

Amaranth FOUNDATION



HOME DIARY AND RESOURCE FOLDER

What's in my diary?

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How to use my diary

This diary belongs to you so it is completely up to you how you use it. You may not feel the need to use it, you may use it every day, or your carer may find it useful to help them keep track of medications, tests etc for you. Whatever works, and helps you to manage your own health care information.

You can let other health professionals know that you are keeping the diary, and if you like, they can jot some notes in here. That way you will remember what was said, or what new information may need to be recorded. It also means that everyone involved in your care can know what's happening, what treatment you've received, what medication you are on, and what tests you've had etc.

It is a good idea to take this diary when you attend an appointment anywhere, or if you are admitted to hospital. It is useful to have all of your information from different doctors, specialists, other health professionals, community nurses, and others all in the one place.

Tips for using your Diary.....

- Keep all your documents together in this binder and take it to all of your appointments
- You can store all important documents or copies of them in this binder, so that everyone knows immediately where things are.

You can store pamphlets, medication information, and important phone numbers in this binder, so that everything is in place.

From the hour you're born
You begin to die
But between birth and death
There's Life

Simon De Beauvoir

"All Men are Mortal"



About me

My Name: _____

Preferred Name: _____

Date of Birth: _____

My Address: _____

My Telephone Number: _____

My Mobile Number: _____

ALLERGIES/MEDIC ALERTS: _____

I have completed an Advance Care Plan/Directive YES/NO

Date: _____ Location kept: _____

Who knows about my wishes: _____

I have appointed an enduring guardian(s) YES/NO

Location where form is kept: _____

(If no enduring guardian appointed, list your next of kin plus a second contact)

Name:

Address:

Contact Number(s):

Occupation:

Relation:

Name:

Address:

Contact Number(s):

Occupation:

Relation:

I have completed a will: YES/No

Date: _____ Location kept: _____

Who knows about my wishes: _____

I have appointed a Power of Attorney: YES/NO

Name:

Address:

Contact Number(s):

Medicare Number: _____ Reference Number: _____

Private Health Insurance Provider: _____ Number: _____

DVA number: _____

Pension Card number: _____

Other: _____

My Care Team

This could include physiotherapists, speech pathologist, dieticians and so on, from your local Community Health Service or other health professionals you see, as well as service providers such as Meals on Wheels or Home and Community Care.

<i>Health Professional</i>	<i>Name</i>	<i>Phone number</i>

My Health Care information and History

Current illness(es): (e.g. high blood pressure, diabetes, depression, high cholesterol)

Past medical history: (e.g. gallbladder removed, heart bypass, hip replacement, stroke, TIA)

Past treatments and Procedures (type of surgery, date, year)

My family health history includes: (breast cancer, heart disease, mental illness)

Other information: (concerns, dietary issues)

My future Plans and Goals for care

It's really important to me that I.....

It's really important for my family to be able to.....

I'd really like to be able to.....

I'd rather not have the following.....

What medication am I taking?

Keeping track of your medication, including pain medication, can often be difficult and confusing. Medication can be changed, or doses increased or decreased. You may also be taking other supplements such as vitamins, herbal remedies or naturopathic medicines. Keeping all this information together can help your doctor and other health professionals keep track of what you are on and for what reason. This can help avoid unnecessary side effects or problems.

Name of Medicine	How much? How often?	Reason for taking?	Start date	Precautions Things to be aware of
<i>EXAMPLE: Diabex</i>	<i>1 before breakfast, 1 before dinner</i>	<i>Diabetes</i>	<i>31/12/08</i>	

What medication am I taking? Cont.

Name of Medicine	How much? How often?	Reason for taking?	Start date	Precautions Things to be aware of
EXAMPLE: Diabex	1 before breakfast, 1 before dinner	Diabetes	31/12/08	

Recent medical tests, treatments and procedures

Use this page to keep track of the different tests, treatments and procedures you may have. This will help you to remember when something was done and what the outcome was.

Date	Test/treatment etc	Notes
<i>EXAMPLES</i> 31/12/11	<i>Full blood count</i> <i>Blood pressure</i> <i>Chemotherapy</i> <i>Dialysis</i>	<i>Shows anaemia</i> <i>130/90</i> <i>Completed course</i> <i>Completed today, next dialysis on Wed</i>

Recent medical tests, treatments and procedures cont.

Date	Test/treatment etc	Notes
EXAMPLES 31/12/11	Full blood count Blood pressure Chemotherapy Dialysis	Shows anaemia 130/90 Completed course Completed today, next dialysis on Wed

Self management at home

This table will help you keep track of concerns such as bowel function, body temperature, blood sugars and nausea. It can be useful for you and your carer to monitor any symptoms or problems as they arise. It might be good to take it to other health appointments, particularly if you are concerned about any changes that you have noticed.

Date	Blood sugar levels	Blood pressure	Temperature	Nausea/ Appetite	Other
<i>EXAMPLES</i> 31/12/11	<i>4.6 before breakfast</i>	<i>120/ 85</i>	<i>37°</i>	<i>Diarrhoea/constipation/normal Poor – keeping food diary</i>	<i>Felt a bit down, not wanting to talk. Slept for long periods.</i>

Self management at home cont.

Date	Blood sugar levels	Blood pressure	Temperature	Nausea/ Appetite	Other
EXAMPLES 31/12/11	4.6 before breakfast	120/ 85	37°	Diarrhoea/constipation/normal Poor – keeping food diary	Felt a bit down, not wanting to talk. Slept for long periods.

Pain management at home

You are the only one that knows how much pain you are feeling

When your doctor or health care worker asks you about your pain, you may not remember how bad the pain was or know how to describe it. The following questions will help you to describe what you have been feeling.

If writing is too painful, ask a family member or friend to do it for you, or you could use a tape recorder.

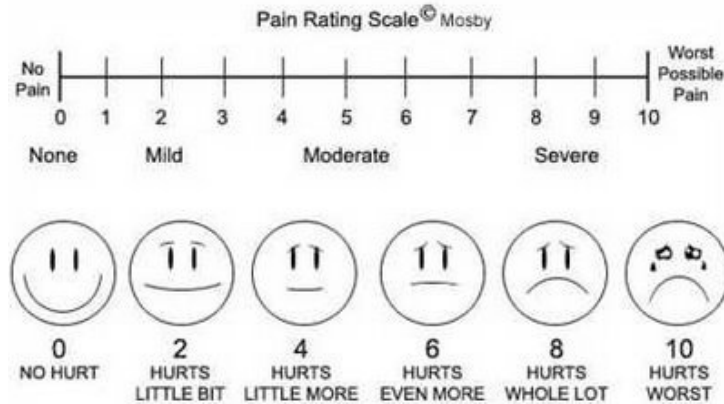
1. Where does it hurt? (List every place that the pain hurts)
2. Does the pain move? Does the pain feel different in different places?
3. How does the pain feel? (The following words may be helpful: burning, stabbing, sharp, aching, throbbing, tingling, dull, pounding or pressing)
4. Did you have pain when you woke up or did it start later?
5. Does the pain change during the day?
6. What, if anything, makes the pain better or worse?
7. What medications are you taking? Do they help? (Never, Sometimes, Always? List all the medications that the Doctor gave you **and** the ones you have bought yourself)
8. Have you stopped taking any medicines because they made you sick, sleepy, constipated or for other reasons?
9. Do you do anything to make the pain go away other than taking medicine ie: getting a massage, meditating, heat?
10. Do you have trouble sleeping because of the pain?
11. Does the pain stop you from spending time with your family and friends?

You don't have to write sentences. Just write the words that describe how you are or have been feeling. If thinking about the pain every day is too hard, put the diary away for a few days and go back to it when you are ready.

Note: See 'G.P. Checklist is plastic sleeve

Pain Scales and Tools

Mark on the scale below the level of pain that you are experiencing. Many health professionals use the Mosby Pain Rating Scale to monitor an individuals' pain and administer pain relief.

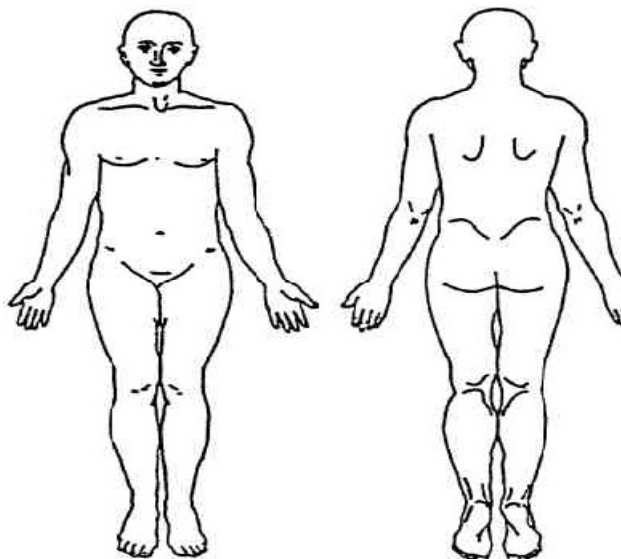


Adapted from: Pain Assessment Scales <http://www.painedu.org/>

On the next page is a table where it can keep a track of the pain, again it may be useful to take this record to other health professionals for further medical advice.

Where is your pain?

Sometimes it is hard to describe where you are experiencing pain. You may find it useful to mark on the drawings below, the areas where you feel pain. Sometimes even using colour to think about the intensity of pain is also useful for yourself and other health professionals.



Adapted from: Pain Assessment Scales <http://www.painedu.org/>

Keeping track of the pain/ other symptoms

Date	Time	What brought on the pain/symptom?	Scale of pain? 1 – no pain 10 – Worst possible	What made the pain/symptom ease?
EXAMPLES 31/12/11	1:00pm	Too much movement, sweeping, walking	6	Taking pain relief such as endone, rested

Good Communication

Good communication between you and the health care team is important to **maintaining good health care**. You and the team must **work well together**.

Each person is responsible for providing **regular information** and for **listening to what each person is saying**. If you have any questions, you must speak up so that the health care team can **know what your concerns are and help you find answers**.

Below are some suggestions of ways in which you can help to maintain good communication between you and the health care team:

- 1) **Be prepared for your health care team appointment** with a list of concerns and questions. Perhaps you could talk to your carer, family or friends before the appointment to see whether they have concerns or thoughts on what you might need to know. This can help you feel confident about the health care being received and make sure that your questions are being answered. **On page 22 of this diary is a Patient and Carer Checklist** that will help you with this. Please find loose copies of this form in the back of your diary.
- 2) **Have your thoughts written down before your appointment**. This can help the members of your team understand more quickly and completely what you want them to know. Having the health care team read what you have written may be an easier way to communicate. Using tools such as the **pain scale** and **pain diary on pages 14 and 15** or looking up words in the **terminology section on page 27** may help you to communicate and better understand the care.

- 3) **Be honest about how you are feeling and never feel as though you can't ask questions.** *It is not always easy to describe your experiences or to speak up about a concern that you have. The only way for your team to work together to make sure you have the best possible health care, is for you to tell the team what your concerns are.*

*If you are unsure of what to ask about or of what others are talking about perhaps you could look in the **terminology section on page 27** of the diary. Add in any terms that you are unsure of and ask about them or put in any difficult to remember words for later reference.*

- 4) **Making notes of appointments and getting your care team to write in your diary** is a good way of keeping track of who you have seen and what happened. This can also be useful when health professionals ask who else is involved in your care.

*When you are unwell or when you are caring for someone it can be a very busy and confusing time, using the sections in the diary marked **My Care Team on page 5 and Appointments, Home visits and Communication on pages 20 and 21** can help to simplify things and mean that you don't have to try to remember details of everything. This will also mean that the care you receive is well co-ordinated and the team members can be regularly updated on each other's actions.*

5. Make sure the thoughts and feelings of all family members are explored, sometimes in the stress of caring for a loved one's important events can be forgotten, or certain family members' questions comments and feelings can be overlooked. The **communication diary on page 22 -23** is a good way of ensuring this doesn't happen. In this section you, your family members or caregivers have the opportunity to record thoughts, feelings or note any changes that happen during the day. This becomes a nice record and can provide comfort for family members and caregivers after you have died.

Appointments, Home visits and Communication

Date	Time	Name/ Service provider	Where	Reason/ Outcome/ Comments <i>Service provider may also write notes</i>
EXAMPLES: 31/12/11	11am	GP – Dr X	Wagga	General check up, blood results (copy in folder) Discussing and signing Advance Care Plan and Enduring Guardian Forms
	2pm	Amaranth – Julianne	Home	
	4pm	Home Care – Mrs J	Home	Showering and cleaning

Appointments, Home visits and Communication

Date	Time	Name/ Service provider	Where	Reason/ Outcome/ Comments Service provider may also write notes
EXAMPLES: 31/12/11	11am	GP – Dr X	Wagga	General check up, blood results (copy in folder) Discussing and signing Advance Care Plan and Enduring Guardian Forms Showering and cleaning
	2pm	Amaranth – Julianne	Home	
	4pm	Home Care – Mrs J	Home	

Communication Diary

<i>Date</i>	<i>Time</i>	<i>Name</i>	<i>Comments, changes, thoughts or feelings.</i>

Communication Diary cont.

<i>Date</i>	<i>Time</i>	<i>Name</i>	<i>Comments, changes, thoughts or feelings.</i>

Patient carer checklist

Doctor or service provider:	Date:
Reason for appointment:	Time of appointment:
Length of appointment: (please tick) Standard (1 problem): Long (2 or more problems):	Things to do after seeing the doctor or service provider
Things to ask your Doctor or service provider:	Medical Tests ordered/arranged
Prescription renewals: Please list:	Other appointments:
Changes to medications	Changes to treatment:
Carer issues/ problems	Other instructions (i.e: diet, exercise)
Home medication review requested: Yes: No:	Referrals requested/organised
Mental Health Care Plan requested: Yes: No:	Other issues to discuss
GP Chronic disease Care Plan requested: Yes: No:	Case Conference planned/booked Yes: No:

Services to help me

This section provides a list of services that you may be interested in contacting for support and information.

Name of service	Contact details	Role
Amaranth Foundation	<p>Office 02 6033 1738</p> <p>Fax 02 6033 3507</p> <p>Referrals info@amaranth.org.au</p> <p>Website www.amaranth.org.au</p>	<p>Provides compassionate, holistic psychosocial care for people living with serious chronic or life limiting illness as well as their family and carers. Outreach services to many rural towns including Corowa, Henty, Cootamundra, Coolamon, Leeton, Griffith, Tumut, Albury and other surrounding area.</p>
Community Health Centres	<p>Cootamundra (02) 6940 1111 Junee (02) 69248201 Temora (02) 6977 4951 Coolamon (02) 6927 3548 Leeton (02) 6953 1205 Narrandera (02) 6959 1166 Jerilderie (03) 5886 1300 Berrigan (03) 5888 5300 Finley (03) 5883 3627 Corowa (02) 6033 1340 Griffith (02) 6966 9900 Tumut (02) 6947 1811 Henty (02) 6929 4999</p>	<p>Service providers of comprehensive health care for local communities including nursing, mental health, dietitian, speech pathology, podiatry, occupational therapists</p>
Hospitals	<p>Cootamundra (02) 69420444 Junee (02)6924 8200 Temora (02) 6977 1066 Coolamon (02)6927 3303 Leeton (02) 6953 2766 Narrandera (02) 6959 1166 Jerilderie (03) 5886 1300 Berrigan (03) 5888 5300 Finley(03) 5883 1133 Corowa (02) 6033 7555 Griffith (02) 6969 5555 Tumut (02) 6947 3047 Henty (02) 6929 4940</p>	

<i>Carers Australia</i>	1800 242 636 (9am – 5pm) After hours service call Lifeline 13 11 14 www.carersaustralia.com.au	<i>Carers Australia and the network of carers associations in each state and territory's purpose is to improve the lives of carers. The service provides counselling, advice, advocacy, education and training. We also promote the recognition of carers to governments, businesses and the wider public.</i>
<i>Carers NSW</i> <i>Commonwealth Respite and Carelink Centre</i>	02 9280 4744 For carers wanting emergency respite call 1800 052 222 contact@carersnsw.asn.au www.carernsw.asn.au	<i>An association for relatives and friends caring for people with a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who are frail.</i>
<i>Intereach NSW</i>	1800 052 222 Wagga Wagga 69258791 Albury 60 517 800 Burgona 03 50 210 678 Deniliquin 03 58 815 440	<i>24 hr, 7 day/week service to support carers of people living with chronic illness, cancer or requiring palliative care</i>
<i>Ageing, Disability and Home Care</i>	(02) 8270 2000 info@dadhc.nsw.gov.au http://www.dadhc.nsw.gov.au/dadhc/	<i>Provide support & services to older people, people with disabilities & their carers in NSW.</i>
<i>Centrelink</i>	<i>Disability, sickness and carers line - 13 27 17</i>	<i>Provide assistance with enquires regarding disability support pension, mobility allowance, carer payment, carer allowance and sickness allowance</i>
<i>Can Assist</i>	<i>Lilier Lodge 317 Edward St Wagga (02) 8217 3400 02 69255240 admin@cancerpatients.com.au http://www.canassist.com.au/</i>	<i>Service providing financial and practical support for people living with cancer in NSW.</i>
<i>Riverina Scooters</i>	02 6921 4444 0428 694 335 www.riverinascooters.com.au	<i>Supply and delivery of Rehabilitation, Mobility & Aged Care Equipment</i>
<i>Life line</i>	13 11 14 http://www.lifeline.org.au/	<i>Provide 24-hour over the phone emotional support in times of crisis or when callers may be feeling down.</i>
<i>Kids Helpline</i>	1800 55 1800 www.kidshelpline.com.au	<i>Provide access to telephone counselling, web counselling and email counselling</i>

		<i>for people under 18 years.</i>
<i>Accessline</i>	1800 900 944	<i>Provide 24 hour crisis support helpline for people experiencing problems around mental health, drug and alcohol, sexual assault and other issues.</i>
<i>Beyond blue</i>	1300 224 636	<i>Provides callers with access to information and referral to relevant services for depression and anxiety related matters.</i>
<i>Black Dog Institute</i>	9382 4530	<i>Offers specialist expertise in depression and bipolar disorder.</i>
<i>Cancer Council helpline</i>	13 11 20 www.cancercouncil.com.au info@cancer.org.au	<i>Phone assistance for people living with cancer, their families and carers.</i>
<i>Leukaemia Foundation</i>	1800 620 420 info@leukaemia.org.au Sydney: 9902 2222 www.leukaemia.org.au	<i>Personal support and care for patients and families living with leukaemia, lymphomas, and myeloma.</i>
<i>Alzheimer's Australia</i>	1800 100 500 www.alzheimers.org.au	<i>Provides understanding & support for people with dementia, their family & carers, practical information & advice & information about other services.</i>
<i>Dementia Care Australia</i>	(03) 9727 2744 www.dementiacareaustralia.com	<i>Support for both people with dementia and their carers.</i>
<i>Motor Neurone Disease (MND) Australia</i>	02 9816 5322 0408 461 932 Email: info@mndaust.asn.au Web: www.mndaust.asn.au	<i>Advocates for needs based care and support to help people living with MND to live better for longer.</i>
<i>Australian Lung Foundation</i>	1800 654 301 www.lungfoundation.com.au	<i>Provides a national network of patient support groups for people with COPD and other lung conditions.</i>
<i>Kidney Health Australia/ Australian Kidney Foundation</i>	Kidney Health Information Service (KHIS) 1800 4 kidney 1800 4 543639 www.kidney.org.au health@kidney.org.au	<i>Information and referral service, for people with, or affected by, kidney and urinary disease.</i>
<i>MS Society</i>	1800 042 138 (Freecall) msconnect@msaustralia.org.au www.msaustralia.org.au	<i>For Information, Advice and Support for people living with MS, their Family and Friends, Health Professionals and the community.</i>

<i>National Heart Foundation</i>	1300 36 27 87 heartline@heartfoundation.org.au	<i>Provides useful information on a variety of heart health topics for patients, their families and carers.</i>
<i>The Stroke Society</i>	1800 787 653 http://www.strokefoundation.com.au/	<i>Works with the patients, carers and stroke survivors to reduce the impact of stroke on everyday lives.</i>
<i>Palliative Care Australia</i>	02 6232 4433 www.palliativecare.org.au	<i>The peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life.</i>
<i>Palliative Care NSW</i>	61 403 699 491 Email: info@palliativecarensw.org.au Website: www.palliativecarensw.org.au	
<i>Palliative Care VIC</i>	Phone: +61 3 9662 9644 Email: info@pallcarevic.asn.au Website: www.pallcarevic.asn.au	
<i>Diabetes Australia</i>	Phone: (02) 6232 3800 Fax: (02) 6230 1535 Email: admin@diabetesaustralia.com.au www.diabetesaustralia.com.au	<i>Supports people with diabetes. Registering with the NDSS can help you to get subsidies on diabetes equipment.</i>

Terminology

Sometimes the words that medical and health professionals use can be foreign or confusing to us. Understanding this language is important and can help you to feel comfortable and more confident in asking questions and understanding your care or that of the person you are caring for.

Below are some common terms and definitions used by medical and health professionals. On the next page there is room for you to write down other terminology that you may not recognise, in order that you can find out its meaning or so that you can remember the meaning for “next time”.

Term	Definition
Advance Care Plan/Directive	<i>A set of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios. They become effective in situations where the person is no longer able to make decisions. For this reason advance care directives are also, though less frequently, referred to as living wills. An advance care directive has legal status and therefore is part of the separate legislative arrangements in each State and Territory in Australia.</i>
Advance Care Planning	<i>A series of steps you can take to help you make Plans for your medical Care in Advance. The process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person’s understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning supports patients in communicating their wishes when they can no longer make decisions, or when they are facing the end of their life. The discussions also help family members and significant care givers know the preferences and wishes of the person they are caring for.</i>
Advanced disease	<i>A disease that is at a late stage or towards the end of the expected trajectory.</i>
Amaranth Social Worker	<i>A Medicare accredited social work (SW) professional, registered with the Australian Association of Social Workers. These SW have considerable clinical experience and are qualified to assess and screen for psychological distress, support your care planning, act as a single point of contact, provide case management if required, advocate for services to support the person or family, and can work with community groups to identify gaps or difficulties in accessing services. Amaranth SW provide therapeutic counselling such as acceptance and commitment therapy, mindfulness, interpersonal therapy,</i>

	<i>cognitive behaviour therapy and grief and loss counselling.</i>
Bereavement	<i>Bereavement is the total response to a loss and includes the process of 'recovery' or healing from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and 'recover' in their own way.</i>
Case Conference	<i>A meeting held between a group of medical and health professionals and other service providers to plan, discuss and exchange information around the care of a patient. The patient and their carer may or may not be present.</i>
Chronic and complex condition/disease	<i>A medical condition or disease that can significantly impact on a person's overall quality of life. Often this type of condition can cause a person to be unable to perform basic physical and social functions. Chronic and complex conditions are characterised by persistent and recurring health consequences lasting for an extended period of time (generally more than six months)</i>
Dignity Therapy	<i>Conducted by Amaranth Social Workers - an approach comprised of tape-recorded sessions, which gives you the opportunity to speak about aspects of life of which you feel proudest. Things you feel are, or were, most meaningful, and aspects of your personal history you would most want remembered. These sessions are transcribed, edited, and returned to you and your loved ones, thereby bolstering your sense of purpose, meaning, and worth, while tangibly experiencing your thoughts and words as having continued value.</i>
End of life	<i>That part of life where a person is living with, and impaired by, an eventually fatal condition or life limiting illness, even if the prognosis is ambiguous or unknown. This is also considered a stage of life where a person reviews their life's journey.</i>
End of life care	<i>End of life care combines the broad set of health and community services that care for the population in general and individuals personally, at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community – working together to meet the needs of people requiring care.</i>
Enduring Guardian	<i>A person appointed by an individual to make medical/health decisions on their behalf. The Enduring Guardianship will only become active at a time where the individual does not have the capacity to make certain decisions for themselves. These decisions may only include medical and lifestyle decisions such as where the individual lives and what services and treatment they should receive.</i>

Holistic	<i>Holistic is a whole made up of interdependent parts. You are most likely to hear these parts referred to as the mind/body/spirit connection or physical, mental, emotional, spiritual aspects. When this meaning is applied to the treatment of illness, it is called holistic medicine and includes a number of factors, such as dealing with the root cause of an illness, increasing patient involvement and considering both conventional and complementary therapies.</i>
Memory box	<i>A therapeutic tool used to collect and keep things that remind people of their loved ones that may have died. They are made to illustrate the possibility of attaching stories to memorabilia which are then kept in a box. Memory boxes are very useful in assisting a grieving child or teenager to mourn the loss of a loved person in their life who has died. A living memory box – The building of ‘memory boxes’ while the loved one is still reasonably well and able to visit places with the family can be a useful way of collecting things that, at a later date, can provide the child with tangible memories. A memory box – Gathering together photos and memorabilia to place in a box of personal memories after the person has died.</i>
Multidisciplinary Team	<i>Consists of a mix of different health care disciplines. Members of this team will share common goals, share relevant patient information and work together in the planning and delivery of patient care. Members of a multidisciplinary team might include GPs, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, speech pathologists, dieticians, volunteers, pharmacists or care assistants. An interdisciplinary team is a team of providers who work together to develop and implement a plan of care. Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. An interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, speech pathologists, pharmacists, and personal care workers. Other disciplines may be part of the team if resources permit.</i>
Narrative therapy	<i>Narrative therapy is sometimes known as involving ‘re-authoring’ or ‘re-storying’ conversations Narrative therapy seeks to be a respectful, non-blaming approach to counselling and community work, which centres people as the experts in their own lives. It views problems as separate from people and assumes people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to change their relationship with problems in their lives. Curiosity and a willingness to ask questions to which we genuinely don’t know the answers are important principles of this work</i>

Palliation	<p><i>To palliate is to alleviate a symptom without curing the underlying medical condition. The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms, and is not necessarily limited to care provided for eventually fatal conditions.</i></p> <p><i>Palliation in relation to end of life care is the relief of symptoms and suffering caused by all eventually fatal or life limiting conditions. Palliation can help a patient feel more comfortable and improves quality of life but does not cure the disease. Palliation of symptoms is a key goal of care for both end of life and palliative care.</i></p>
Palliative Care	<p><i>Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. Care is provided holistically and encompasses medical care along with physical, psychosocial and spiritual care.</i></p>
Practice Nurse	<p><i>A practice nurse is an enrolled or registered nurse employed by a General Practice. A practice nurse can see patients of the practice regarding certain aspects of care and treatment such as injections, blood pressure, minor health checks, health assessments and other generalised health care.</i></p>
Primary carer	<p><i>The primary carer is generally in the close kin network of the patient and is usually self identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, eg the administration of medications. They provide the primary support role for the patient at all levels of need. The carer does not have to live with the patient to be considered the primary carer.</i></p>
Psychosocial Support	<p><i>Support provided to the patient, their carer and family that encompasses psychological, social and spiritual care, emotional and spiritual or existential care. It includes and incorporates the values of dignity, respect and autonomy.</i></p>
Respite	<p><i>Respite is a break from the caring role and/or a support to the caring role that is suited to the patient's individual needs and those of their carer. Respite can include a range of in-home and out-of-home options such as the provision of domestic assistance within the home to ease pressure on the caring role or out- of-home hospice care provided for a patient for a short period of time.</i></p>

Social Worker	<p><i>A health care professional who assesses the social needs of individuals, families and groups, assists and empowers people to develop and use the skills and resources needed to resolve social and other problems, and further human well being and human rights, social justice and social development..</i></p> <p><i>Social Workers can specialise in a range of areas, such as palliative care, oncology, mental health, grief and loss, or work in a generalist environment. A SW can become accredited with Medicare to provide services to people under a referral from their local doctor or specialist. A clinically accredited SW is a member of their professional organisation, and has undertaken considerable training or experience in their chosen field of practice.</i></p>
Support care providers	<p><i>Support care providers include assistants in nursing and personal care staff in aged care homes, volunteers, charitable organisations, complimentary therapists (for example, massage therapists, music therapists and aromatherapists), pastoral carers, and others who provide a supporting role in the care of a patient living with an eventually fatal condition and their family and carers.</i></p>
Terminal condition	<p><i>A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing.</i></p>

Resources

A handy list of resources that you may want to ask about or get a copy of:

- Amaranth Foundation Advance Care planning booklet
- Amaranth Foundation 'Dignity Therapy' brochure
- Amaranth Foundation 'Memory Box' brochure
- Amaranth Foundation 'Continuing Bonds' brochure
- Amaranth Foundation 'Planning for your last days'

- Dying to know – Bringing death to life (<http://www.pilotlight.org.au/Dying-to-Know>)

- Livestrong Guidebook Planner and Journal (Lance Armstrong) (<http://www.livestrong.org/Shop>)

- St John's Carer's handbook

Notes