# My Palliative Care TOOLKIT













Practical tips for your journey through palliative care

The Palliative Care Team is available 24 hours on (03) 4215 5700







We, Barwon Health,
acknowledge the Traditional
Owners of the land, the
Wadawurrung people of the Kulin
Nation. We pay our respects to the
Elders past, present and emerging.





The Barwon Health Palliative Care Program is committed to supporting all people in the LGBTIQA+ community\*.



# All are welcome

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



Please advise your team if you need support to access any part of the Palliative Care Program.





### With thanks

Barwon Health Palliative Care wishes to extend thanks to everyone involved in the development and production of this resource, including:

- City of Greater Geelong for financial support through the Healthy & Connected Communities Grant scheme.
- Hospice Foundation Geelong for financial support of the LGBTIQA+ Project Officer role. hospicefoundationgeelong.org.au
- Local LGBTIQA+ Consumer Advisors for sharing their lived experience and co-designing this resource.
- Palliative Care Australia for use of content from their "Dying to Talk" discussion cards.



\* The LGBTIQA+acronym used in this toolkit stands for lesbian, gay, bisexual, transgender, intersex, gueer/questioning and asexual.

### Welcome to My Palliative Care Toolkit

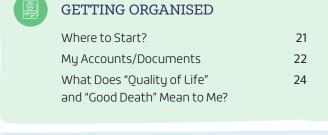
### This is not your "typical" medical document.

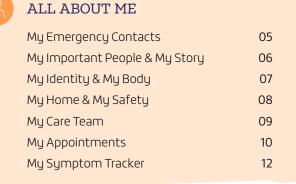
This is a resource for you to use when the timing is right for you.

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.

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Extra Pages



**Most importantly** – support is available. Ring **(03) 4215 5700** at any time if you need to speak to a member of the team.

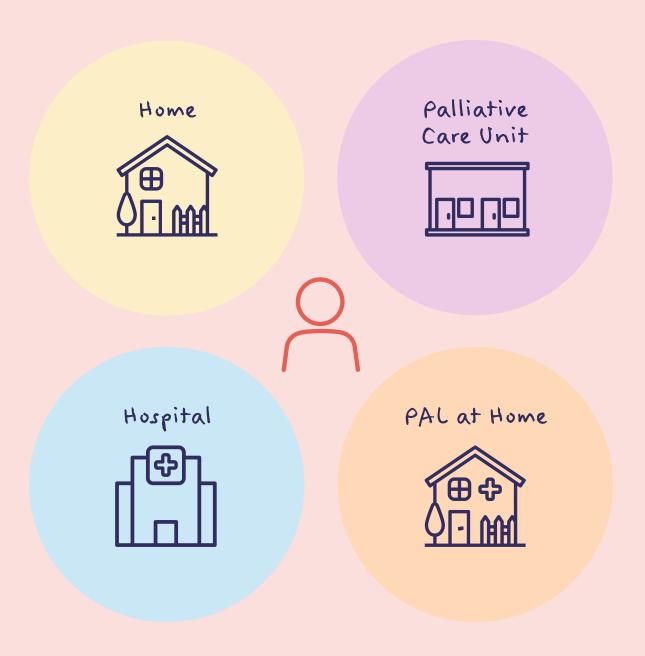
If you live outside the area supported by Barwon Health, contact Palliative Care Victoria to find your closest service: **(03)** 9662 9644 or pallcarevic.asn.au

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### 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.



### 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 quality of life.

Support for you Support in Support for being your your family authentic and chosen solf family Help in Palliative Symptom planning relief your care in Care (pain, etc) your location of choice Maximising Answers quality to your of life questions Respite





### Who is Palliative Care?

### My care team





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



# Emergency Contacts

This document recognises that "family" can take many shapes and forms – including biological family, chosen family, 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 #:



# 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.



**Note:** 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 LGBTIQA+ identity:	
Preferences for who provides my personal care	/wound care:
Preferences or limitations around what inform	nation I'd like the team to record:
What I'd like my care team to know about mu	
(including trans identity/intersex variation,	/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:
rang.
Access to home/property:



# My Care Team

#### BARWON HEALTH PALLIATIVE CARE TEAM: (03) 4215 5700 (24 HOURS)

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 tool kit if needed.

Date:	Date:
Time:	Time:
Details:	Details:
Date:	Date:
Date.	Date.
Time:	Time:
Details:	Details:
Date:	Date:
Time:	Time:
Details:	Details:



Date:	Date:
Time:	Time:
Details:	Details:
Date:	Date:
Time:	Time:
Details:	Details:
Date:	Date:
Time:	Time:
Details:	Details:



# My Symptom Tracker

Some people find if helpful to track their symptoms and feelings – either for their own knowledge or to share with their care team. As a starting point, this toolkit provides you with the ability to track things for four weeks.

Week I		0	1	2	3	4	5	6	7	8	9	10
Sunday	Pain Nausea Breathlessness or fatigue Emotions	<u></u>	-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0		-0 -0 -0	
Monday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		<u> </u>	O	<u> </u>	_	_	-0 -0 -0			
Tuesday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>	-0- -0- -0-					-0 -0 -0 -0	-0 -0 -0 -0			
Wednesday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		<u> </u>	_	<u> </u>	_	-0- -0- -0-				
Thursday	Pain Nausea Breathlessness or fatigue Emotions	_		<del></del> 0	———	<del></del> 0	-0- -0- -0-	<del>-</del>	-0- -0- -0-			
Friday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>			0							
saturday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>			-0- -0- -0-				-0- -0- -0-			





If your symptoms are changing in a way that is causing you concern, call your care team on (03) 4215 5700.

Week 2		0	1			4	5		7	8	9	10
Sunday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		_			-0 -0 -0 -0		-0 -0 -0 -0	-0 -0 -0 -0	-0 -0 -0 -0	
Monday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		_ <u></u>		O_						—
Tuesday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>										— — — —
Wednesday	Pain Nausea Breathlessness or fatigue Emotions	O—		O	<u> </u>	<u> </u>		<u> </u>	_			—
Thursday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		_ <u></u> _								
Friday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		0	0	0	-0- -0- -0-					
saturday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		-0 -0 -0 -0								



# My Symptom Tracker

Week 3		0	1				5		7	8	9	10
sunday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>					-0 -0 -0					— — — — —
Monday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>			O	O_	<u> </u>					_
Tuesday	Pain Nausea Breathlessness or fatigue Emotions	O—	—O—		O			<u> </u>	O_			—○ —○ —○
Wednesday	Pain Nausea Breathlessness or fatigue Emotions	O—	—0—					<u> </u>				—○ —○ —○
Thursday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>			O							—○ —○ —○
Friday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		_	_	_						— — — —
saturday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>	-0- -0- -0-	-0- -0- -0-			-0- -0- -0-					—○ —○ —○

Week 4		0	1	_			5			8	9	10
sunday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>					-0 -0 -0 -0					—
Monday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>			O	O_			_			_
Tuesday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>					0					
Wednesday	Pain Nausea Breathlessness or fatigue Emotions	0—		—0—								—
Thursday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>	<del>_</del>									—○ —○ —○
Friday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>		_	_	_		_	$\overline{}$	$\circ$		— — — —
saturday	Pain Nausea Breathlessness or fatigue Emotions	<u> </u>					-0- -0- -0-	-0- -0- -0-				—

### Practical Support

Family and friends often ask "How can I help?" – sometimes this is the hardest question to answer. Having ideas in mind can be really helpful. Here are common things that can be really helpful practical supports:

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,	0. 0		

Types/amounts/allergies/brand preferences/etc:

### Pharmacy delivery

Address, etc:

### Washing clothes/linens

Help with gardening

#### Pet care

#### Other practical ideas

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

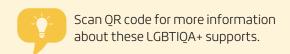


Another important tip is that it is OK to say "no" to offers of support if you aren't up for it.

Some people have found it helpful to hang a sign on the door to advise others as to whether or not they are up for a visit

# Community Support



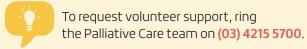




### Volunteer Support

Barwon Health has 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.





## Emotional Support

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

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



spend time in the bush



spend time on the beach



Allow space for your feelings



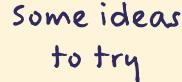
Light a candle



Put on your favourite music



Visit a favourite place





Talk with a loved one





Allow space for quiet



Try an art activity



Goona gentle walk

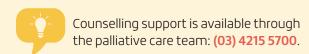


Do some light gardening



Get a massage

My idea(s):	My idea(s):
My idea(s):	My idea(s):
My idea(s):	My idea(s):



### Where to start

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

> Use this toolkit including extra pages at the end

Download GatherMyCrew app

Hang up a whiteboard

Ask for a Barwon
Health volunteer to
visit and help set up some
organisational systems.
Ring (03) 4215 5700

Download an organiser app

Ask friends & family for help

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.

Bank:
Superannuation:
Email account(s):
Utilities:

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

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

# 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 / orsexuality

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.

Listening to my favourite music

Re-connecting with estranged people

Connecting with LGBTIQA+ 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

My idea:

My idea:

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

Not being alone

Special thanks to Palliative Care Australia for use of some of these questions from their "Dying to Talk" resources. Additional questions were developed by LGBTIQA+ community members.

Completing a bucket list:	
My ideas:	

# Preparing My Documents

#### 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:

Phone: (03) 4215 5700

• Barwon Health's Advance Care Planning Team:

Phone: 1300 715 673

Email: acp.program@barwonhealth.org.au Visit: barwonhealth.org.au/servicesdepartments/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:

Phone: (03) 4215 5700

### 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:

Phone: (03) 4215 5700

### 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-youselfwith-a-will-kit

• Legal Aid:

Visit: legalaid.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?

### Funeral specifics:

- location
- who is invited?
- who is not invited?
- readings
- music

- rituals
- stories to be told (or <u>not</u> 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. 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!





If you need support with coming up with an idea or carrying out an idea you can request support from a volunteer on **(03) 4215 5700**.



Journal	 When you journal, consider writing freely without worrying about spelling or grammar. Also, consider using drawings or symbols to express your ideas.



Journal



Journal



Journal

#### Koorie Pride

kooriepridevic.org.au

### Living Positive Victoria

livingpositivevictoria.org.au

### Queerspace / drummond street



(03) 9663 6733

queerspace.org.au

#### Rainbow Door



1800 729 367



0480 017 246 (text)



switchboard.org.au/rainbow-door

### switchboard out & About Program



1800 729 367

switchboard.org.au/lgbtiolderpeople

### Switchboard QLIFE



1800 184 527



switchboard.org.au/qlife

#### Thorne Harbour Health



(03) 9865 6700



thorneharbour.org

### Wellways



1300 111 400



wellways.org







#### WISE reviewed

This document has been reviewed by consumers to ensure it is **W**ritten **I**nformation **S**imply **E**xplained.

