



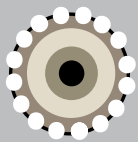
**Palliative Care**  
Australia  
*Matters of life and death*

Aboriginal and Torres Strait Islander  
**Discussion Starter**  
**WORKING OUT WHAT'S RIGHT FOR YOU**

## The artwork featured on the front and back cover is *'Dying to Talk'* by Allan Sumner.

*"Dying to Talk"* is a story about one's journey over the course of their life. It is a reflection of the patient's memories, their loved ones and everything that is important to the patient at this particular time in their life. It conveys a story of the patient's journey through life and everything that they have done and achieved.

It shows significant dwelling places of the patient, perhaps places of friends, family, cultural sites and even health services. Many people create their own journeys and experience many things over the course their lives and so this artwork is a true reflection of a person's life.

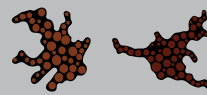


### Dwelling place of the palliative care patient

This symbol represents the dwelling place of the palliative care patient. It is situated in the middle of the artwork to show that it is an important place, a place they may call home and a place of comfort. The patient is also depicted in the middle to acknowledge patient-centred care.

### Journey lines & dwelling places

The journey lines and dwelling places are all connected to the patient. Depicted in the middle of the artwork It is the patient's journey over their life time. The journey lines and dwelling places show the patient's familiar paths in life. These are the places they may have visited or even lived.

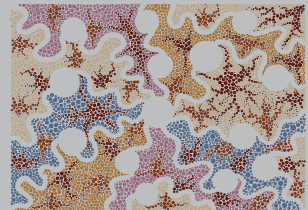


### Life experiences

These circles represent the many life experiences of a patient in different places. These experiences are memories. As patients come to the end of their journey these memories become even more important. Sharing these memories and celebrating one's journey can bring comfort to the patient, their families and friends.

### Land, lakes & sea

The blue dots represent the rivers, lakes and sea. The beige, light orange and purple dots represent the land. These are all places of significance.



### Allan Sumner

Born in 1975, Allan Sumner is a descendent of the Ngarrindjeri people who come from the Lower Murray and the lakes of the Murray River along the Coorong of South Australia. He is also descendent of the Kaurna people from the Adelaide Plains and the Yankunytjatjara people from Central Australia.

# Let's talk

## What would happen if you were very sick?

If you become so sick that you couldn't talk, your family and health worker may need to make decisions for you.

Talking about how this would make you feel and what you want in advance will make their decisions easier and less stressful.

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## What's involved?

### 1: Thinking about you and your family

Think about what is and isn't important to you and your family.

### 2: Thinking about your health care

Think about where you want or don't want to be cared for, who you want and don't want to care for you and the things you do and don't want.

### 3: Preparing your discussion

Prepare for talking with your family, a friend or your health worker.

### 4: Reviewing your discussion

Think about how your talk went. What went well and what didn't go so well?

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## What's next?

We have included some other planning activities that may support you and your family.

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# 1. Thinking about you and your family

What is important to you? What is important to your family?

How can you help your family make decisions?



**What are some of the things you value most in life?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

**What brings you joy and happiness?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

**Are there any cultural and family traditions that are important to you?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>



If you were very sick, how do you think your family would cope?  
*Put a mark on the line to show your answer.*

○ — ○ — ○ — ○ — ○ — ○ — ○ — ○ — ○ — ○  
Family would be able to cope Family would not be able to cope

**If you were very sick, what things would you and your family get strength from?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

**Are there any fears you have about the end of your life?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

**What would you like to do before you die? Are there any places you would like to visit or people you would like to see?**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>



## 2. Think about your health care

What care would you want?

Who would you want to care for you and where?

Is there anything you wouldn't want?



**If you were very sick, how much would you like to know about your illness?**

*Put a mark on the line to show your preference.*

  
As much as possible Only basic information

**How much would you like your family to know about your illness?**

*Put a mark on the line to show your preference.*

  
As much as possible Only basic information

**Is there anyone you want to know as much as possible?**

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**Is there anyone you don't want information given to?**

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**Where would you prefer to be while you need care?**

- |   |  |
|---|--|
| <input type="checkbox"/> At home              | <input type="checkbox"/> In a hospice  |
| <input type="checkbox"/> In an aged care home | <input type="checkbox"/> In a hospital |

Somewhere else:

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**How important to you is this preference?**

Not important Very important

**Would you prefer to be buried or cremated?**

Buried  Cremated  Other *Write below*

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**How important to you is this preference?**

Not important Very important

**Is there a particular location you would prefer for your burial or ashes?**

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**How important to you is this preference?**

Not important Very important

**Is there a particular location you would prefer for your funeral?**

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**How important to you is this preference?**

Not important Very important





For these questions, put a mark on each line to show your preference.

If you were sick and you were not going to get better...

**Would you want a quiet space with a few people, or lots of noise and people?**

—  —  —  —  —  —  —  —  —

Quiet space with a few people Lots of noise and people

**Would you want all available treatments for your illness even if they might make you feel sicker, or to be comfortable?**

—  —  —  —  —  —  —  —  —

Available treatments Comfort

**How important is it to you to visit country?**

—  —  —  —  —  —  —  —  —

Not important Very important

**How important is it for you to be on country when you die?**

—  —  —  —  —  —  —  —  —

Not important Very important

**How important is it to you to be buried or cremated on country?**

—  —  —  —  —  —  —  —  —

Not important Very important

**How important is it to you that your organs are donated?**

—  —  —  —  —  —  —  —  —

Not important Very important

**Is there anything else that is important to you?**

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### 3. Preparing to talk

Who do you want to talk to?

Who would you prefer to make decisions for you?

What do you want to share?



You can talk to as many people as you like. Think about the people who you want to make decisions for you.

**Who do you want to talk to?**

_____	_____
_____	_____
_____	_____

**What do you want to share?**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_



Talk when you feel ready. If you set yourself a target day, it might encourage you.

**Target day:**

\_\_\_\_\_



## 4. Reviewing your talk

How did your talk go?

Did you share what you wanted to?

What else do you need to do?



**How do you think your talk went?**

Not good Great

**Is there anything that you didn't talk about? What else do you want to share?**

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**Is there anyone else you want to talk to?**

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If you have no success talking to your chosen person after a few attempts, you might need to consider talking to someone else.



## What's next?

How do you make sure your wishes are known?

What can you prepare?

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### Learn more about palliative care

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. Palliative care is for people of all ages who have a serious illness that cannot be cured and provides support and care that focuses on your quality of life and living well. Palliative care is based on your individual needs and may include:

- pain and symptom management
- emotional, social, spiritual and cultural concerns
- the supply of equipment and other aids
- links to other services, such as respite care, home care and financial support
- counselling and grief support
- assistance for carers and families.

Palliative care can be provided at home, in hospital, in a hospice or in residential aged care. You might like to consider where you would like to be cared for, and what that care might look like.


Talk to your health worker, or visit [palliativecare.org.au/what-is-palliative-care/](http://palliativecare.org.au/what-is-palliative-care/) to find out more.

### Document your wishes in an Advance Care Plan

Writing down your wishes can help your family and health worker make sure you receive the care you want. You want to be sure that your family know what you want and don't want if they ever need to make decisions for you.

An Advance Care Plan (ACP) or an Advance Care Directive (ACD) outlines your wishes. You can discuss these with your health worker and write a plan. You can then upload your ACP or ACD to your 'My Health Record' to make sure it's available when it's needed.

Talk to your health worker or visit [myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/acp](http://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/acp) to find out more.



## Identify your decision maker

It is important to identify your decision maker, especially if your chosen person is not your legally recognised next-of-kin. You want to be sure that your family and health worker can legally identify someone as your decision maker.

Talk to your health worker, or visit [palliativecare.org.au/advance-care-planning](https://palliativecare.org.au/advance-care-planning) to find out more.

## Organise your Legal Will

A Will is a legal document that communicates what you want to happen to your assets as well as items of cultural and sentimental value, your children and pets when you die. If you don't have a Will, or you haven't reviewed it recently, speak to your health worker or solicitor.

Visit [moneysmart.gov.au/life-events-and-you/over-55s/wills-and-power-of-attorney](https://moneysmart.gov.au/life-events-and-you/over-55s/wills-and-power-of-attorney) to find out more.

## Organise your Emotional Will

Although not a legal document, an Emotional Will provides a way for you to share your thoughts, values, hopes and dreams with your family and future generations to come.

You can share as much or as little as you want. An Emotional Will can be a supportive tool for your family, as it can protect them culturally and emotionally. You might like to include your funeral plans, where and how you want to be buried, and what you hope for your family's future.

## Register as an organ and tissue donor

People who need an organ or tissue transplant are usually sick because an organ is failing. As an organ donor, you can save the lives of up to 8 people.

Aboriginal and Torres Strait Islanders on the transplant waiting list get less transplants than others due to other cultural groups not matching well. Aboriginal and Torres Strait Islanders are more likely to be a match for each other.

If you want to be an organ and tissue donor, you should register and let your family know.

Visit [donatelife.gov.au/decide](https://donatelife.gov.au/decide) to register and find out more.



## Plan your social media

If you use social media, have you thought about what you want to happen to your accounts when you die? It is important to share your wishes about social media with your family as each platform has its own rules about what your family can do with your accounts.

Visit [bit.ly/pca-socialmedia](https://bit.ly/pca-socialmedia) to find out more.

## Plan your funeral

If you can plan your funeral, it might reduce arguments and stress at a time that will be difficult for your family. You may even want to pre-pay for your funeral, or keep a savings account to cover costs.

You might talk to your family about where you want your funeral to be, who you want to be there and the speakers and music. You might also talk about what you don't want.

## Let a trusted person know where they can find things

Let a trusted person know where to find your important documents in case they need them. They may be stored in a physical location, on a computer, online or with your solicitor.



## **Disclaimer**

Palliative Care Australia (PCA) thanks The Conversation Project and the Institute for Healthcare Improvement in Boston, MA, USA. Their Conversation Starter Kit is in many ways the inspiration for this resource.

Any resource provided by PCA for the purpose of the 'Dying to Talk Campaign' is strictly informative and should not be considered as legal advice or legally binding. None of the resources provided by PCA for the purpose of the 'Dying to Talk Campaign' should be considered as a substitute for the prescribed or recommended 'Advance Care Plan' forms of each State or Territory. PCA makes every effort to ensure the quality of information provided however will not be liable for any loss or damage suffered by any person arising in connection with any information provided. All information provided is general in nature.

For additional information relating to advance care planning, please speak to your health professional for advice about your specific circumstances, including the legislative requirements in your State or Territory, or visit the Advance Care Planning Australia website [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au) or call the advisory service on 1300 208 582, 9am - 5pm (AEST) Monday to Friday.



Palliative Care Australia gives thanks to the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), Australian Indigenous Doctors' Association (AIDA), Indigenous Allied Health Australia (IAHA) and all others involved in the project for their support, advice and contributions to the Aboriginal and Torres Strait Islander Discussion Starter.







**Palliative Care  
Australia**  
*Matters of life and death*



**CATSINaM**  
Congress of Aboriginal and Torres  
Strait Islander Nurses and Midwives  
*Unity and Strength through Caring*