

# My Palliative Care TOOLKIT



Practical tips for  
your journey through  
palliative care

Victorian Palliative Care Advice Service

Call 1800 360 000 from 7am - 10pm, every day of the year

**My local Palliative Care Team is available on:**

# All are welcome

Language is a powerful tool that shapes our understanding of the world and our relationships with others. Inclusive language fosters a sense of belonging, respect, and dignity by acknowledging diverse identities, experiences, and perspectives. The words we choose can either build bridges or create barriers, making it essential to use language that affirms and welcomes all individuals. Thoughtful communication helps prevent exclusion, stereotypes, and misunderstandings. By embracing inclusive language, we create environments where people feel seen, heard, and valued, ultimately strengthening social cohesion and mutual respect.

The LGBTIQ+ acronym used in this toolkit stands for lesbian, gay, bisexual, transgender, innate variations in sex characteristics (intersex), queer/questioning and asexual. The term “queer” has a negative history for many older Australians; however, this acronym is used in line with Victorian Government language guidelines.

We acknowledge Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders both past and present. *Source: VACCHO.*

Please advise your care team if you need support with translation into your language.

## With thanks and document legacy

The inaugural toolkit was an initiative of Palliative Care Services at Barwon Health, with financial support from the Hospice Foundation Geelong and the City of Greater Geelong. It was a local project fully supported and informed by the community. Palliative Care Victoria, recognising the success of the document, and with Barwon Health's permission, has developed it into a resource for use across Victoria.

# Welcome to My Palliative Care Toolkit

## This is not your “typical” medical document.

This is a resource for you to use when the timing is right for you.

Everyone has a different experience of palliative care, and therefore, this resource has been designed for you to dip in and out of when you are ready.

You can keep the information you write in this toolkit for yourself – or you can use it as a way to share information with your loved ones and care team.



## PALLIATIVE CARE

What is Palliative Care?	2
Where is Palliative Care?	3
Who is Palliative Care?	4



## ALL ABOUT ME

My Emergency Contacts	5
My Important People & My Story	6
My Identity & My Body	7
My Home & My Safety	8
My Care Team	9
My Appointments	10
My Symptom Tracker	12



## GATHERING SUPPORT

Practical Support	16
Community Support	17
Volunteer Support	18
Emotional Support	19



## GETTING ORGANISED

Where to Start	21
My Accounts/Documents	22
What Does “Quality of Life” and “Good Death” Mean to Me?	24



## END-OF-LIFE PLANNING

Preparing My Documents	27
Preparing for a Funeral or Celebration	28



## TIME FOR ME

Things I'd like to Do or Try	30
Journal	31



Additional Resources	35
----------------------	----

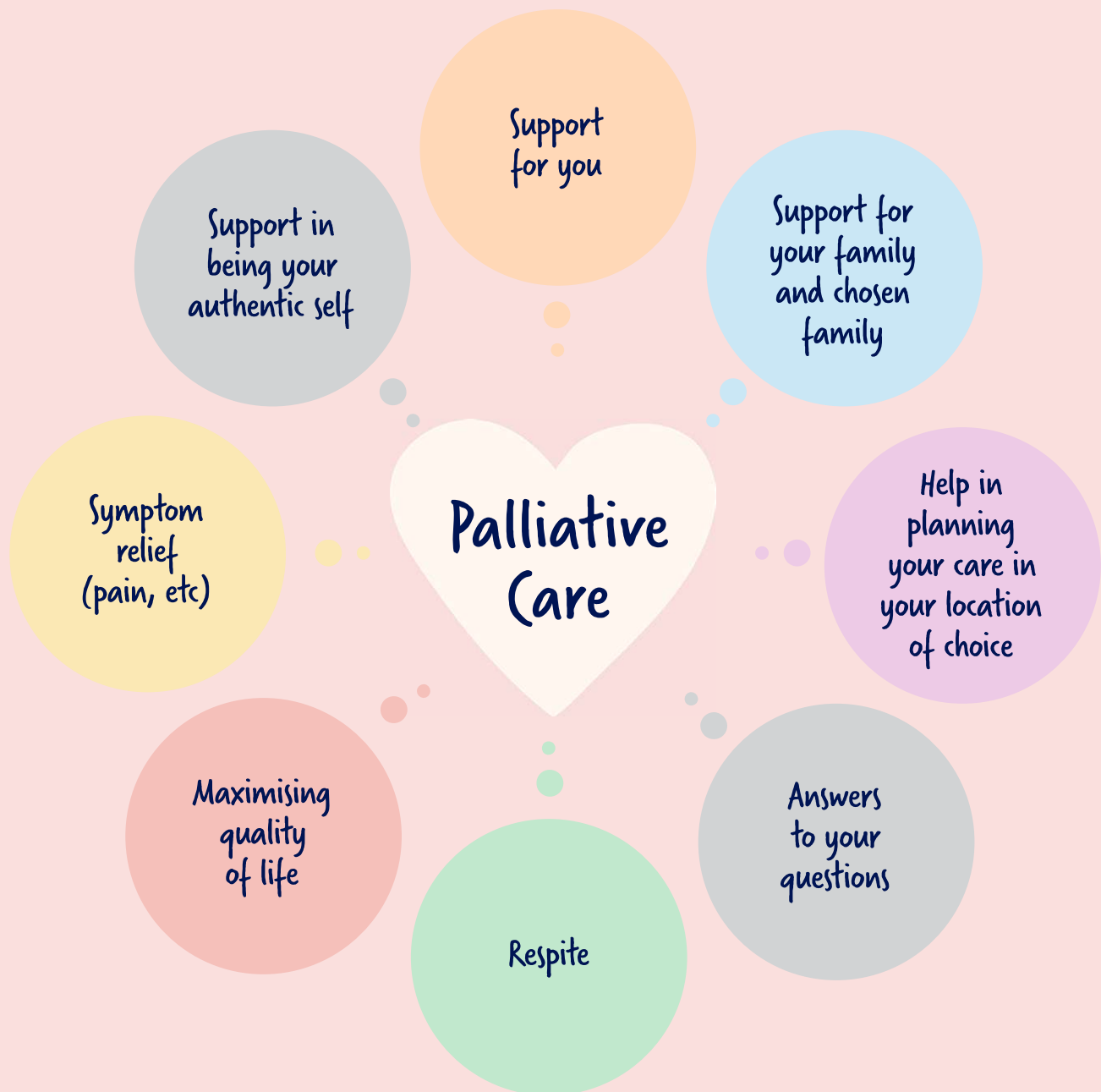


Extra Pages	36
-------------	----



## What is Palliative Care?

Palliative care aims to support people living with a terminal diagnosis. The care focuses on supporting the person who has the illness as well as their loved ones. Palliative care focuses on the person's quality of life.



This is just an overview of Palliative Care. Your care team will provide more information and can answer your questions.



# PALLIATIVE CARE

## Where is Palliative Care?

Your care team can explain all of your options for where to receive your care. They can also help you think about where you would like to die.

Home



Palliative  
Care Unit



Hospital



Your local  
palliative care team





## Who is Palliative Care?

### My care team



Some of the more specialised supports might be provided via referral to other services, with your consent.



You may also consider using complementary therapies, but it is **very** important to consult across your team, so everyone knows what medications, treatments and/or supplements you are taking.



# ALL ABOUT ME

## My Emergency Contacts

This document recognises that “family” can take many shapes and forms – including biological family, chosen family, kin, friends, pets, etc. You have the power to define your family and important people throughout this document.

Name:

Pronouns:

Relationship:

Phone #:

Name:

Pronouns:

Relationship:

Phone #:

Name:

Pronouns:

Relationship:

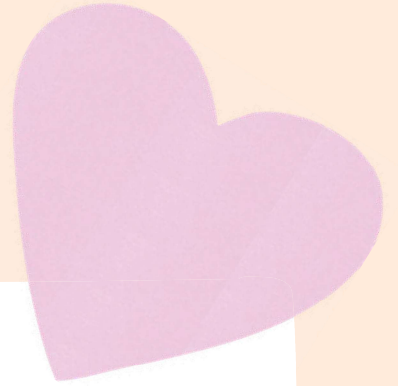
Phone #:



## ALL ABOUT ME

# My Important People & My Story

This space has been left blank for you to write about the important people (and pets) in your life - and important parts of your story that you might like to share with your care team.

A large, white, rounded rectangular area intended for writing, set against a light orange background. The bottom edge of this area is decorated with a dashed orange line that extends across the width of the page.

Throughout this toolkit, the term “care team” is used. This is intended to include everyone providing your care, including palliative care staff and volunteers, community nurses, your doctors and specialists, and anyone else with a caring role.



## My Identity & My Body

This page is to help you consider what information you'd like to share with your care team. You can also share this page with your team if it helps make the conversation easier.

Name I would like my care team to use:

My pronouns:

My LGBTQIA+ identity:

Preferences for who provides my personal care/wound care:

Preferences or limitations around what information I'd like the team to record:

What I'd like my care team to know about my body  
(including trans identity/ innate variations of sex characteristics/other):



## My Home & My Safety

This page is to help you prepare for your care team to visit your home. What would you like them to know?

Who else lives at my home:

Pets:

Parking:

Access to home/property:

other useful information:



## My Care Team

**My local Palliative Care team is available on:**

Extra blank pages are available at the end of this toolkit if needed.

*My Medical Decision Maker:*

*My GP:*

*My Specialist(s):*

*My Pharmacy:*



## My Appointments

Keeping track of my appointments.

Extra blank pages available at the end of this toolkit if needed.

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:



# ALL ABOUT ME

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:

Date:

Time:

Details:











## Practical Support

Family and friends often ask "How can I help?" — sometimes this is the hardest question to answer, but it is important for you and those helping with your care. Having ideas in mind can be really helpful. Here are common things that can be really helpful practical supports:

### Food delivery

Types/amounts/allergies/brand preferences/etc:

### Pharmacy delivery

Address, etc:

### Washing clothes/linens

### Help with gardening

- Mowing the lawn
- Watering
- Weeding
- Pruning
- Harvesting fruit/veg

### Pet care

- Exercise
- Sleepovers
- Bathing
- Vet visits

### Other practical ideas

- Taking out the bins
- Washing windows
- Washing dishes
- Vacuuming

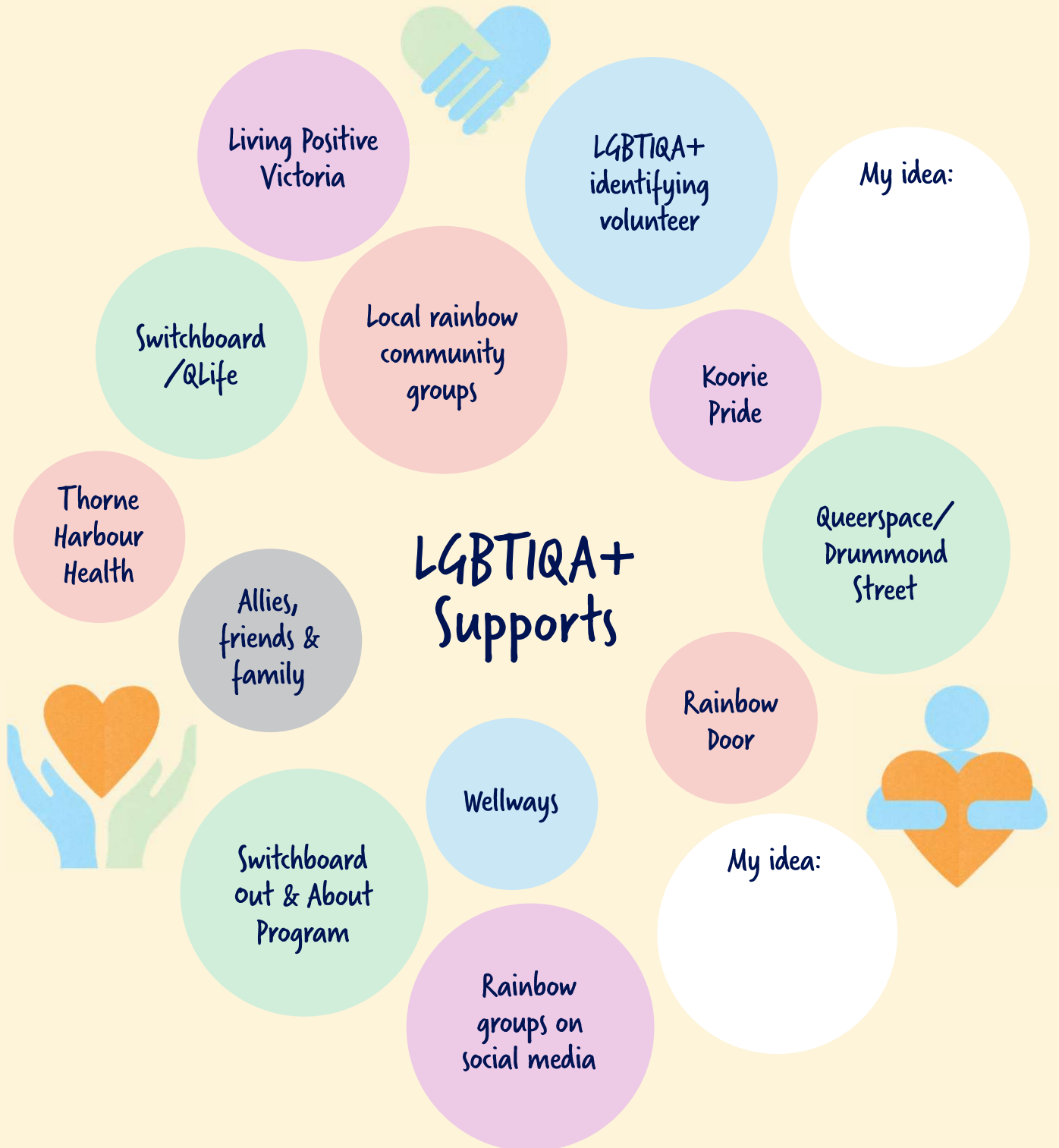


Accepting offers of support can be hard – particularly if you have always valued your independence and privacy. Managing a serious illness can take its toll – on the person with the illness, but also on their closest loved ones. Accepting small offers of help not only makes family and friends feel useful but can also provide some respite for full-time carers.

However, it is always OK to say “no thanks, not today” if you aren’t up to it. Some people have found it helpful to hang a sign on the door to advise others on whether or not they are up for a visit.



## Community Support



For more information about these LGBTIQA+ supports use the titles above to start a web-search.



## Volunteer Support

There are a wide variety of volunteers who have a great deal of skills and experiences. They can support you at a time and place that best suits you.



To request volunteer support, start by talking with your Palliative Care team, or search online for palliative care volunteers in your area.



## Emotional Support

This page provides an opportunity to consider what you might find useful around your emotional needs.

Here are some tips to help you come up with ideas.



Spend time in the bush



Light a candle



Allow space for your feelings



Spend time on the beach



Put on your favourite music

### Some ideas to try



Visit a favourite place



Try an art activity



Talk with a loved one



Allow space for quiet



Go on a gentle walk



Do some light gardening



Get a massage



# GATHERING SUPPORT

My idea(s):

My idea(s):

My idea(s):

My idea(s):

My idea(s):

My idea(s):



Counselling support is available through your palliative care team.



## Where to start

It might feel like there are a lot of things to organise. These are some tips that you might find helpful.

Hang up a whiteboard

Use this toolkit – including extra pages at the end

Download GatherMyCrew app

Download an organiser app

Ask friends & family for help

Get help from your local IT whiz, or a tech savvy volunteer, to set up support on your mobile phone or home computer

Do you have tips for other people?  
Please share your ideas with us!



## My Accounts/Documents

We now live in a world where we have a lot of documents, accounts, and passwords. This page is to encourage you to consider which trusted person/persons have access to this information on your behalf.



**We do not recommend writing down account numbers and passwords in this book.**

Bank:

Superannuation:

Email account(s):

Utilities:



# GETTING ORGANISED



**We do not recommend writing down account numbers and passwords in this book.**

*Home/property:*

*Will and/or Advance Care Plan:*

*Social media account(s):*

*Insurance policies:*

- Home
- Car
- Health



## GETTING ORGANISED

# What does "Quality of life" & "A good death" mean for me?

These pages are for you to reflect on what is important for you.

Preparing a will

Being independent for as long as possible

Having my care team understand my gender identity and / or sexuality

Being cared for in my place of choice

Access to fresh air

Being informed about my illness

Reducing stress for my loved ones

Leaving a legacy

Prepare an Advance Care Directive

Being connected with friends & family



You can circle the ones that are important, cross out the ones that aren't, add your own notes, or use them as prompts for conversations with your care team or loved ones.



# GETTING ORGANISED

Listening to my favourite music

Re-connecting with estranged people

Connecting with LGBTQIA+ Community

Saying goodbye to loved ones

Finding comfort and closure in accepting past estrangements

Having my pets with me

Considering what "quality of life" means for me

Pain management

Planning my own funeral or celebration

Making sure my loved ones are cared for

Having my gender identity, sexuality and/or loved ones acknowledged after my death

My idea:

My idea:

Not being alone



# GETTING ORGANISED

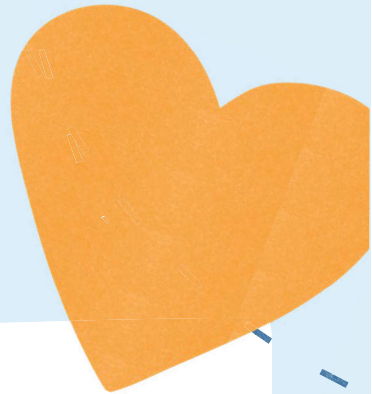
Completing a bucket list:

My ideas:



## Preparing My Documents

Discussions about death and dying are difficult and are often emotional. Acknowledging this, it is important to consider and act on the below as early as possible because it is much harder to do when it becomes urgent or when your loved ones are grieving.



### Support person

#### What is it?

You can identify a “support person” who is able to access your medical information and speak with your care team. They are not legal decision makers – but are there to provide you with support with receiving information from your team and considering decisions.

#### Who can help me?

- **Your Palliative Care team**

### Advance Care Directive

#### What is it?

A document that helps you consider what is important to you based on your values and wishes. It is also a legally binding document that captures what care you do - and do not - want.

#### Who can help me?

- **Your Palliative Care team**
- Your GP
- Your lawyer
- Web-search for ‘advance care planning’

### Medical Treatment Decision Maker

#### What is it?

This is a legal document that allows you to appoint a trusted person to ensure your medical goals are followed if you reach a point when you can no longer make your own decisions.

#### Who can I appoint?

This is entirely your choice. You get to choose the person you trust.

#### What is their responsibility?

This person is legally responsible for carrying out what you have documented in your Advance Care Plan.

#### Who can help me?

- **Your Palliative Care team**
- Your GP
- Your lawyer
- Web-search for ‘medical treatment decision maker in Victoria’

### Legal Will

#### What is it?

A will is a legal document that determines what will happen to all of your valuable items after your death, including but not limited to: your money, possessions/property, pets, and items of sentimental value.

#### Who can help me?

- **A lawyer**
- **State Trustees (in partnership with the Victorian State Government):**  
Phone: **1300 138 672**
- **Do it yourself with a Legal Will Kit:**  
Visit: [statetrustees.com.au/wills/do-it-yourself-with-a-will-kit](http://statetrustees.com.au/wills/do-it-yourself-with-a-will-kit)
- **Legal Aid:**  
Visit: [legaid.vic.gov.au/wills-and-estates](http://legaid.vic.gov.au/wills-and-estates)



## Preparing a Funeral or Celebration

If you are keen to plan your own funeral or celebration of life, it's good to know that there is no one-size-fits-all approach. Here are a few things to consider.

What do I want?

What do my loved ones want?

What is my budget?

Which funeral director matches what I'm looking for?



# END-OF-LIFE PLANNING

## Funeral specifics:

- location
- who is invited?
- who is not invited?
- readings
- music
- rituals
- stories to be told (or not told) at my funeral
- others?

## What location would I prefer?

- Return to Country
- funeral home
- natural setting (beach, etc)
- place of worship
- home
- pub
- other!

## What support(s) do I want for my loved ones?

## Would I like to have a "living wake" before I die?



It is also OK if you do not want a funeral.

There is no legal requirement to have a funeral and there are low-cost/low-key options becoming more available. The important thing is to make sure your people know your preferences.

This page can help you share your wishes with your loved ones.



## Things I'd like to do or try

This page is to help you brainstorm what you'd like to try or do!



Visit somewhere special



Write a letter to a loved one



Have a special meal



Go to a concert



Go to an event



Try something new



Spend time with animals



Spend time with loved ones

Blank space for brainstorming ideas.

Blank space for brainstorming ideas.

Blank space for brainstorming ideas.

Blank space for brainstorming ideas.

Blank space for brainstorming ideas.

Blank space for brainstorming ideas.



If you need support with coming up with an idea or carrying out an idea it is highly likely many people around you would jump at the opportunity, or you could request support from a trained palliative care volunteer.











## ADDITIONAL RESOURCES

This resource list is limited. That's on purpose. Listed alphabetically below are some well-known and regarded sources to get you started. By including websites only, we've aimed to increase the likelihood that the information remains current over time. Services change, phone numbers change – websites are usually the most up-to-date place to start.

**Grief Australia** – leading voice on grief and bereavement, providing evidence-informed counselling, training, and research.

 [grief.org.au](http://grief.org.au)

**Intersex Peer Support Australia** – an intersex peer support, information and advocacy group for people born with variations in sex characteristics and their families.

 [isupport.org.au](http://isupport.org.au)

**Koorie Pride** – building visibility, strength and connection for Aboriginal and/or Torres Strait Islander LGBTIQAS&B+ people across Victoria.

 [koriepridevic.org.au](http://koriepridevic.org.au)

**Living Positive Victoria** – representing all people living with HIV in Victoria and committed to the advancement of human rights and wellbeing of all people living with HIV.

 [livingpositivevictoria.org.au](http://livingpositivevictoria.org.au)

**Queerspace** – for community, by community. Counselling. Case management. Advocacy. Research. Training. Professional development. Consultancy.

 [queerspace.org.au](http://queerspace.org.au)

**Palliative Care Victoria** – the peak body for palliative care and end of life care in Victoria.

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

**Switchboard** – peer driven, support service for the lesbian, gay, bisexual, transgender and gender diverse, intersex, queer, asexual (LGBTIQ+) communities and their allies, friends, support workers and families.

 [switchboard.org.au](http://switchboard.org.au)

**Thorne Harbour Health** – providing a range of services which include prevention education, treatment and care of LGBTIQ+ and people living with HIV (PLHIV).

 [thorneharbour.org](http://thorneharbour.org)

**Transgender Victoria** – Victoria's leading body for transgender, gender diverse and non-binary (TGD) people.

 [tgv.org.au](http://tgv.org.au)

**Victorian Palliative Care Advice Service** – immediate palliative or end-of-life advice and support for clinicians and the community.

 [pcas.org.au](http://pcas.org.au)

**Victorian Pride Centre** – modern centre providing meeting space for LGBTQ+ groups, plus community services and advocacy.

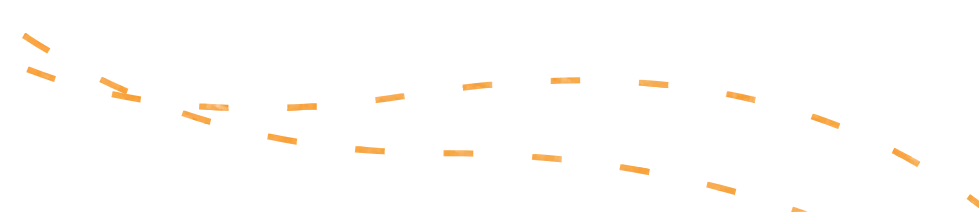
 [pridecentre.org.au](http://pridecentre.org.au)

**Wellways** – one of Australia's largest and most respected mental health, wellbeing and carer service providers.

 [wellways.org](http://wellways.org)

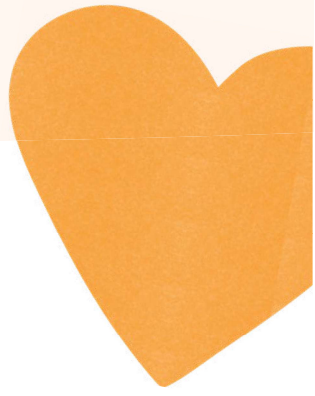


## EXTRA PAGES





# EXTRA PAGES



**This document has been designed  
with and for members of the  
LGBTIQA+ community.**

Feedback on the use and/or  
content of this toolkit is welcome.

Contact Palliative Care Victoria on  
03 9662 9644 or [info@pallcarevic.asn.au](mailto:info@pallcarevic.asn.au)



**Palliative Care  
Victoria**  
*Living, dying & grieving well*

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