

KBHAC

Dillybag

Support and decision making for sickness and end of life care

KBHAC



KINCHELA BOYS HOME
ABORIGINAL CORPORATION



Acknowledgement

Kinchela Boys Home was built on the stolen land of the Dunghutti. We would like to acknowledge the Dunghutti and other First Nations people of this country whose boys were kidnapped under the policies that created the Stolen Generations.

The Dillybag

The resources and tools contained in this Care Alert Dillybag have been created for the KBHAC community to use to plan and manage their health, wellbeing, wishes and legacy related to end of life.

Statement of support for this work at this time

This is a time of great importance for survivors of Kinchela Boys Home, as the last remaining generations are ageing and approaching end of life. We have responsibility to support our uncles and descendants as they transition from this world to the next.

We pay our respects to survivors and descendants of Kinchela Boys Home who have passed and thank the Uncles who have shared so openly their wishes for their own end of life planning and guided the development of this tool.

This booklet is intended to support one of the most important times in life and to ease pain and suffering that so many of the Kinchela Boys Home community has experienced throughout their lives due to policies created under the Stolen Generations.

My Care Alert Dilly

Support Tool and Conversation Guide

Purpose of the conversation guide:

This conversation guide was developed for KBHAC staff and descendants to facilitate the completion of important end-of-life care documents with Uncles / Aunts. This is important because it means those around Uncles and Aunts know what they want and don't want if there is a health emergency or when the time comes.

There are a number of support tools included in this dilly bag. Some can be used to make decisions if an uncle, aunt or descendent is unwell, others are important documents to follow end of life wishes. There is also information around caring for yourself and others when there is sorry business.

Preparation:

It is important that whoever is supporting the completion of documents are prepared and confident in asking the questions. The questions are sensitive and difficult but are important to ask. Stress and conflict can arise in families and communities without clearly knowing and documenting what Uncles and Aunts want and do not want when it comes to their end of life.

Under each stage or document are instructions on what to say and how to complete the Care Alert Dilly Bag and documents. *The suggestions in ITALICS are examples of what to say.*

1) Preparation for the sensitive nature of the yarns

Facilitating these conversations can be difficult and emotionally draining. It is important to take your time and spread the conversations out so you don't drain yourself too much or the person you are supporting.

Take a break between each conversation and ground yourself. You may need some time to reflect on the conversation, you can share with colleagues any thing you are learning about the process as a way to improve it.

There are a number of important documents in this dillybag. **Take time to read them and get familiar with them.** You can slowly start completing them with an Uncle, Aunt or descendent or they may choose to complete the documents on their own.

Phrases you can use to prepare and start the process of documenting and completing the documents:

Uncle / Aunt there are some important documents in this dillybag that can make sure your wishes are followed if you get sick and can't get better. Can I show you some of them?

Is it ok if we start filling out one of them?

I'm going to ask you a few questions that are a bit sensitive but it's important to have this yarn. We don't know what will happen to any of us today or tomorrow so it's important we know what you want and don't want when the time of end of life comes.

We can stop and pick up the yarn another time if gets too much, just let me know.

I'm going to have to write some things down, I'll then check it with you again.

You can change anything in your wishes down the track or any time.

Can I sit with you next week and we can fill out some more?

2) Care Alert Dilly Bag

Show Uncle / Aunt the Care Alert Dilly Bag. This is an A3 plastic envelope with magnets on the back. The purpose of this Dilly Bag is for it to live on Uncle / Aunts' fridge. It holds important information like:

- Emergency contact details
- What medications/treatment plan Uncle / Aunt is on
- End of Life Wishes document
- Completed Advanced Care Directive
- Any other health information

Explain to Uncle / Aunt that you will start asking questions related to documents that will live in the Dilly Bag. If there is an emergency people can take the Dilly Bag and know what Uncle / Aunts wishes are and who to contact and what current medications they are on

3) End of Life Wishes document

This will take about 30 - 40 minutes to complete.

Start working through the questions and write down responses.

If Uncle / Aunt needs a break that's ok, or if they don't know an answer tell them you can come back to it later.

4) Advanced Care Directive

An Advanced Care Directive is an important health document. It needs to be signed by a doctor which KBHAC will organise. It then is kept on a health file so if you end up in hospital people can know what you want to happen.

I'm going to ask some difficult questions, but they are important. We need to know what you would want doctors to do if you were seriously unwell.

Note for facilitator: this document needs to be witnessed when it is signed by Uncle / Aunt and then a doctor needs to go through the answers with Uncle / Aunt. The doctor will sign and lodge the form.

5) Care Companion

The Care Companion is a document that Uncle, Aunt or KBHAC descendent can take with them to their doctor or specialist if they have been told they are very sick.

The Care Companion is about making decisions together on what treatment and support the person with the illness wants. You can help Uncle, Aunt or KBHAC descendant complete the first section of the document before they go see their doctor. They can keep this document with them to help in their journey of making choices and support.

6) Important information document

This document can be completed by a KBHAC staff member over the phone with Uncle / Aunt or family member. It asks questions about:

- Emergency contact/s details
- Uncle / Aunts doctor
- Current health conditions
- Medications
- Other important information

7) KBHAC Loss and Grief Support and Self Care Guide

The KBHAC Loss and Grief Support and Self Care Guide has been developed to support staff and the KBHAC community in caring for others and themselves when it comes to sorry business.

8) KBHAC Template for Crisis Coordination

This is an interactive tool that KBHAC staff can use to coordinate support for KBHAC community member

9) Fact sheets

There are a range of factsheets around burials and pricing related to funerals as support information.

KBHAC Care Alert Dillybag

Important Information

Please complete

My name is:	
Contact	Details
Please contact this person / people in case of emergency	<ul style="list-style-type: none">• Full name• Relationship to you• Phone Number
My doctor is	<ul style="list-style-type: none">• Full name• Phone Number
Other healthcare providers I use are	<ul style="list-style-type: none">• Full name• Phone Number
The medications I am currently on are	<ul style="list-style-type: none">• Name of medication, dosage and how often you take it
My current health conditions are	<ul style="list-style-type: none">• Any illnesses or conditions?
I am allergic to	<ul style="list-style-type: none">• Any allergies?
I am currently on the following treatment plan	<ul style="list-style-type: none">• Treatment plan info goes here
Other important information	<ul style="list-style-type: none">• Anything else you think might be relevant goes here



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End of Life Wishes

Participant Name's end of life wishes

Date: Day / Month / Year

- () Will (completed / not yet completed)
- () Enduring guardian (appointed / not yet appointed)
- () Enduring Power of Attorney (completed / not yet completed)
- () Advance Care Directive (completed / not yet completed)
- () Do not resuscitate directive (completed / not yet completed)

The following is an example of a 'personal' plan (This is not a legal document but an example of a **PLAN**). You may also choose to use the Dying to Talk discussion guide found here:

This is the death plan of (insert name of person)

I wish (*insert name/s*) to be responsible, if possible, for carrying out the wishes contained in this plan, to enable me to have the death that is my preference. (*Note, this person could be a close family member or friend with whom you have discussed your death plan and who has agreed to take on the responsibility of carrying out the wishes contained in your plan*).

I wish to die at: (insert where you would like to die if possible. e.g. home, hospital, somewhere else?)

- This is who I would like to be with me when I die if possible:
- The people that I'd want near me are (insert name/s of people):
- The people I do not want around me when I am dying or at my funeral are (insert names of any people that do you not want around you, if any): Everyone is allowed to come to my funeral
- Familiar objects I would like to see around me (Note: perhaps photographs of close relations, friends, or places that hold special memories for you. Favourite objects you would like nearby, such as a journal and pens, radio). Add here:
- What I wish to hear (insert names of favourite songs, bands, radio stations etc). Add here:

- Hymns or other readings I would like delivered at my funeral: (Note - thinking of the solace and pleasure particular pieces of music, hymns, poems and readings have given you during your life. If you would like any particular people to read anything specific.) Add here:
- What I want to smell: (Note- thinking of scented lotions or flowers, to create a special space for yourself and those who are close to you). Add here:
- What I might like to taste: (Note - enjoying some favourite foods and beverages as you can manage, in final weeks and days). Add here:
- What I want to feel: (Note- perhaps you would really like to be gently held, and touched and would appreciate some massage for comfort and connection during your last weeks and days): Add here:
- Do you have any concerns about when the time comes and you are dying? What are they? (we can help address these as best as we can). Add here:

(Note - that your hair be kept tidy, and eyes and mouth care frequently attended.

- After my death I would like to be dressed in:
- My choice of funeral venue:
- My preference is for burial or cremation:
- Where would you like to be buried? Has this been organised? If not are there any contact details you have for the place of choice?
- My favourite music to be played at the funeral:
If we ever meet again I'll leave this world loving you
- Are there any particular pictures or videos you would like shared?
- My chosen speakers are:

What words of wisdom do you have for your children and grandchildren? *Insert here:*

Example of what your wishes for your death are below. Please write your own or feel free to change this as you wish.

My wish is for a peaceful death, free of anxiety or worry. I wish to ensure that everything has been attended to before my death including my will, advance care directive and enduring power of attorney. The location of important documents including bank accounts, insurance and property deeds will be noted. After my death any accounts and affairs will be managed by (insert name/s) are the executors of the will. My plan is to discuss this with my family and closest friends, with the intention to attend to this soon.

Name:

Signature: Date:

End of Life Support

Key questions to ask to support and advocate for the dying person

Atul Gawande recommends asking the patient these four questions:

1. What is your understanding of what is happening now?
2. What are your fears, worries and goals?
3. What outcomes are unacceptable/acceptable to you?
4. Is there anything you want me to do for you right now?

Factsheet: What to expect when someone is dying

Introduction: Family members look to a doctor and nurse to help them know what to expect when a loved one is dying. No matter the underlying causes, there is a common final path that most people take as part of the dying process.

To start this conversation, you could try saying: ***Many people like to know what may happen so they will be prepared, would you like to know too?*** If they say yes, describe the features on this list and answer their questions.

1. **Social Withdrawal** is normal for the dying as the person becomes less concerned about his or her surroundings.

Separation begins first from the world—no more interest in television, then from people – no more neighbours visiting, and finally from the children, grandchildren and perhaps even those persons most loved.

With this withdrawal comes less of a need to communicate with others, even with close family.



2. **Food:** The dying person will have a decreased need for food and drink as the body is preparing to die.

This is one of the hardest things for some family to accept. There is less interest in eating and appetite—even for their favourite foods.

The patient is not starving to death—this is a normal process of the body starting to slow and then shut down. Liquids are preferred to solids—follow the patient’s lead and do not force feed.



3. **Sleep:** The patient will spend more and more time sleeping; it may be difficult for them to keep their eyes open.

This is because of a change in the body’s metabolism as a result of the disease.

Tell family to spend more time with the patient during those times when he/she is most awake.



4. **Disorientation:** The patient may become confused about time, place, and the identity of people around him/her.

He/she may see people who no one else can see, such as family members who have already died. While the patient may not be distressed, it might be distressing to family or health professionals.

Gently bring the person back to their surrounds if he or she asks. There is no need to ‘correct’ the person if they are not distressed.



5. **Restlessness:** The dying person may become restless and pull at the bed sheets. These symptoms are also a change in the body's metabolism.

Talk calmly with the person so you don't frighten them. If the person is a danger to themselves or others, the doctor may prescribe sedating drugs to help the patient rest.



6. **Decreased Senses:** Hearing and vision may decrease. Soft lights in the room are often best. Never assume that the person can't hear you, as hearing is the last of the five senses to be lost.



7. **Incontinence of urine and bowel movements:** can commence in the months, weeks, and days before death.

If appropriate, some family members may want to participate in direct personal care. Some people may not want family or friends to assist with personal care.

The nurse can help place absorbent pads under the patient for more comfort and cleanliness, or a urinary catheter may be used.

The amount of urine will decrease, and the urine become darker as death becomes near.



8. Physical Changes as death approaches:



- Blood pressure decreases; the pulse may increase or decrease.
- Body temperature can go up and down; fever is common.
- Increase in sweat.
- Skin color changes: flushed with fever, bluish with cold. A pale yellowish colour (not to be confused with jaundice) often accompanies approaching death.
- Breathing changes. Breaths may increase, decrease or become irregular; periods of no breathing (apnea) are common.
- Congestion may happen as a rattling sound in the lungs and/or upper throat. This happens because the patient is too weak to clear the throat or cough. It does not distress the person, but the sound can distress the family. Raising the head of bed and swabbing the mouth with water give comfort and give the family something to do.
- The arms and legs may become cool to the touch. The hands and feet become purplish. The knees, ankles and elbows are blotchy. These symptoms are a result of decreased circulation.
- The person will often be unconscious before death and not respond to touch or sound.

9. How to Know Death has Occurred



- No breathing and heartbeat.
- Loss of control of bowel or bladder.
- No response to verbal commands or gentle shaking.
- Eyelids slightly open; eyes fixed on a certain spot.
- Jaw relaxed and mouth slightly open.

Acknowledgement: This Factsheet was adapted with permission from a family information handout (The 'Blue Sheet') given to families of San Diego Hospice & Palliative Care Program.

References

1. Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. Oxford Textbook of Palliative Medicine. 2nd ed. Oxford, England: Oxford University Press; 1998.
2. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *BMJ*. 2003; 326(7379):30-4.
3. Ferris FD, von Gunten CF, Emanuel LL. Competency in End of Life Care: the last hours of living. *J Palliat Med*. 2003; 6(4):605-613.

My Care Companion

Decision Aid

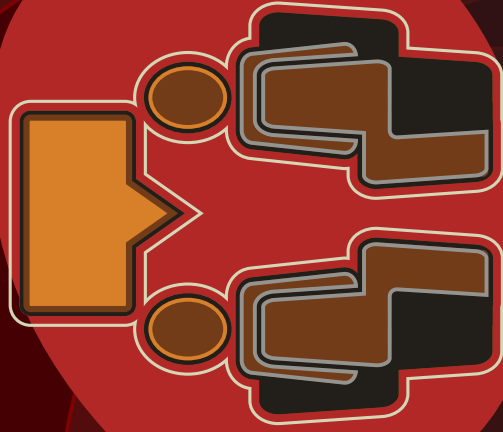
Belonging to _____



Supporting you to have honest conversations and make decisions about treatment and care

Your Care Companion is a tool for shared decision making – helping you, your healthcare team and those close to you explore treatment and care options to make decisions that support your values

It will support you to have conversations about...

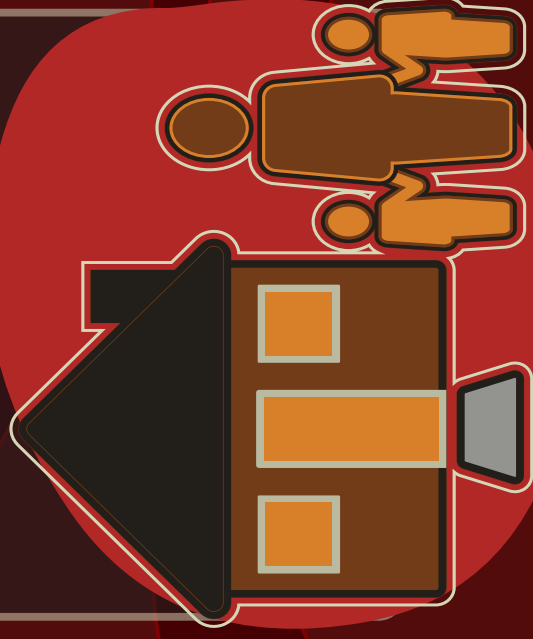


truth telling

do you want to know about your current health condition and what might happen in the future?

values & preferences

what matters to you and how will this influence your decision making?





decision making

what specific decision(s) do you need to make about your treatment and care?

next steps

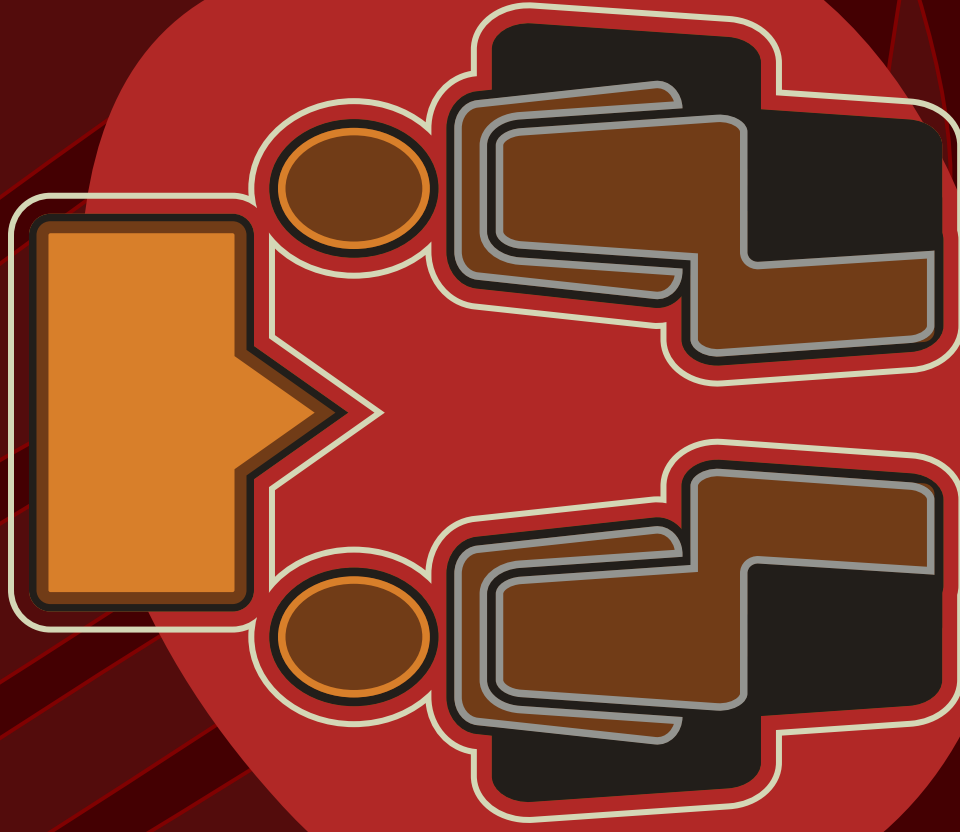
do you need any extra information or support?



truth telling

do you want to know about your current health condition and what might happen in the future?

have this conversation with your doctor or most qualified healthcare professional



I had this conversation with:

Date:

what do you want to know?

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A Life-limiting condition (or illness) is one that will shorten a person's life, though they may continue to live active lives for many years.

completed by **you**

I want to know about my current health condition

I want to know if this condition could limit my life

I want to have a say about my treatment and care

I want to know what might happen with my condition in the future

completed by your **doctor**

What is your patient's current health condition?

Is this a life-limiting condition? In what way?

What decision(s) needs to be made now?

What decision(s) might need to be made in the future?

values & preferences

what matters to you and how will this influence your decision making?

complete this section on your own

OR

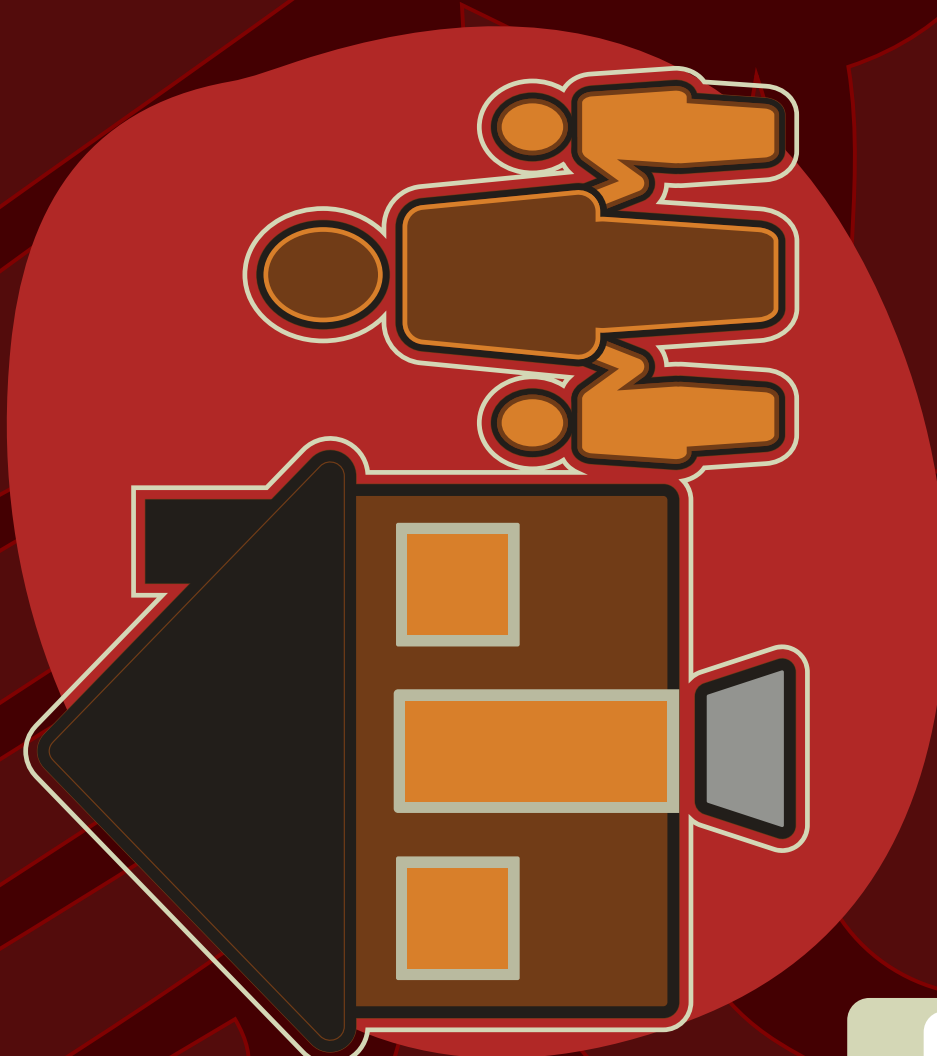
have this conversation with your doctor or most qualified healthcare professional

OR

have this conversation with your carers, family or trusted friend

I had this conversation with:

Date:



completed by **you**

Values

What does **quality of life** mean to you?

What 3 things are currently most important to you in life?

1

2

3

How might these things influence you when making decisions about your treatment and care?

Preferences

When making decisions about your treatment and care, is there anyone you would want to have with you?

- ? On my own Carers Family Elders ?
- ? Close friends Health professionals ?

What role do you want to play in making these decisions?

- I want someone else ? to drive the process I want help from those closest to me ?
- ? I want to have full control ?

Is there anything else we can do to support you in making these decisions?

- ? I want the information written down ?
- ? I need things explained in plain language
- I want time to consider my options

decision making

what specific decision(s) do you need to make about your treatment and care?

have this conversation with your doctor or most qualified healthcare professional



The decision we need to make is:

I had this conversation with:

Date:

completed by **your doctor**

Option 1

benefits
risks



Option 2

benefits
risks



Option 3

Managing Symptoms

benefits
risks



completed by **you**

I would recommend option because...

I would choose option because...

next steps

do you need any extra information or support?

have this conversation with
your doctor or most qualified
healthcare professional

I had this conversation with:

Date:



completed by **you**

knowledge _____

Do you know the benefits and risks of each option?

YES NO

If you answered NO, what additional questions do you have?

values _____

Are you clear about which benefits and risks matter most to you?

YES NO

If NO, revisit the **Values & Preferences** and/or **Decision Making** sections, focusing on your needs

support _____

Do you have enough support and advice to make a choice?

YES NO

If you answered NO, would you like to meet with any other person or healthcare professional?

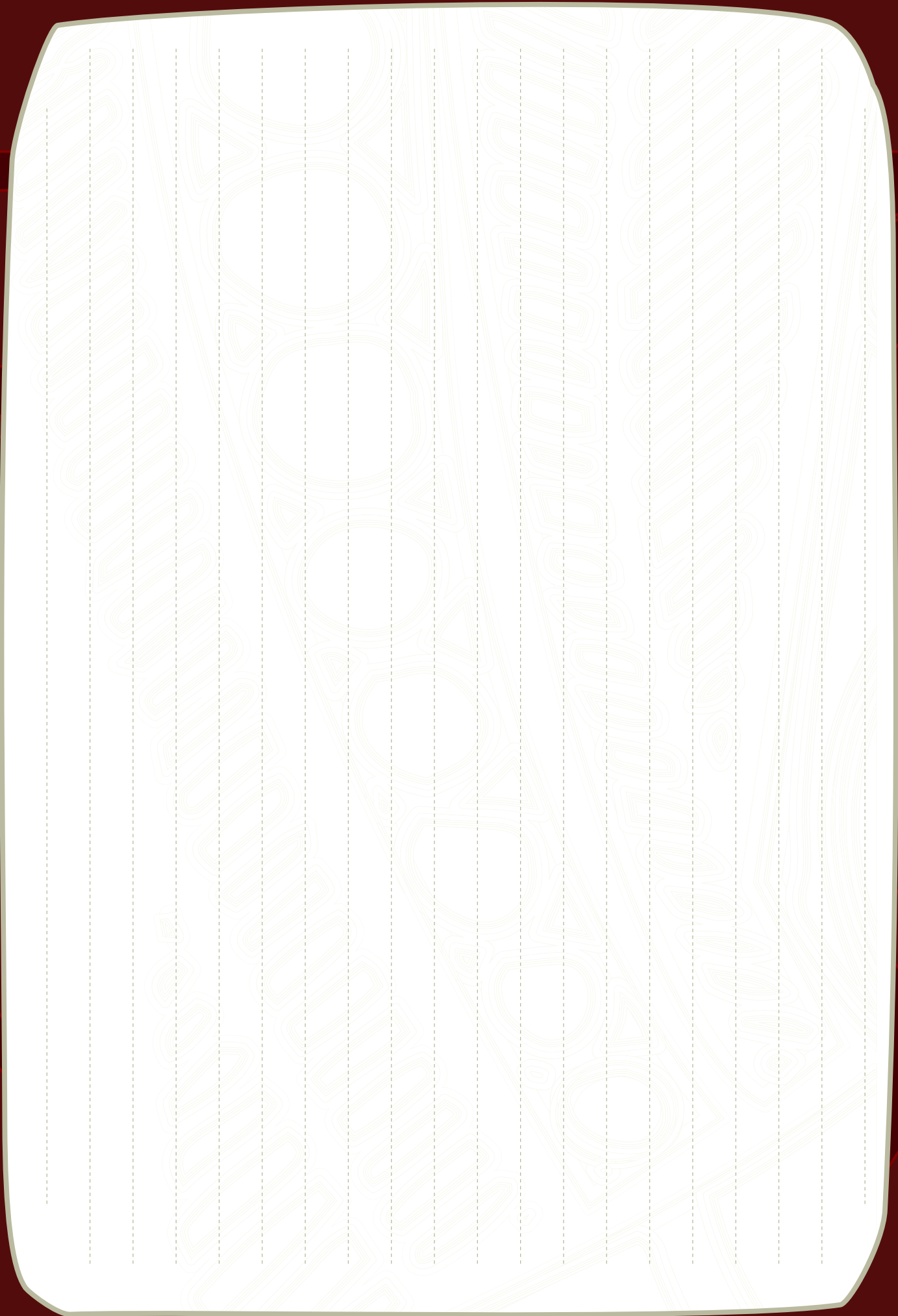
certainty _____

Do you feel sure about the best choice for you?

YES NO

If NO, revisit the **Decision Making** and/or **Next Steps** sections, focusing on your needs

Notes



Your Care Companion is yours to keep.

If you let KBHAC know and they can help you:

Carry it with you when having future conversations with your carers, family, trusted friends or healthcare team

If your situation has changed or you have another decision to make:

you can ask for a new booklet or add pages to this one

If you have made a decision about treatment or care:

Are there any other documents that need to be updated?



KBHAC Template For Crisis Support Coordination

Name:

Description of situation:

Location where support/s are needed:

How many people need support?

What are the supports that are needed (go through examples of support that can be provided)

Brainstorm who can provide this support.

List names and locations of people – make sure to get phone numbers / email addresses

Neighbours

Family (who and where are they located)

Friends (who and where are they located)

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Paid services (NDIS etc)

Carers NSW

Carer Gateway

Examples of support to discuss with those requiring support to help identify what they need are below:

Medical

Attend appointments

Help organise records

Help change dressings

Bring in meals (inpatient)

Attend medical treatment

Manage medication

Collect script from pharmacy

Check to see if Uncle / descendent has My Care Alert Dilly Bag and if key documents have been completed

Food

Help with online order

Grocery shopping

Bake lunch snacks

Meals

Make school lunches

Drop off bread and milk

Transport

Lift to medical appointment

Lift to meeting

Lift to provide company – social gathering

Lift for shopping

Lift to run errands

Home

Change bed linen

Manage outdoor bins (put bins in and out)

Take rubbish out

Clean floors

Tidy the house

Mow lawn

Clean bathroom/s

General gardening

Laundry

Pets

Exercise pet

Feed pet

Pet sitting

Pet sleepovers

Other assistance

Manage updates with family and friends

Manage social media

Pay bills

Fill car with petrol (or organise fuel voucher)

Collect and sort mail

Disaster emergency assistance (fire / flood etc)

Coordinate communication with family and friends

Pay bills

Fill car with petrol (or organise fuel voucher)

Record damages for insurance purposes (floods / fires)

Help me find temporary storage

Find a temporary place to stay

Help clean up after emergency / disaster

Drop off snacks for clean up helpers

Drop off food that does not require refrigeration

Drop off bottled water

Organise medical appointments

Organise medications

Sorry Business

Manage updates with family and friends

Manage social media

Pay bills

Organise go fund me funeral fund if required

Ageing

Complete My Aged Care Registration

Organise home care assessment

(things to coordinate and support with while waiting for home care assessment to go through)

Take carer out (respite)

Tips on how to offer support:

- ▶ If they are socially isolated – offer a visit for a cup of tea
- ▶ If they need medical care – offer to take them to an appointment
- ▶ If they have young kids – suggest a playdate or go look after them for a while so they can get some rest
- ▶ If they have live next door – take their weekly bins out
- ▶ If you are a close friend or supporter – offer to do their laundry / change their sheets

Most requests on Gather My Crew are for:

- ▶ Cooking dinner
- ▶ Doing the laundry
- ▶ Come for a visit
- ▶ Drop off lunch snacks
- ▶ Transport to appointments (medical)
- ▶ Drop off / pick up kids from school
- ▶ Walk the dog
- ▶ Make lunchboxes for kids
- ▶ Take carer out

Loss and Grief

Support and Self Care Guide

Grief is a normal reaction when somebody dies, or you lose something or someone important to you. The intense experience is a healthy and natural process.

Grief can have many layers and can be experienced in relation to the loss of a person, or something or someone important to you.

Feelings

There is no right way to feel. This is a list of some common feelings. You may feel some or all of these, or other feelings.

Shock Denial Self Blame

Guilt Anxiety Confusion

Sadness Relief Anger Regret

Abandonment Despair

Body

It is normal for your body to respond to grief and loss. It is important to take good care of yourself and understand that grief affects the body and mind.

Exhaustion Headaches Nausea

Weight loss or gain Changes to sleep patterns

Changes to eating, feeling hungry / not feeling hungry

Body aches If you are sick, you may feel worse

Suicidal thoughts

Thoughts of suicide can occur when experiencing grief and loss. This is a serious indicator of an overwhelming level of distress. It is important to gain professional help and have strategies in place.

If you have lost someone from suicide, you may be vulnerable to suicidal thoughts. The suicide call-back service is a useful service after death from suicide. Suicide Call Back Service – 1300 659 If you need urgent assistance you can call emergency 000 for assistance.

Grief and Aboriginal people

Aboriginal people experience grief in relation to many areas of their lives. A current death can bring up deep and complicated feelings about previous losses. These losses can include the loss of family or friends and historical losses such as country, language, community or traditions.

When a death occurs this can raise a range of complicated feelings that may be related to other experiences of loss and grief. Acknowledging that grief as an Aboriginal person has many layers and additional complexities is important. For example, it is important to acknowledge the impact of previous and current difficulties that will affect how you grieve. Examples could be the impact of separation from family or feeling worried for loved ones who may be in prison or children who have been removed.

It can help to draw on your spirituality, community, strong family and community relationships, connection to country, and rituals.

Grief Resources that may be helpful

- ▶ <https://healthinonet.ecu.edu.au/learn/health-topics/social-and-emotional-wellbeing/grief-loss-trauma/>
- ▶ <https://grieflink.org.au/factsheets/grief-of-indigenous-people/>
- ▶ <https://www.instagram.com/bipocdeathgriefftalk/?hl=en>

Things to do that can help

Remember grief is a process that takes time.

Be kind to yourself and try to do things that support your physical, mental and spiritual health.

Remember that much of what you might be feeling or thinking is related to grief and loss.

Try to eat well and try to limit caffeine and alcohol.

Try to exercise; even a five-minute walk outside can help.

There is no right or wrong way to grieve. Grief is complex and has many layers.

Taking action can help give your mind and body some relief.

Think of things that feel good for you. It could be:

listening to music

watching your favourite tv show

spending time on country

being with friends or family.

Having a laugh can be an important part of coping with grief.

If you start feeling worse or feel like you can't do everyday things after a few months, it may be time to see your doctor or seek professional help. You can also call 13 YARN for support - 13 92 76.

Viewing the body

There are different thoughts on viewing the body. If a loved one has died seeing, touching and speaking to your loved one can be an important moment at this time. Doing what feels right and supportive of yourself and your physical, mental and spiritual health is the most important thing.

What nourishes your soul / spirit?

It may be good to talk with other community members about your loss. Sharing connections at times of grief and loss is powerful and important.

What spiritual practices support you?

This could include connecting with country, your spirit and ancestors, meditation, if you are religious then connecting with your faith, speaking with someone who shares your spirituality about the loss.

Carers of children

It can be helpful for children to stay close to their loved ones at this time (if it's manageable for you) as children feel most secure with their family and community even if there are difficult times happening.

Substance use

Substances such as alcohol, drugs or food may be sought for comfort, and while they may offer comfort in the short term, there can be longer-term health impacts to be mindful of. Accessing support may help.

What can I do to help?

There is no right or wrong thing to say. The way you can support someone who is experiencing grief and loss can be based on your relationship with the person, and what you know they value for example, some people appreciate just sitting in silence together, others may want a hugs and to hold someone's hand.

Don't assume the person can tell you what they need or want, most likely they don't know themselves.

Practical actions can be important, for example:

Be there (sometimes this is enough)

Tell them you are sorry for their loss and are there to support them, in silence or with practical tasks

Cook a meal, bring some groceries, or help with housework – eg a load of washing

Give the grieving person some time to have a rest. If they have caring responsibilities can you assist with caregiving to give them a break?

Let the person talk and be patient if stories are repeated. It is important to know that when a death is traumatic the grieving person might tell the same story repeatedly as a way of understanding what has occurred.

Listen

Connect with your community and help bring friends/community to the person if that is appropriate.

Acknowledg their experiences are a normal part of grieving

Talk about the person who has died if the grieving person would like to (or it is appropriate to do so), share or listen to stories.

Don't forget your own needs and self-care.

You need to be well to support others.

Be kind to yourself, take breaks, and be mindful of your own needs. Remember your own experiences of grief that may be affected at this time and need your care.

Factsheets: Funeral and Burial

Courtesy of Cemeteries & Crematoria NSW

Pricing and what to expect

There are no set costs for burial, placement of ashes or cremation in NSW. Costs will vary across the state and will be determined by a number of factors.

Funerals

Even a simple funeral will have some basic requirements. It is important to understand what services are provided by a funeral director. General information and guidance about funeral directors are available from NSW Fair Trading (visit: fairtrading.nsw.gov.au and search for 'funeral directors'). Funeral directors must provide information about funeral goods and services as shown in the Funeral Information Standard, available from NSW Fair Trading (visit: fairtrading.nsw.gov.au and search for 'funeral information standard').

Costs and fees

In general, there are no standard fees and charges for burials and cremations, and placement of ashes (interments) in NSW. Costs are set by operators and vary significantly throughout the state. Charges depend on factors including

- location of the cemetery (metropolitan, regional, or rural)
- the choice of interment within a cemetery (e.g., lawn or monumental)
- the choice of memorials.

Interment fees cover a range of activities including administration, recording keeping obligations and site preparation and management (including the opening and closing of a grave). Before entering into a contract or agreement, make sure you receive an itemised quote and that you understand each item. If you are unsure of any items including cost, speak with your funeral director, or cemetery or crematorium operator

This is a stressful time for families and sometimes there can be misunderstandings about which fees have been paid and which are still outstanding. If at any time you are unsure of outstanding expenses, seek clarification from your funeral director, or cemetery or crematorium operator.

Burial costs

There is no standard cost for burial across NSW. Costs can vary between metropolitan and regional areas and between operators. If possible, compare quotes from a few different cemeteries to make an informed choice. There are generally three main parts to burial costs:

- **Interment right fee** – this is a sale fee for the interment right. This fee covers the operator's costs of preparing the site as well as maintaining the site and surrounding area. Some cemetery operators offer ongoing maintenance for an annual fee.
- **Burial fee** – this is a fee for the burial process. This covers the operator's costs of opening and closing a grave and landscaping after the burial. After-hours fees may apply for burials outside of normal business hours, for example burial fees are often higher on Saturdays, Sundays, and public holidays.
- **Memorialisation fee** – this is a sale fee for a memorial (for example a headstone, plaque or other monument or memorial) and generally includes having it inscribed and erected at the site.

Burial costs can be offered in a package, for example some operators offer a package that includes the site, interment fee and memorial. However, the parts of this package should still be clear in the contract.

There can be a range of additional fees on top of the basic costs, for example:

- the cost of using a casket-lifting device
- the cost of bottom sand-filling
- administrative charges
- the cost of grave digging
- the cost for processing an application for memorialisation
- installation of a memorial
- engraving a plaque
- a one-off maintenance fee
- late payment fees
- surcharge for individuals who reside outside the local government area.

Cremation and ash interment costs

As with burial, there is no standard cost for cremations or ash interments across NSW. It can depend on how ashes will be stored and how ashes will be managed (whether scattered or placed in a niche). If possible, compare quotes from a few different cemeteries/crematoria to make an informed choice. Cost can include:

- the cremation,
- ash interment (depending on what is done with the ashes):
 - a niche for the ashes in a garden, columbarium or burial site
 - placement of the ashes
 - a memorial or plaque.

Ashes can be kept in an urn (or similar) by the family or be scattered.

Many crematorium operators also offer a 'no service, no attendance' cremation, which can reduce the cost.

Some cemetery and crematorium operators offer packages, for example a complete package that includes cremation, chapel, single niche, interment, and memorial plaque.

Additional fees may apply for cremations outside of normal business hours, for example fees are often higher on Saturdays, Sundays, and public holidays.

For more information

More information on cost and pricing can be found on the CCNSW website <https://www.cemeteries.nsw.gov.au/community/planning-burial-and-cremation>

It is also worth looking at the websites for cemetery and crematoria operators in your area to see if they have basic pricing available on their website or call them and ask for a quote.

CCNSW understands this is a complicated and multi-faceted process, during a difficult time. If you are unsure about any details, always seek clarification from the operator or funeral director.

Aboriginal cultural and spiritual principles

Please note this is a summary of the licence conditions. For more details read the Interment Industry Scheme information Operators of Cemeteries and Crematoria.

The Aboriginal cultural and spiritual principles were developed through engagement with key Aboriginal stakeholders, CCNSW's Industry Consultation Group, Aboriginal cemetery operators and a survey distributed to Aboriginal peoples through CCNSW's key stakeholders.

These proposed principles are intended to help cemetery and crematoria operators better meet the needs of Aboriginal people when it comes to burial and cremation. They are written to show recognition of, and value and respect, for Aboriginal peoples, cultures, societies, histories, and connection to Country. This includes recognising the diversity within and between Aboriginal peoples and promoting awareness of the unique significance of what is commonly referred to as Sorry Business to Aboriginal people.

It is expected that operators will take reasonable steps to comply with the Aboriginal cultural and spiritual principles. The expected level of compliance will be scaled based on the assigned licence category of an operator.

The principles include:

1. Operators must inform themselves of the Aboriginal communities, including Traditional Owners, in the region in which they operate, and of Aboriginal cultural and spiritual practices and requirements for burial and cremation.

This is an important principle for all cemetery operators, but the actions taken to inform themselves may look different for operators of different sizes. For smaller operators, this could simply involve knowing which Aboriginal lands their cemeteries are located on, and which key local bodies represent those lands. They should also familiarise themselves with the guidelines on Aboriginal burial and cremation requirements which will be published by CCNSW. For medium or large operators, a deeper level of information could be sought –for example finding more out about Aboriginal communities in their area through ABS data analysis, engaging with relevant Local Aboriginal Land Councils and Registered Native Title Body Corporates.

2. Operators must inform themselves of, and record (unless expressly asked not to make a record), any Aboriginal cultural and spiritual requirements in relation to each burial or cremation.

Not every Aboriginal person will have the same requirements for their burial or cremation. Operators are required to ask whether any consumers have Aboriginal cultural or spiritual requirements they would like met in relation to each burial or cremation. This may be through a funeral director or directly with the consumer. Where an Aboriginal consumer doesn't want their requirement to be recorded, this should be respected by the operator.

3. Operators must satisfy requests to meet Aboriginal cultural or spiritual requirements in relation to burial or cremation, where the request is practicable and aligns with all relevant laws, including work health and safety obligations.

This principle makes it clear that operators must meet all Aboriginal culture or spiritual requirements where the request is within the law and complies with work health and safety obligations. While the principle does not include Aboriginal cultural or spiritual requirements which may relate to acquiring a dedicated area of land for Aboriginal peoples or to the erection of structures these requirements should be considered if raised as community needs or grievances in relation to Principle 5.

4. For services provided to satisfy a request to meet Aboriginal cultural and spiritual requirements under Principle 3 (above), the Operators must set out the basis for any charge incurred to meet these requirements (and this must be reflected in the fees and charges itemised in the contract as per A.2.3.v).

This principle means that Operators need to show all charges related to meeting Aboriginal cultural and spiritual requirements and that these charges need to be included in the contract. This principle aims to provide information on the actual costs for Aboriginal requirements relating to the interment, and that the costs be clear and transparent.

5. An Operator commonly providing Aboriginal burials or cremations for Aboriginal communities must, in respect of each community:
 - a) engage with relevant Aboriginal communities about their cultural and spiritual requirements relating to interment, and
 - b) undertake good faith negotiations to accommodate the identified community needs and to resolve any grievance

Where Principle 1 requires operators to have a high-level understanding of local Aboriginal peoples and of Aboriginal requirements in general, Principle 5 requires Operators who commonly provide burials to seek a deeper level of understanding and to engage with local communities about what their specific requirements are. Resolving grievances and accommodating community needs should be done in good faith, which does not mean community requests must always be met or disputes always resolved in favour of the community but sets standards for how operators work with communities.

If requested, the operator must provide the Cemeteries Agency with documents or information outlining steps taken by the operator to comply with Aboriginal Cultural and Spiritual Principles.

Burial without a conventional coffin

Conventional coffins or caskets are commonly used for burials in NSW but there are other options available that can meet cultural requirements or personal preferences.

Options for burial in NSW

A person may have a religious, spiritual, or cultural reason for burial without a coffin, or it may be a personal preference. Regardless of the reason, it is possible, with the appropriate permissions, to be buried in NSW without a conventional coffin. Growing numbers of NSW consumers and families are seeking alternative options for burial which meet their beliefs, values, and preferences.

The following options are increasingly available, can be used at conventional cemeteries, and can be discussed with a funeral director:

- caskets made of willow, wicker or wool;
- cardboard coffins, which can include customisable designs;
- biodegradable scattering tubes, earth urns, corn starch urns or salt urns;
- biodegradable burial suits made from mushrooms and other micro-organisms; or
- burial shrouds made from biodegradable material, such as 100% cotton, bamboo, linen, or wool.

If you wish to have a shrouded burial, there are additional steps that need to be taken:

Steps required in NSW to be buried in a shroud

In NSW, a conventional coffin or casket is required for burial or cremation. However, an application can be made to NSW Health for an exemption to be buried in a shroud on both religious and non-religious grounds. (Burials-Exemptions from Public Health Regulation 2012 for Community and Religious Reasons (nsw.gov.au). Some cemeteries in NSW have arrangements in place for certain community or religious groups, meaning an individual exemption is not required. It is worth checking this with the operator of the cemetery where you intend burial to occur before completing the exemption form. Shrouded cremation is not presently allowable in NSW.

A family member, funeral director or cemetery operator can seek approval for an exemption from NSW Health on your behalf. Funeral directors and cemetery operators can help you develop your shrouded burial plans, or those of your loved ones. These plans must include the use of a coffin until such time as the body is placed into a grave.

Making a complaint or enquiry to Cemeteries & Crematoria NSW (CCNSW)

What is the role of CCNSW?

CCNSW is a NSW Government agency that regulates cemetery and crematoria operators in NSW and provides information on burial and cremation options to the public. CCNSW aims to ensure that everyone in NSW has the right to a dignified burial or cremation, that is respectful of religious and cultural beliefs. CCNSW also has a role in addressing and resolving complaints concerning cemeteries and crematoria, including Crown land, local government, private, church and community-operated cemeteries and crematoria.

What to do if you have a complaint or enquiry

Firstly, it is recommended that an attempt is made to resolve the issue with the cemetery or crematorium operator directly. If this is unsuccessful, or you are unhappy with the outcome, you can contact CCNSW or NSW Fair Trading, depending on the nature of the issue:

- Contact NSW Fair Trading if your complaint relates to consumer law matters, such as an issue relating to a Funeral Director not providing a service you paid for.
- Contact CCNSW if your complaint relates to the management or maintenance of cemeteries and crematoria, including the purchase of an interment right (a burial site or a location to place ashes) or customer service provided by the cemetery or crematorium operator.

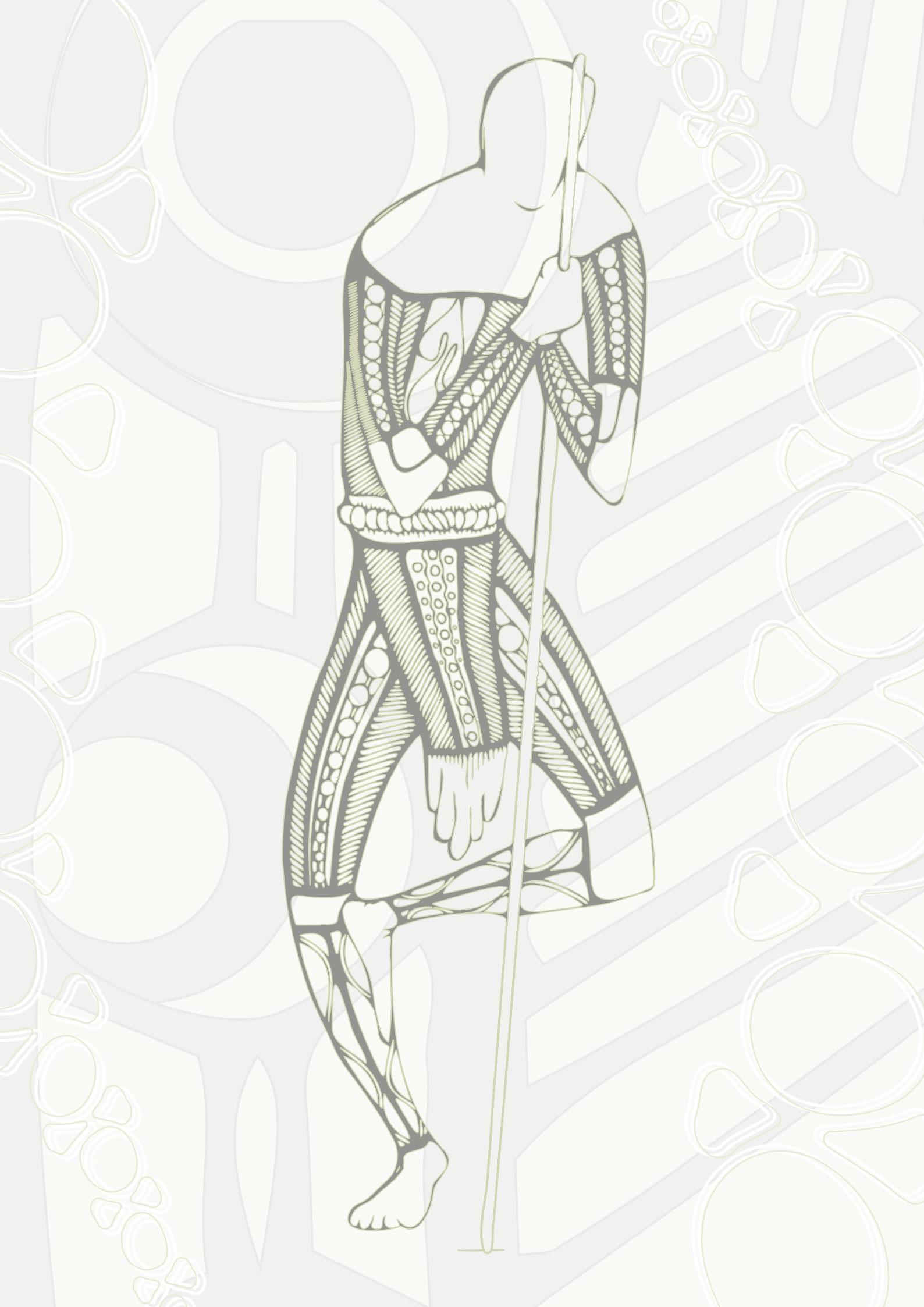
If you are unsure as to which agency to lodge your complaint with please contact CCNSW (contact details are below) and we can assist you.

How to lodge a complaint or make an enquiry

CCNSW offers a number of ways to lodge a complaint or make an enquiry. You can:

- Lodge a complaint online at <https://www.cemeteries.nsw.gov.au/complaints-and-enquiries/complaints> by completing the online form;
- Make an enquiry online at <https://www.cemeteries.nsw.gov.au/complaints-and-enquiries/enquiries> by completing the online form;
- Email ccnsw.info@cemeteries.nsw.gov.au; or
- Call us on 02 9842 8473.

If you are using the web page online form or email, please assist us with handling your complaint or enquiry by including a summary of the issue, the name and location of the cemetery or crematorium operator and the action or outcome you are seeking. Please send all relevant attachments with your complaint or enquiry, for example, photographs and any correspondence you have had with the operator, including attempts made to resolve the issue.



Advance Care Directive

Courtesy of NSW Health

Common Terms

An Advance Care Directive is an important way of letting people know your wishes about your healthcare and treatment should you find yourself in a position where you are seriously ill or injured and not able to make decisions.

Advance Care Planning

Advance Care Planning involves thinking about what medical care you would like should you find yourself in a position where you are seriously ill or injured and cannot make or communicate decisions about your care or treatment. It includes thinking about what is important to you - your values, beliefs and wishes.

Advance Care Planning can include one or more of the following:

- talking with your family, carers and/or health professionals
- developing an Advance Care Plan
- making an Advance Care Directive.

Ideally Advance Care Planning happens early, when you are well and are able to understand the choices available to you about your healthcare and treatment. However it can be done at any time you have capacity.

An Advance Care Plan records preferences about health, personal care and treatment goals. It may be completed by discussion or in writing.

If you are able to make decisions about your future healthcare, you can make an Advance Care Plan by yourself or together with people that you trust and/or who are important to you.

If you are not able to make decisions, an Advance Care Plan can be made by a family member or someone who knows you well, together with a health professional. It should include your known wishes about treatment.

Advance Care Directive

An Advance Care Directive is a way to say what healthcare treatments you would like to have or refuse, should you find yourself in a position where you are seriously ill or injured and unable to make or communicate decisions about your treatment and care.

An Advance Care Directive may include one or more of the following:

- the person or people you would like to make medical decisions for you if you are unable to make decisions
- details of what is important to you, such as your values, life goals and preferred outcomes
- the treatments and care you would like or refuse if you have a life-threatening illness or injury.

Person Responsible

In NSW the *Guardianship Act 1987* states that the Person Responsible is (in order):

1. Your guardian

This is a person or people who have been legally appointed to make medical and/or dental decisions for you. In some situations a guardian may be appointed for someone, but most people are able to choose their own guardian.

If you are 18 years of age or older and have capacity, you can appoint an **Enduring Guardian** (you can appoint one or two). When you appoint the Enduring Guardian(s) you can decide what medical and/or dental decisions you would like them to be able to make for you, if you do not have the capacity to make the decision yourself.

Your Enduring Guardian must consider your Advance Care Directive before they make a decision.

2. Your spouse, de facto or same sex partner

Person with whom you have a close and continuing relationship.

3. Your carer

Person who currently provides support to you or did before you entered residential care. This person cannot be a paid carer. The carer support payment is not considered payment.

4. A close friend or relative

Person with whom you have an ongoing relationship.

Substitute decision maker

A substitute decision maker is a person who is appointed or identified by law to make decisions for an individual whose decision making capacity is impaired. A substitute decision maker may be appointed by the individual (for example appointing an Enduring Guardian or making a Power of Attorney), appointed for the individual (for example a guardian appointed by the Guardianship Division), or identified as a substitute decision maker for medical and dental treatment by the NSW Guardianship Act 1987 'Person Responsible' hierarchy.

Values statements

Some people may choose to record general statements about what is important to them - their values, beliefs and wishes - on their Advance Care Directive or in their Advance Care Plan. The following values statements are provided as examples of what you may wish to include in Section 2 of the form (there is no right or wrong - it is entirely up to you what you record to let others know):

Beliefs and values:

It is important for me to be able to communicate in some way, even if I cannot speak.

Life has meaning when I can enjoy nature and when I can practise my faith.

I value my privacy.

Physical or mental health concerns that you may want considered:

I do not want to struggle to breathe.

I do not want to be in pain.

It is important to me that I spend time in my garden.

Other information that you would like considered:

I would like to stay at home as long as it is not too hard on my family or the people caring for me.

I would not like to die at home.

I worry that my family or the people caring for me will not know what to do.

I want flowers in my room.

Cultural, spiritual and/or social care:

I would like prayer, religious or spiritual rituals in my own language.

I would like my music to be played.

Advance Care Directive

SECTION 1

Your Details and Your Person Responsible

Family name: _____

Given names: _____

Date of birth: _____

Address: _____

I have been provided with and read the 'Making an Advance Care Directive' information booklet. YES

I have legally appointed one or more people as my Enduring Guardian/s and they are aware of this Advance Care Directive. YES

ENDURING GUARDIAN 1

ENDURING GUARDIAN 2

Name: _____

Home phone number: _____

Mobile phone number: _____

Email address: _____

I have not appointed an Enduring Guardian

If, because of my medical condition, I am not able to understand and make decisions about my treatment or can't tell the doctors or my family, my Person Responsible as determined according to the hierarchy within the NSW Guardianship Act (1987) is:

PERSON 1

PERSON 2

Name: _____

Relationship: _____

Home phone number: _____

Mobile phone number: _____

Email address: _____

Advance Care Directive

SECTION 2 Personal Values about Dying

Information about your values is important as it is not possible for this document to cover all medical situations. Information about what is important to you may help the person who is making decisions on your behalf when they are speaking to the doctors about your care and treatment.

In this section you can include:

- things that are important to you at the end of life (your beliefs and values)
- issues that worry you, and
- personal, religious or spiritual care you would like to receive when you are dying.

If you do not want to complete this section, you should sign the bottom of this section on the next page.

If I am unable to communicate and not expected to get better:

- I would like my pain and comfort managed; and
- when deciding what treatments to give to me or not to give me, I would like the person/people making health decisions for me to understand how the following would make me feel (initial the box that is your choice).

If I am unable to communicate by any means, and not expected to get any better:

VALUES	Bearable	Unbearable (I would like treatment discontinued and to be allowed to die a natural death)	Unsure
1. If I no longer have control of my bladder and bowels, I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. If I no longer have control of my bladder and bowels, I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. If I cannot feed, wash or dress myself I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. If I cannot move myself in or out of bed and must rely on other people to reposition (shift or move) me, I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. If I can no longer eat or drink and need to have food given to me through a tube in my stomach I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. If I cannot have a conversation with others because I do not understand what people are saying, I would find life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Advance Care Directive

SECTION 3

Directions about Medical Care

This section applies to when you are unable to make or communicate decisions about your health care and medical treatment, including CPR. If you are able to communicate you will be included in decisions about your care.

If you **do not want to complete this section**, you should sign the bottom of this section.

Cardio Pulmonary Resuscitation (CPR)

CPR refers to medical procedures that may be used to try to start your heart and breathing if your heart or breathing stops. It may involve mouth to mouth resuscitation, very strong pumping on your chest, electric shocks to your heart, medications being injected into your veins and/or a breathing tube being put into your throat.

CPR

If I am **not expected to recover**, or if my life is unbearable as indicated in my Personal Values About Dying, Section 2 on page 2, **THEN, if my heart or breathing stops** (please tick one box only)

I would accept CPR

OR

I would not accept CPR. Do not try to restart my heart or breathing

OTHER MEDICAL TREATMENTS

If I am **not expected to recover**, or if my quality of life is unbearable as indicated in the table my Personal Values About Dying, Section 2 on page 2 and 3, **THEN the following treatments would be UNACCEPTABLE to me** (initial the box/boxes that apply to your wishes):

Artificial ventilation through a tube (also called 'life support', 'breathing machine')

Renal dialysis - (kidney function replacement)

Life prolonging treatments that require continuous administration of drug

OTHER (e.g. food and fluid through a tube). Please list below:

Even if I am expected to get better I would never want the following medical treatments:

I do not want to complete Section 3:

(Signature)

Advance Care Directive

SECTION 4

Specific requests for Organ, Tissue and Body Donation

If you do not want to complete this section, you should sign the bottom of this section

My wishes about organ, tissue and body donation for transplantation following my death are (initial your choice for each statement):

	Yes	No
I would like to donate my organs and tissues for transplantation following my death.	<input type="checkbox"/>	<input type="checkbox"/>
I have discussed my organ and tissue donation wishes with my family and friends and they are aware of my decision.	<input type="checkbox"/>	<input type="checkbox"/>
I would like to, or have already made arrangements to, donate my body for education and/or scientific research	<input type="checkbox"/>	<input type="checkbox"/>

Antemortem interventions for organ donation (treatment/s immediately before my death only for the purpose of organ donation)

	Yes	No
It is my wish to donate my organs for transplantation after my death. If I am dying, I consent to the doctors providing treatments for my organs before my death (including artificial ventilation, insertion of intravenous lines and administration of medications) intended only for the purpose of enabling me to donate my organs and tissue for transplantation.	<input type="checkbox"/>	<input type="checkbox"/>

I do not want to complete Section 4:

(Signature)

Advance Care Directive

SECTION 5

Authorisation

PERSONAL DETAILS

By signing this document, I confirm that:

- I have read the accompanying information booklet, or had the details explained to me.
- I understand the facts and choices involved, and the consequences of my decisions.
- I am aware that this Advance Care Directive will be used in the event that I cannot make or communicate my own health care decisions. If I am able to communicate, I will be asked to make decisions about my care.
- I have completed this Advance Care Directive of my own free will.

(Signature)

____/____/____
(Date)

DETAILS OF WITNESS*

I confirm that _____ signed this document on ____/____/____

Signed: _____ Name (please print): _____

Address: _____ Phone: _____

TREATING HEALTH PROFESSIONAL*

Name: _____ Designation _____

Address: _____

Phone: _____

Email: _____

I confirm that I had no reason to doubt the capacity of the person

I confirm that _____ had capacity and was and was aware of the implications of the information in this Advance Care Directive.
(Medical officer only)

(Signature)

____/____/____
(Date)

*While not legally required, it is strongly recommended that a witness co-signs this Advance Care Directive and/or a health professional witnesses you sign this form. Once completed this form is to be given to your Personal Responsible, Enduring Guardian and medical professionals.



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