

Amaranth FOUNDATION



Looking Forward..Looking Back..

Amaranth Practical Planning Guide

"Looking Forward...Looking Back"

From the Slim Dusty Album: "Looking Forward..Looking Back" 2001
Written by Don Walker

Looking forward, looking back
I've come a long way down the track
Got a long way left to go
Making songs, from what I know.

Making sense of what I've seen
All the love we've had between
You and I, along the track
Looking forward, looking back.

There are strange days
Full of change on the way
But we'll be fine, unlike some
I'll be leaning forward, to see what's coming.

Looking forward, looking back
I've come a long way down the track
Got a long way left to go
Making songs, from what I know.

If I'm alone at night, I can see
Through all the triviality
Of the day and I'm okay
I just think of those who are dear to me.

Looking forward, looking back
I've come a long way down the track
Got a long way left to go
Making songs, from what I know
Making songs, from what I know
Looking forward, looking back ...

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PLANNING FOR THE REST OF YOUR LIFE

Many people have strong opinions about what would be important to them as they approach the end of their lives. Other people have certain things that they would rather avoid. For this reason it is important to take some time to think about what you would like at the end of your life – at the time of your death and how you would like to have others celebrate your life.

This may sound like a scary topic, but planning now will help to take much of the stress off your loved ones when the end does come and you will be sure that they know what your wishes are.

MY LIFE STORY...

Taking the time to write down your life story will give you time to reflect on your life, achievements and the events that have made your life your own. Sharing these things with your family by writing them down can be both therapeutic to you and act as a memory for your loved ones for years to come.

Full Name
Better known as/ or nicknames
Date of Birth
Place of Birth
If born overseas – date arrived in Australia
Usual address
How long at this address?
Retired Yes / No
Pension Type and Number
Self funded retiree Yes / No
Occupation (if retired – state former occupation)

Marriage details:

First Marriage	Second Marriage (if appropriate)
Date of first marriage	Date of second marriage
Age at date of marriage	Age at date of marriage
Place of marriage	Place of marriage
Spouses given name/s	Spouses given name/s
Maiden name	Maiden name

If subsequent marriages, please indicate and provide details overleaf: Y/N

Family Details

Father	Mother
First name	First name
Surname Name	Surname
	Maiden name
Met	Married

Siblings

Sibling's First names	Age	Date of Birth	M/F

Children

Children's First names	Age	Date of Birth	M/F

Other close family members/friends

Name	Contact details (home phone, mobile, email)

Early childhood – localities and interests

Schools attended – awards/achievements

Academic or trade qualifications and achievements

Interesting stories – early childhood, war/military service/marriages, divorces, children, significant relationships

Details of any club affiliations, positions held, hobbies, interests, travel stories

Special stories, sayings, readings, poems, songs

Next of Kin	Phone Number	Address
Person responsible / Enduring Guardian / Power of Attorney	Phone Number	Address
Solicitor's name	Phone Number	Address

SOME QUESTIONS TO THINK ABOUT

Planning how you, or the person you are caring for, want to live during the final stages of life, is an ongoing process. The process begins with a diagnosis of an advanced serious disease, or life limiting illness, or when a chronic illness becomes more complex and complications develop. It then extends to and includes the final days and hours of life. You can create your ideal situation for your last days by planning and involving the people, places and activities that fill your life with hope, purpose and meaning. Planning can even relate to how you would like to be treated and what interventions you may want as your illness advances and you are faced with the uncertainty of the end of life, and how you want to be cared for after death. Planning can also include how you want people to remember you or think of you after you have died, not just what you did, but the person you were and the values that were important to you.

Here are some questions to think about:

- ✚ When you are dying, do you want to remain at home for as long as possible, surrounded by people who care for you and love you?
- ✚ Have you considered dying at home?
- ✚ If you have thought about this – is it possible? Can your local health care team support your needs, and that of the people caring for you, including your physical, spiritual, social and emotional needs?
- ✚ Have you made decisions as to who you want to be with you when you are dying? And have you asked them? Will they feel comfortable and be able to cope?
- ✚ Are there any rituals or traditions that you would like to consider leading up to and around the time of your dying?
- ✚ Have you thought about what sort of funeral you would like? The readings, the eulogy, the music, the flowers, the coffin, donations?
- ✚ If you have pets, have you thought about what you would want to happen to them, or who may care for them?

Many people have expressed a wish to die at home. With the help of your care team, including your local doctor, the community nursing service, the specialist palliative care team, allied health professionals and family and friends this can be possible. But it needs planning.

It can sometimes be difficult for a person to stay at home to have a peaceful home death when there is not enough support or resources available. In these cases, some people feel that the security of the hospital or aged care facility makes the process of dying and being cared for easier for themselves and for their care givers.

CLARIFYING YOUR VALUES AND BELIEFS

Values and beliefs are at the core of every person's life. These are the things that give life purpose and meaning. Our values define who we are, and can inform the decisions we make. Talking to people that are caring for you, and your health care team about what your values are, can ensure that your wishes are respected.

If you are unable to let people know what you want and value, then your Person Responsible, Enduring Guardian or Power of Attorney will also need to know what you value with regards to your health and the way you believe you want your future health care needs to be considered. This will ensure that when decisions are made that affect your care, they will be the ones that you would have made for yourself. It is also important for your local doctor or specialist to understand your preferences and the things that you value. After you have thought about your values and preferences, you may like to prepare an Advance Care Plan, or Advanced Directive (Ask Amaranth for a booklet on this).

The following are several scenarios that may help you clarify your thinking.

	Very important	Somewhat important	Not important	Not Sure
Avoiding pain and suffering even if it means that I may not live as long				
Being alert, even if it means that I may be in some pain				
Being around my family and close friends				
Having religious or spiritual leaders / ministers at my side when I die				
Being able to tell my life's story and leave good memories when I die				
Reconciling differences and saying good bye to family and friends				
Being at home when I die				
Staying at home for as long as possible and practical				
Being in hospital when I die				
Being kept alive long enough for my family to see me before I die, even if I am unconscious				

What are your biggest hopes for the rest of your life?

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What are your biggest fears about the rest of your life?

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What are some things that you would like to do that could make your last weeks, days or hours more peaceful?

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What are some things that you would like your family or care givers to do to make your last weeks, days or hours more comfortable and peaceful?

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What are some of the values that you have had that you would like your family to remember about you?

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*You lay there
Not so much sleeping as leaving
Many of those who loved you
Stood or sat around you...
That fearful, tearful moment was not far away
Yet...
The room was alive with love
Pain had succumbed to peace
Ending surrendered to beginning...*

Cancer Council Victoria

DEALING WITH UNFINISHED BUSINESS

There can be a positive side to preparing for your own death – dealing with unfinished business, forgiving grievances, developing rituals or changing life's priorities. Dealing with some of these things while you are still well enough may help take the stress off you and your loved ones - since you will all feel that things are in order.

“Death is as much a process as an event.”

Use this checklist to help you make sure all of your unfinished business is completed to help take the stress off your loved ones.

ISSUE	DETAILS	NOTES	DATE COMPLETED
Will and Executors of the Will			
Power of Attorney and enduring Power of Attorney			
Enduring Guardian			
Advanced Care Directives/Plan			
Centrelink Benefits			
Pension			
Change of entitlements			
Carers Allowance			
Check eligibility for Bereavement Allowance			
Funeral Director			
Information required for death certificate:			
Parents full name and occupation			
Dates and place of marriage			
If immigrant – date of arrival in Australia and country of origin			
Benefactor for Life Insurance Policies, Superannuation policies			

ISSUE	DETAILS	NOTES	DATE COMPLETED
Signatures of bank accounts			
Banks and financial institutions			
Credit Cards			
Name changes / Notifications			
Aust. Tax Office			
Car Registration			
Clubs / organisations			
Department store cards			
Drivers Licence			
Electricity account			
Gas Account			
Local Doctor			
Health Fund			
Insurance Companies			
Life			
House and Contents			
Car			
Income Protection			
Other Insurance			

ISSUE	DETAILS	NOTES	DATE COMPLETED
Local Government			
Electoral Role			
Rates			
Landlord			
Medicare			
Passport			
Post Office			
Seniors card			
Solicitor			
Telephone Company			
School / TAFE/ University			

Notes:..... Things to remember.....

MY FUNERAL PREFERENCES

Planning your own funeral or simply listing your preferences will help your family know what you would like and help to make decisions easier for them.

FUNERAL DIRECTOR	CONTACT DETAILS

My wishes

Details or responsible person

Burial – where would you like to be buried? OR	
Cremation – where would you like your ashes placed?	
What type of service would you like – church/graveside/other	
Location of service	
Preferred time of service	
Celebrant / Minister of Religion	
Eulogy written/read by	
Any special inclusions?	
Floral preferences	
Newspaper preferences	
Printed order of service: Any special requests	
Music selections	
Readings	
Powerpoint presentation of life/photos/ other similar ideas	
Do you want a viewing before the funeral?	

Do you want the coffin/casket open for viewing?	
Viewing for (family only/ anyone wishing to pay their last goodbyes?)	
Who do you want to be there?	
Who don't you want to be there?	
Type of coffin / casket preferred? Wood, Metal, Environmental, Sealed Metal, Shrouded in Australian flag, Other	
Clothing	
Jewellery	
Glasses	
Other	
Gathering/wake after funeral service	
Any special requests:	
Location	
Catering	
Other	
Headstone inscription	
Donations Would you like donations to go to a charity, if so who?	

PEOPLE ACCOMPANYING THE COFFIN/CASKET

Many people are now choosing to accompany the coffin/casket into the church/chapel after people are seated. If you would like this, who would you choose to do this?

INTO THE CHURCH/CHAPEL		OUT OF THE CHURCH/CHAPEL	
Name	Contact Details	Name	Contact Details

The following is an excerpt from *Caring for the Living and the Dying*, by Michael Barbato (2010)...

Death resembles birth in so many ways. Both are processes defined and controlled by nature, and both are accompanied by fear and anticipation. Each journey is different, of varying duration and ends in transition, one into life and the other into death. While the birth journey is well understood and divided into stages, the death journey is less clearly demarcated but nonetheless has its own stages of labour.....

NOTES ABOUT CARING FOR YOURSELF

Going through the process of planning for your own death or the death of a loved one can, at times, be very difficult, so it is important to remember to take care of yourself. Below are some strategies you may find useful.

SUPPORT STRATEGIES:

1. Remind yourself that you are human, and do not have to know what to do all of the time
2. Ask for help when you need it. This is a sign of wisdom rather than failure
3. Allow yourself to make mistakes and still feel OK as a person
4. Value the relationships you have, say the things that are important to say
5. Have conversations about issues other than work, caring roles or social issues
6. Look for opportunities for personal development
7. Let off steam emotionally and physically on a regular basis
8. Become familiar with the signs of stress and develop ways to deal with them
9. Be aware of "elephants in the room" – those unspoken issues, try to find opportunities to bring these up with your loved ones
10. And most importantly – give your sense of humour a regular airing

"Birth and Death and Bookends of Life"

Merrill Collett. At Home with Dying

A FEW POINTS TO REMEMBER WHEN CARING FOR A LOVED ONE WHO IS DYING

The most important person, in the care team, is the one who provides the day to day care. This is usually an immediate family member. It is important to understand that the course of a life limiting or terminal illness is unpredictable and despite the best intentions of everyone, the burden of care can become overwhelming. For this reason it may not be wise to promise to continue to care at home or to not let the person go to hospital, or an aged care facility. A conditional promise that care will continue for as long as humanly possible and medically reasonable may be worth considering and offering.

- ✚ When a person is dying their hearing is the last sense to go – be aware that your loved one can hear everything that you say. Therefore it is good to talk to your loved one as you have always done. Even if the person appears to be unconscious or not responding, there is still the opportunity to say the things that need to be said
- ✚ You may enjoy being involved in the caring tasks if your loved one is in hospital. Ask the staff if you can help with mouth care, foot massage, and personal care.
- ✚ Everyone's contribution to the care of a dying person counts – no one is more important or less important. Even the little things make a difference.
- ✚ You may be experiencing anticipatory grief before your loved one dies. These feelings can include anger and anguish, apprehension and fear, remorse and guilt, and feelings of separation and loss. Acknowledge these feelings as part of the grieving process.
- ✚ Once the needs of the dying person are understood and accepted, family and care givers are able to refocus on the goals of care. The person who is dying and their loved ones can retain the hope of finding or re finding the values of their lives, resolving what was not previously unresolved, discovering or re discovering spirituality.

✚ We often hear the phrase “pain and suffering”.

Suffering is a concept used to describe something that has to be endured, and traditionally has been associated with pain that could not be relieved. Suffering has been defined as: “...the loss of control over what happens to you in a situation in which you perceive yourself as being threatened or in danger of disintegration as a person.

Any mechanism that provides you with a sense of control reduces the sense of suffering”.¹

It is important to ask the person you love what is causing them the most suffering or concern. Do not assume it is always pain.

“How does one become a butterfly?” She asked pensively..

You must want to fly so much that you are willing to give up being a caterpillar”

Paulus 1997-2003

WHEN THE HEALTH OF THE PERSON YOU LOVE STARTS TO DECLINE:

You may not always know the signs that the health of the person you love is declining, or the significance of the changes. The following are general signs only, and in some people they can occur faster or slower.

Signs that are commonly seen in the last a few days:

- ✚ More rapid deterioration, often day by day
- ✚ Increasing weakness, being bed bound and requiring increasing help with personal care
- ✚ Difficulty taking liquids and medication by mouth
- ✚ Impaired concentration, possible muddled thinking and difficulty in sustaining even the briefest conversations
- ✚ Increasing drowsiness

¹ The Dying Process: A Guide for Caregivers Hospice Foundation of America. 2005.

Generally in the hours or days just prior to death, the following signs can be noticed:

- ✚ Bluish tinge to the skin which can be cold to touch. This doesn't mean that the person is cold or needs extra blankets. This is a normal process and is the body's way of ensuring that essential circulation goes to the major vital organs.
- ✚ Changes in breathing patterns – breathing may slow down, become shallow or faster. There can be long gaps between breaths. Breathing may sound a bit "rattly" or "gurgling".
- ✚ Increased drowsiness and reduced awareness and ability to understand conversations. The person may become less aware of things around them and not be able to stay awake.
- ✚ Uncharacteristic or recent restlessness and sometimes agitation.
- ✚ Fast, weak pulse and generally lower blood pressure.

WHAT TO SAY, WHAT TO DO

The biggest concern for people who are caring for or visiting a dying relative or friend is, "What do I say"? The best advice is to be physically and emotionally present, to listen and to show empathy. Avoid false statements such as "You are looking better" or "Stay positive". Just because the person you are caring for or visiting is dying, they have not changed. They are still the same person, so relating to them as you would have done or as you know them is important. Silence is as important as the conversations. By saying "I don't know what to say", if that is the case, is about being honest and empathetic.

"What dying people fear most is the loneliness that may accompany their dying. The inability to share their fears, anxieties and wishes and to be blatantly honest about their life and death is more painful than the thought of death itself..."

Michael Barbato (2010) Caring for the Living and the Dying

AFTER THE PERSON DIES








SOME CHECKLISTS THAT MAY ASSIST WITH PLANNING




















What happens at the Hospital	
The hospital staff will notify the doctor to issue a death certificate	
Family members if not present may need to be notified – they may be able to help with some of the tasks	
When you feel ready – ring the funeral director. The Hospital staff may do this on your behalf, but you do not have to rush this process. There is plenty of time to spend with your loved one.	
If appropriate, sign the hospital transfer form nominating your Funeral Director	

What to do at home	Checklist
Notify the doctor to issue a death certificate	
Family members if not present may need to be notified – they may be able to help with some of the tasks	
When you feel ready – ring the funeral director. You do not have to rush this process. There is plenty of time to spend with your loved one.	
If appropriate, sign the transfer form nominating your Funeral Director	

Formal notifications	Checklist
Relatives, close friends, neighbours – if you have a list made up prior to the death, this can be a task allocated to a close friend or another family member	
Executor of the Will	
Power of Attorney	
Community Services	
📞 Meals on Wheels	
📞 Community Nursing	
📞 Community Care Services	
Solicitor, or Public Trustee	
Funeral benefit Fund, Superannuation Fund	
Banks and Financial institutions	
Land lord – if appropriate	
Employer, School, University – if appropriate	

HELP WITH THE FUNERAL

Before you go to the Funeral Director it may be useful to think about the following things:	Tick when completed
 The wording of the funeral notice – check the person's requests	
 The newspapers you may want to display the funeral notice	
 Personal details of the person who is dying (take certificates if possible)	
o Birth	
o Marriage / Divorce details (details of all marriages and divorces)	
o Parents full names (including maiden name of mother)	
o If an immigrant, information about when the person arrived in Australia	
 Clothes you would like to wear or the clothes that the person who is dying has chosen	
 Any jewellery or special items that you would like to remain with the person who is dying or has died	
 Whether you or the person who is dying has any special requests eg: donations to charity	
 If the person was a Veteran, then the RSL may be able to provide an Australian flag for the coffin, and perhaps a guard of honour	

PLANNING THE FUNERAL	
The following will be things to be arranged with the Funeral Director	
 Venue, Time and date of the funeral	
 Availability of a Minister of religion, or celebrant	
 If cremation has been chosen – arrangements with the crematorium	
 Arrangements with the cemetery staff	
 Transfer of the person from hospital/home to the Funeral Home	
 Selection of coffin	
 Selection of flowers	
 Clothes for the deceased to be dressed in	
 Determine who may wish to dress the deceased, with the funeral director	
 Time for a viewing and where	
 Completion and lodgement of the Register of Death form	
 Completion of cremation forms (if appropriate)	
 Funeral notices in newspapers	
 Donation envelope and collection box if required	
 Confirmation of who may be pall bearers	
 Ordering a copy of the Death Certificate (this may take some weeks)	
 Choosing an inscription for the cemetery plate	
 Remembrance book for signatures or comments	
 Estimation of Funeral Costs	

WRITING A EULOGY

Your loved one may have written some points in the 'my life story' section on page 4 which may be useful to use in the eulogy. As a helpful guide, the following may be of assistance:

- ✚ When and where was your loved one born?
- ✚ Nicknames and or names known to others?
- ✚ Parents names – where they met and married?
- ✚ Brothers and sisters
- ✚ Early childhood – localities and interests
- ✚ Schools attended - awards if significant
- ✚ Academic or trade qualifications and achievements
- ✚ Interesting stories about early childhood. Favourite sayings, quotes or other memorable sayings
- ✚ Details about any war or military service
- ✚ Details of marriages, divorces, children, significant relationships
- ✚ Details of any club affiliations, positions held
- ✚ Details of hobbies, interests, travel stories
- ✚ Details of historical significance
- ✚ Preferences, likes, dislikes
- ✚ Special readings, poems, or poetry may be included
- ✚ Values that the person had that were really important to them and to others
- ✚ How the person contributed to the family or to important relationships

REFERENCES

Information used to compile this resource:

Barbato. M (2010) Caring for the Living and the Dying

www.funeraladvice.com.au

www.orbits.com.au

www.whiteladyfunerals.com.au

www.betterhealth.vic.gov.au

www.cancervic.org.au (Cancer Council, Victoria)

www.gt.nsw.au (Guardianship Tribunal)

www.livingcaringworking.com

www.centlelink.gov.au (Centrelink)

www.palliativecareaustralia.org.au (Palliative Care Australia)

www.ncahs.nsw.gov.au/advance-care-planning/ (North Coast Area Health Service)

www.health.nsw.gov.au/patient_care/planning/index.asp (Advanced Care Planning Program, NSW Health)

Hospice Foundation of America (2005) The Dying Process: A Guide for Caregivers

"Their booklet is a very practical one and should be most helpful to those who need it. Thank you for sending on the request."

Best wishes Joy (McKean)

From the Slim Dusty Foundation 2011.

DEDICATION

We would like to thank the many families and patients that we have worked with that have shared their stories and also advised us about the things that have supported them as they are dealing with the process of death and dying. Many of these families have shown extraordinary courage and personal strength as they dealt with difficult issues, and shared very intimate and personal stories and feelings, values, and the things that provided them with hope and meaning in their lives. It is a privilege and an honour to have known and worked with so many people and families. We see them as being part of our extended Amaranth family.

We would also like to thank Joy McKean, the wife of Slim Dusty and Don Walker, the author of "Looking Forward, Looking Back" for their kind permission in using the lyrics to this song as the title of the resource. It has added a wonderful personal dimension to this resource and we are sure this will be greatly appreciated by anyone who needs to use it.

I would also like to thank my parents John and Joan Santamaria, as it is their courage in the face of living with terminal illness that provides the inspiration for the ongoing work of the Foundation.



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