 9345 5374

**www.**[rch.org.au/rch\\_palliative/  
for\\_families](http://rch.org.au/rch_palliative/for_families)



***Don't be afraid to ask, yarn with your Aboriginal Health Service, Aboriginal Health Worker, GP or specialist care team.***

***Let them know your concerns and fears.***

***Inform them that you want the best culturally appropriate palliative care journey for you and your family.***

***This is your spiritual and wellbeing journey for quality of life***

## Victorian Aboriginal community controlled health organisations/services

<p><b>Aboriginal Community Elders Services (ACES)</b> 5 Parkview Ave, Brunswick T 03 9383 4244</p>	<p><b>Gippsland and East Gippsland Aboriginal Co-operative</b> 37-53 Dalmahoy St, Bairnsdale T 03 5152 1922 or 03 5150 0700</p>
<p><b>Ballarat and District Aboriginal Co-operative</b> 5 Market St, Ballarat T 03 5331 5344</p>	<p><b>Goolum Goolum Aboriginal Co-operative</b> 43 Hamilton St, Horsham T 03 5381 6333</p>
<p><b>Bendigo and District Co-operative</b> 13-15 Forrest St, Bendigo T 03 5442 4947</p>	<p><b>Gunditjmara Aboriginal Co-operative Ltd</b> Harris Park Reserve, Warrnambool T 03 5564 3333</p>
<p><b>Budja Budja Aboriginal Co-operative</b> 20-22 Grampians Rd, Halls Gap T 03 5356 4751</p>	<p><b>Kirrae Health Services Inc</b> 1 Kirrae Avenue, Purnim 3278 T 03 5567 1270</p>
<p><b>Dandenong &amp; District Aborigines Co-operative Ltd inc. Bunurong Health Services</b> 3 Carroll St, Dandenong T 03 9794 5933</p>	<p><b>Lake Tyers Health and Children Service</b> Rules Rd, Lake Tyres T 03 5155 8500</p>
<p><b>Central Gippsland Aboriginal Health and Housing Co-operative</b> 15-17 Collins St, Morwell T 03 5136 5100</p>	<p><b>Mallee District Aboriginal Services</b> 120-122 Madden Ave, Mildura T 03 5022 1852</p>
<p><b>Dhauwurd Wurrung Elderly and Community Health Service</b> 18 Wellington St, Portland T 03 5521 7535</p>	<p><b>Moogji Aboriginal Council East Gippsland Inc.</b> 52 Stanley St, Orbost T 03 5154 2133</p>

<p><b>Mungabareena Aboriginal Corporation</b></p> <p>21 Hovell St, Wodonga  <b>T 02 6024 7599</b></p>
<p><b>Murray Valley Aboriginal Co-operative</b></p> <p>87 Latje Rd, Robinvale  <b>T 03 5026 3353</b></p>
<p><b>Ngwala Willumbong Cooperative</b></p> <p>93 Wellington St, St Kilda  <b>T 03 03 9510 3233</b></p>
<p><b>Njernda Aboriginal Corporation</b></p> <p>84 Hare St, Echuca  <b>T 03 5480 6252</b></p>
<p><b>Ramahyuck District Aboriginal Corporation</b></p> <p>117 Foster St, Sale  <b>T 03 5143 1644</b></p>
<p><b>Rumbalara Aboriginal Co-operative Ltd</b></p> <p>20 Rumbalara Rd, Mooroopna  <b>T 03 5820 0000</b></p>
<p><b>Swan Hill and District Aboriginal Cooperative</b></p> <p>70 Nyah Rd, Swan Hill  <b>T 03 5032 5277</b></p>
<p><b>Victorian Aboriginal Health Service</b></p> <p>186 Nicholson St, Fitzroy  <b>T 03 9419 3000</b></p>

<p><b>Wathaurong Aboriginal Co-operative</b></p> <p>62 Morgan St, North Geelong  <b>T 03 5277 0044 or 03 5277 2038</b></p>
<p><b>Winda Mara Aboriginal Corporation</b></p> <p>21 Scott St, Heywood  <b>T 03 5527 2051</b></p>

**Victorian Aboriginal Community Controlled Health Organisation Inc.**

VACCHO is the peak body for Aboriginal health in Victoria and champions community control and health equality for Aboriginal communities.

It is a centre of expertise, policy advice, training, innovation and leadership in Aboriginal health. VACCHO advocates for the health equality and optimum health of all Aboriginal people in Victoria.

17-23 Sackville Street  
 PO Box 1328  
 Collingwood Victoria 3066

**T 03 9411 9411**

**F 03 9411 9599**

**E enquiries@vaccho.com.au**

**www.vaccho.org.au**

## Aboriginal Hospital Liaison Officers within Victoria

<b>Austin Hospital (Heidelberg)</b> 03 9496 5000	<b>Orbost Regional Health</b> 03 5154 6648
<b>Bairnsdale Regional Health</b> 03 5150 3365	<b>Peninsula Health (Frankston)</b> 03 9784 8375
<b>Ballarat Health Services</b> 03 5320 4610	<b>Portland Health</b> 03 5521 0333
<b>Bendigo Health Care Group</b> 03 5454 7131	<b>Robinvale District Health</b> 03 5051 8160
<b>Barwon Health (Geelong)</b> 03 5226 7669	<b>Royal Children's Hospital (Melbourne)</b> 03 9345 6111
<b>Echuca Regional Health</b> 03 5485 5836	<b>Royal Women's Hospital (Melbourne)</b> 03 9344 2000
<b>Goulburn Valley Health (Shepparton)</b> 03 5832 2450	<b>Swan Hill Hospital</b> 03 5032 1111
<b>Latrobe Regional (Traralgon)</b> 03 5173 8383	<b>St Vincent's Hospital</b> 03 9288 3438
<b>Mildura Base Hospital</b> 03 5022 3333	<b>South West Health Care (Warrnambool)</b> 03 5564 4192
<b>Monash Medical Centre (Clayton)</b> 03 9594 2290	<b>West Gippsland Health Care (Warragul)</b> 03 5623 0611
<b>Mercy Hospital for Women (Heidelberg)</b> 03 9270 2609	<b>Wimmera Health Care (Horsham)</b> 03 5381 9373
<b>Northern Hospital (Epping)</b> 03 8405 8000	

## Victorian Palliative Care Services

Metropolitan Region	Name	Contact number
<b>Eastern</b>	Caritas Christi Hospice, Kew	03 9231 5000
	Caritas Christi, St Vincent's Hospital, Fitzroy	03 9231 5000
	Eastern Palliative Care, Ringwood	1300 130 813
	Eastern Health Palliative Care Unit, Wantirna	03 9955 1200
<b>North and West</b>	Austin Health Palliative Care Unit, Heidelberg	03 9496 2542
	Austin Health Consultancy Service, Heidelberg	03 9496 6796
	Banksia Palliative Care Service, Heidelberg	03 9455 0822
	Melbourne City mission Palliative Care, Nth Fitzroy	03 9486 2666
	Mercy Palliative Care, Sunshine	03 9364 9777
	Parkville Integrated Palliative Care Services	03 8559 7960
	Western Health - Sunshine Hospital Palliative Care Unit, St Albans	Inpatient: 03 8345 1792 Consultancy: 03 8345 7068
	Northern Health Hospital Palliative Care Service, Epping	Inpatient: 03 8405 8114 Consultancy: 03 8405 8708
	Mercy Health - Werribee Mercy Hospital, Werribee	03 8754 3000

<b>Metropolitan Region</b>	<b>Name</b>	<b>Contact number</b>
<b>Southern</b>	Alfred Health Palliative Care Service, Melbourne	03 9076 6970
	Calvary Health Care Bethlehem, Parkdale	03 9596 2853
	Casey Hospital (Southern Health), Berwick	03 8768 1550
	McCulloch House Monash Medical Centre, Clayton	03 9594 5320
	Peninsula Health Palliative Care Unit, Frankston	03 9784 8600
	Peninsula Hospice Care, Frankston	03 5973 2400
	Palliative Care South East, Cranbourne	03 5991 1300

### **Rural Region**

<b>Barwon</b>	Barwon Health Palliative Care Services, Geelong	Community: 03 4215 5700 Inpatient: 03 4215 6010
	Bellarine Palliative Care, Point Lonsdale	03 5258 0855
	Colac Area Health, Colac	03 5232 5100
	Portland and District Health Palliative Care, Portland	Community: 03 5521 0674 Inpatient: 03 5521 0333
	South West Health Care, Warrnambool	Community: 03 5564 4179 Inpatient: 03 5563 1666
	Western District Health Service, Hamilton	Community: 03 5551 8222 Inpatient: 03 5551 8359

<b>Gippsland</b>	Bairnsdale Regional Health Palliative Care Service, Bairnsdale	Community: 03 5152 0249 Inpatient: 03 5150 3333
	Bass Coast Health, Wonthaggi	03 5671 3333
	Central Gippsland Health Wellington Palliative Care Service, Sale	Community: 03 5143 8885 Inpatient: 03 5143 8600
	Gippsland Lakes Community Health, Lakes Entrance	03 5155 8300
	Kooweerup Regional Health, Kooweerup	03 5997 9679
	Latrobe Community Health Service, Morwell	1800 242 696
	Latrobe Regional Hospital, Traralgon	03 5173 8000
	Orbost Regional Health Service	03 5154 6684
	Gippsland Southern Health Palliative Care Service, Leongatha	Community: 03 5667 5661 Inpatient: 03 5667 5555
	West Gippsland Healthcare Palliative Care Service, Warragul	Community: 03 5623 0870 Inpatient: 03 5623 0611
	Yarram and District Health Service, Yarram	03 5182 0222

*Continued next page*



<b>Grampians</b>	Djerriwarrh Health Services Bacchus Marsh	03 5367 2000
	Ballarat Hospice Care, Ballarat	03 5333 1118
	Gandarra Palliative Care Unit, Ballarat	03 5320 3895
	Central Grampians Palliative Care, Ararat	Community: 03 5352 9465 Inpatient: 03 5352 9300
	Wimmera Hospice Care, Horsham	03 5381 9363
<b>Hume</b>	Albury Wodonga Health Wodonga Campus Palliative Care	02 6051 7423
	Goulburn Valley Hospice Care	03 5822 0068
	Lower Hume Palliative Care	03 5735 8065
	Benalla Home Nursing Service Palliative Care	03 5761 4207
	Moira Palliative Care, Numurkah	03 5862 0558
	Northeast Health Wangaratta Palliative Care	03 5722 5184
	West Hume Palliative Care	Consultancy: 0438 842 389
	East Hume Palliative Care Consultancy Service	Consultancy: 0427 756 675

*If you are having difficulties in locating a palliative care service please contact:*

<b>Loddon Mallee</b>	Bendigo Community Palliative Care Service, Bendigo	03 5454 8929
	Castlemaine Palliative Care Service, Castlemaine	03 5471 3495
	Echuca Community Palliative Care Service, Echuca	03 5485 5230
	Macedon Ranges Palliative Care Service, Kyneton	03 5422 9911
	Maryborough Community Palliative Care Service, Maryborough	03 5461 0390
	Swan Hill Community Palliative Care Service, Swan Hill	03 5033 9236
	Sunraysia Community Palliative Care Service, Mildura	03 5025 9001
	Loddon Mallee Regional Palliative Care Consultancy Service (complex cases only)	
Bendigo	03 5454 6262	
Mildura	03 5025 9001	

## **Palliative Care Victoria**

Palliative Care Victoria (PCV) works to ensure all Victorians with a life limiting illness and their families are supported to live, die and grieve well.

Level 2, 182 Victoria Parade  
East Melbourne Victoria 3002

**T** 03 9662 9644

**F** 03 9662 9722

**E** [info@pallcarevic.asn.au](mailto:info@pallcarevic.asn.au)

**www** [.pallcarevic.asn.au](http://www.pallcarevic.asn.au)

## Other Aboriginal services and contacts of importance

### Aboriginal Community Controlled Health Organisations (ACCHOs)

Aboriginal Community Controlled Health Organisations have been established to address the specific health needs of Aboriginal people and communities. The ACCHOs provide an extensive and comprehensive range of services that assist to address the holistic needs of a person's health and wellbeing.

For a full list of Victorian ACCHOs go to [www.vaccho.org.au](http://www.vaccho.org.au).

### Victorian Aboriginal Funeral Service

This service provides a holistic Aboriginal run and managed funeral service for Aboriginal people, families and communities across Victoria.

The service respects cultural, family and community needs in burying Aboriginal people.

The Aboriginal Funeral Service provides the necessary support, advice and referrals to families who have experienced the trauma of recent death and ensure that all arrangements associated with the planning and administration of a funeral is taken care of and undertaken in a sensitive manner that respects and accommodates the interests of bereaving family

members.

This assists to alleviate the significant trauma and related stress of Aboriginal families who have experienced recent death.

Care of: Aborigines Advancement League  
2 Watt Street  
Thornbury, Victoria 3071  
T 03 9480 7777

***For further information on palliative care please don't be afraid to contact or yarn with your:***

- ***Local Palliative Care services***
- ***GP***
- ***Aboriginal Hospital Liaison Officer***
- ***Aboriginal health service***
- ***Aboriginal Care Coordinator***
- ***Specialist care team***

## Resources

### Carers Victoria

Carers Victoria will provide you and your carer advice, information and support to improve your health and wellbeing, capacity and financial security.

Freecall 1800 242 636

(Within Victoria from local phones, mobile calls at mobile rates)

Level 1

37 Albert Street

or

PO Box 2204

Footscray

Victoria 3011

T 03 9396 9500

E [reception@carersvictoria.com.au](mailto:reception@carersvictoria.com.au)

F 03 9396 9555

TTY 03 9396 9587

[www.carersvictoria.org.au](http://www.carersvictoria.org.au)

### CareSearch

CareSearch is an online resource designed to help those needing relevant and trustworthy information and resources about palliative care. There are sections designed specifically for health professionals and others for patients, for carers, and for family and friends.

E [caresearch@flinders.edu.au](mailto:caresearch@flinders.edu.au)

[www.caresearch.com.au](http://www.caresearch.com.au)

T 08 7221 8233

### Cancer Council Victoria

You can call the Cancer Council Helpline (13 11 20) from anywhere in Victoria to talk with one of their experienced and understanding cancer nurses.

They can provide you with reliable information and practical advice on any type or stage of cancer and they can link you to a range of support services.

615 St Kilda Road

Melbourne VIC 3004

T 03 9514 6100

E [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)

F 03 9514 6800

Support 13 11 20

[www.cancervic.org.au](http://www.cancervic.org.au)

### Advance Care Planning Australia

What is advance care planning?

Advance care planning enables you to discuss and decide on your choice of medical care and have your cultural and spiritual needs be included.

This will assist you to make the right choices and decisions for you and help you communicate your wishes of your journey. It can also assist your partner, carer and family to make the right decisions for you.

For further information on advance care planning, yarn with your local GP, Aboriginal health service, Aboriginal Health Worker or Aboriginal Hospital Liaison Officer. They will be able to assist

in linking you in, gathering the information you require and assist you with the process.

Find forms and fact sheets for your State or Territory.

T 1300 208 582

[www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

## Abbreviations

**ACCHO** Aboriginal community controlled health organisation

**ACCO** Aboriginal community controlled organisation

**AHW** Aboriginal Health Worker

**GP** General practitioner

**HACC** Home and community care

**PCN** Palliative care nurse

**PCS** Palliative care service

## Names and numbers

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*PCN:*

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*GP:*

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*Emergency: 000*

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## The beginning of our journey

As you twirl a piece of ribbon you don't know which way it will turn, and this also applies to the changing paths and journeys we take in our lives.

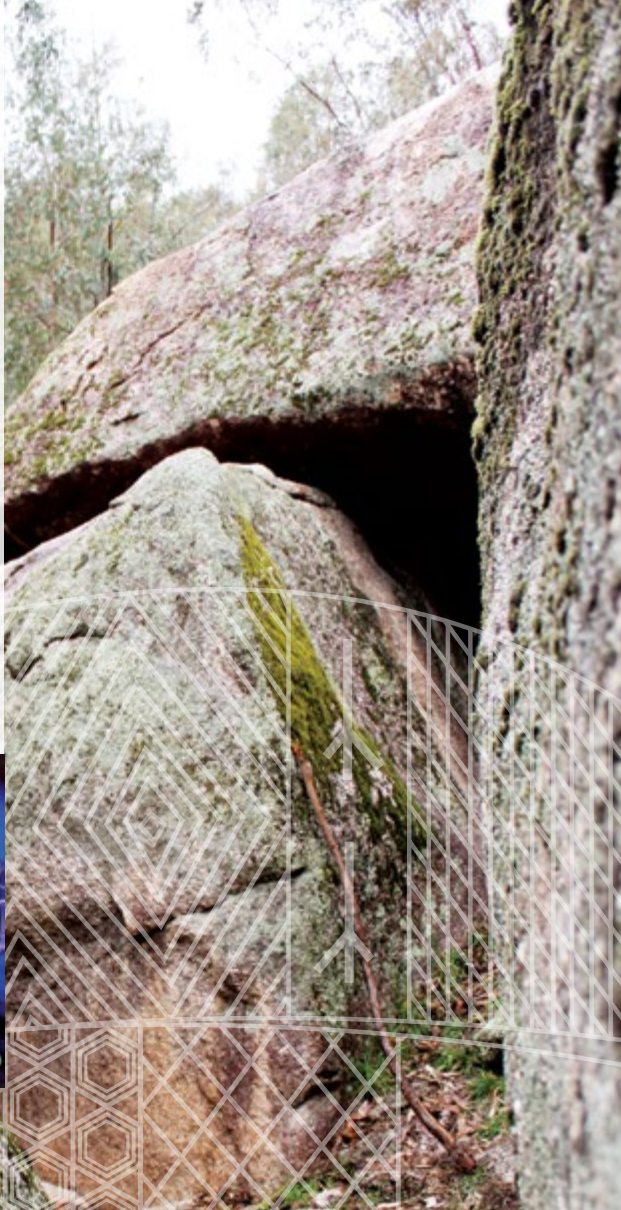
A path travelled together is easier to walk than the path travelled alone. The people in my work symbolise the endless support of our family, friends, community and services ensuring Aboriginal people walk together.

The circles speak of the many people who have travelled in and out of our lives, they too taking the same path into our journey of the Dreaming. All the while our ancestors and family (represented by the auras) guide us there.

### Artist

Kahli Luttrell

Yorta Yorta descendent



# Understanding the palliative care journey

## A guide for individuals, carers, communities and family

### Image credits

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