

Carers guidebook ...

# Supporting end of life care at home



NORTHERN SYDNEY  
CENTRAL COAST  
NSW HEALTH



# *A guidebook supporting end of life care at home*

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## **Are you a carer?**

If you look after a friend or family member who is unable to look after themselves, you are a carer.

You are still a wife, husband, partner, friend, parent, son or daughter – the carer role is just adding something extra.

There is no standard description of a carer as every caring situation is unique. Caring for someone can be a gradual process, or it can happen suddenly. It can last for a few weeks, or several years.

It can occupy a few hours each week, or 24 hours a day.

You might help someone wash or dress themselves.

You might drive them to hospital appointments or do their shopping. You may also provide company and emotional support.

# Help and support

Caring can be hard work and stressful but very rewarding. It can be a confusing time, with lots of new information to take in and many unexpected changes to deal with. It is important for you to make sure health and community care workers know you are a carer. You are an integral part of the care team and it is important that healthcare communication should be a two way process with you included. You may need to remind health providers that you will require ongoing information, assistance and support to be effective in your caring role.

# Using this booklet

This booklet contains information for anyone who may be looking after a friend or relative with a terminal or life-limiting illness. Undertaking the role of carer for end of life care takes a lot of organisation and planning. This booklet provides carers with information on a range of support services, helpful hints from experienced carers and an insight into what to expect as death approaches. Caring for someone as they approach end of life is not something most of us experience everyday. You may choose to read through the entire booklet or skip to sections relevant to your current needs.



# Contents

Page

## PART 1 – CARING AT HOME

Caring for yourself .....	8
Helpful Hints: <i>Lessons from Carers</i> .....	8
Dealing with Stress .....	8
Talk to other carers .....	9
Do you have to be a carer? .....	9
Practical help for Carers .....	10
Advance Care Planning .....	10
Respite – Taking a Break .....	11
Aids & Equipment .....	12
Asking Questions .....	13
Prompt Questions for health professionals .....	13
Helpful Hint: <i>“Asking Questions can help”</i> .....	13
Considering Palliative Care .....	14
Considering Residential Care .....	14
Helpful Hint: <i>“Surviving the Maze”</i> .....	14
Money and benefits .....	14
Work and caring .....	15
Talk to your employer .....	15
Helpful Hint: <i>“Working Carers Gateway”</i> .....	15
Legal & Financial matters .....	16
Helpful Hint: <i>“Organisational Checklist”</i> .....	16
Further Reading/Resources .....	17

# PART 2 – END OF LIFE CARE

- Establishing your Network of Care ..... 19
  - Place of care, Place of death ..... 21
  - Being prepared ..... 22
  - As death approaches ..... 23
  - How will I know...? ..... 24
- When someone dies ..... 25
  - What now? ..... 25
  - Helpful Hint: *After someone dies*..... 25
  - Registering the death ..... 26
  - Organising the funeral ..... 26
  - Who to notify after someone has died ..... 26
- After someone dies ..... 27
  - Talking about your feelings ..... 27
  - Helpful hint: *What helps?* ..... 28
  - When to seek further help ..... 28
  - Helpful Hint: *As time goes on* ..... 29
- Who’s who? ..... 30
- State & National contacts ..... 31
- Local Contacts ..... 32
- Planning Ahead Personal Checklist ..... 33

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For copies of this resource call Carer Support Unit (NSCCAHS) Ph: 02 4320 5556.

(March 2010)

# Caring at home

Many carers have told us that having a network of care to assist, eases the stress of caring and reduces the likelihood of burnout. The network of care may involve other family members, neighbours or paid providers who support the carer in their role – no-one can successfully care for another over a prolonged period of time without additional support. Every caring role is unique.

*At first I was so scared of asking for help, I thought people would think I was not a good wife or they would put Alex in a nursing home. I only needed help with simple things and once they were in place it made all the difference. One of the workers said "with all the care you provide Alex every day it is expected that you will need extra help from time to time" – that was really comforting to me. Carer of husband with Alzheimer's Disease.*

You might need practical support, such as helping the person you are caring for shower. You might want to take a break from caring for a few hours each week. You might also want to plan what would happen to the person you care for in an emergency, such as if you were taken ill. Talk to the Commonwealth Respite & Carelink Centre – 1800 052 222 about the right sort of help for your caring situation.

If you are providing hands-on care, you may need information and advice on the best way to keep both yourself and the person you are caring for safe. You will probably need to know about lifting and moving the person you care for, information about meals and what they can eat, the side effects of medication and how to recognise new symptoms. You will also need information about the illness itself.

*The Carers Handbook: A practical Australian guide to caring for people who are sick, elderly or disabled* is an inexpensive yet comprehensive resource for carers available from Carers NSW telephone: 1800 242 636 (see also Further Reading/Resources section for details p17).

# Caring for yourself

Caring for someone can be physically and emotionally demanding. Your own health is important. If you feel overstretched or become unwell, you will find it difficult to continue in your caring role. So you must consider your needs as well. Make separate health check appointments for you, put them in the diary, and make sure they are kept.

Below is a list of ideas to support you in your caring role generated from Carers who were once in your shoes.

## Helpful Hints: Lessons from Carers

- Cook double portions, so you are not tempted to skip meals.
- Take some exercise – even a short walk just to clear your head.
- Make separate GP appointments for yourself – and keep them!
- Your local health service might offer training on lifting or first aid. If not, talk to your GP about finding similar training courses in your area.
- Be realistic – prioritise tasks and only focus on what you can achieve.
- Don't make yourself indispensable, and responsible for everything.
- If you are offered help, accept it.
- Organise a "telephone tree" to communicate updates about the person's condition rather than calling everyone individually
- Consider "screening calls" rather than answering every time it rings.
- Consider an Advance Care Plan – start discussing your values, beliefs and goals for future health care planning now before a health care crisis occurs. There are a range of tools to assist you and your family start the discussion (See Further Reading/Resources Page 17).

## Dealing with stress

Signs of stress include feeling unable to cope, loss of confidence, lack of concentration, exhaustion or even hostility towards the person you are caring for.

If you feel stressed, it is important to seek advice and support. Many carers turn to family and friends for support whilst others prefer to discuss their concerns with health providers, support group members or carer specific support agencies. The following section explores various strategies and services for carers to help them maintain their vital role at home.



# Talk to other carers

The opportunity to talk with other carers may be a great source of information, support and advice. Support groups are for people with a certain disease or disability and their carers. Health professionals provide carers with information on the specific disease while support group participants provide information on living with the health condition on a day to day basis. This lived experience is what many carers value as a result of their participation in support groups. For details of support groups in your area contact the Commonwealth Respite & Carelink Centre 1800 052 222 or Carers NSW 1800 242 636 or visit the Central Coast Support Groups & Services Directory on <http://www.nscchhs.health.nsw.gov.au/carersupport/cc/servicedirectory.shtml> or call the Carer Support Unit 4320 5556.

# Do you have to be the carer?

It might seem as if you have no choice because of your family situation and relationships. But you do have the right to decide whether or not you take on the role of carer.

People may feel guilty if they do not want to be a carer. Some people feel that asking for help means they cannot cope. But there is nothing wrong with making sure the person you care about receives the best care possible. And you may not always be the best or only person for that role.

There might be some tasks that you are not comfortable with, such as helping the person shower or use the toilet. It may be that your health and wellbeing may be compromised with the expectations of the caring role. The most successful and long term caring relationships are those where carers have a supportive network of people to call on to assist with care.

Depending on locally available community resources you may consider residential care, palliative care in a hospice / hospital / home or a combination. It is best to talk about the options with the people closest to you, healthcare professionals and the person being cared for to develop the best plan that suits your circumstances. Keep an open mind with planning as even the best laid plans may need to be reconsidered.

# Practical help for Carers

## Advance Care Planning

It may be time for both yourself and the person you are caring for to discuss your preferences for future health care and treatment alternatives. Advance Care Planning is a process whereby families talk about their individual values, beliefs and goals for health care treatment in the event they are unable to talk for themselves. Discussing options and preferences may include some form of documentation, known variously as a “Living Will”, an “Advance care directive”, an “Advance health care directive” or other.

The discussion may include topics such as the person’s definition of quality of life, lifestyle decisions, and/or their specific instructions for resuscitation or artificial feeding. It ensures the most important people in your life are aware of your choices should there come a time when you are unable to express yourself. If it is not possible for you to discuss your instructions they can be written down and a copy sent to each person for future reference.

In situations where you cannot speak for yourself health care professionals will seek advice from your substitute decision maker who may be a legal guardian, a family member or friend. It is better to discuss and plan your wishes in advance rather than leaving the decision making to chance or having those closest to you responsible for second guessing your wishes at a time of crisis. Or worse, creating conflict for those you care about if your preferences for health treatment are unclear.

The DVD “Advance Care Planning: A Family’s Journey” available through Hunter New England Health Service is a good tool for you and your family to use to prompt your discussions (see the Further Reading/Resources section for availability).

You may also like to think ahead and discuss preferences for where you would like to be cared for, your funeral plans and any bequests.

Contact your GP or local healthcare provider for information on developing your Advance Care Plan and/or Advance Care Directive. The “ACP – *It’s all about talking and making your voice heard*” workshops and workbook material are available to community members to assist you to discuss and prepare your future health care plans. Contact the Carer Support Unit on (02) 4320 5556 for details of the next Advance Care Planning workshop in your area.

# Respite – Taking a break

Without an occasional break from caring, you may become exhausted or unwell. A break will allow you to do the things you may not have time for while you are caring, such as catching up with friends and family or having a rest.

Carers should consider developing a network of care with other family members, neighbours and friends to share the caring responsibilities. Organise regular times during the week where you have activities apart from caring and involve family and friends in taking over your role.

*“It took time for others to convince me that it would be OK to let go, you know I felt guilty and thought no-one else can care for Mum like I do... but now I can see the benefits... Mum had other family to talk to and laugh with... the kids got to really know their Gran in a way they never would have had I been the only one to care... and I got time for me, to do things that were nothing to do with caring” Carer of mother with terminal cancer*

If this is not possible formal services are available to provide either short-term or regular breaks from caring. This is called “Respite Care.” Appropriately trained staff can provide respite care in the home, community or an appropriate respite facility.

The Commonwealth Respite & Carelink Centre can assist with both practical and emotional support for carers as well as emergency respite care for carers 24 hours a day on freecall 1800 059 059.

Your local Aged Care Assessment Team (ACAT) can assist you to plan for respite in a residential care facility. They will make an appointment to visit you at home, discuss your needs and make recommendations on the most appropriate level of residential care support.

Make sure that anyone who takes over from you has all the information they need. Write down anything important, such as medication and diet, and who to contact in an emergency. Ask the Commonwealth Respite and Carelink Centre for a copy of the *Emergency Planning Kit* to help organise the information.

# Aids & Equipment

People living with terminal illness and their carers should ensure they access all available support services and equipment resources to enable them to remain safe at home for as long as possible. You may want to consider domestic assistance, meals delivery, continence aides, a linen service, aides to assist you both in the bathroom or toilet areas.

Contact Community Nursing (telephone 4356 9400) to discuss your practical support needs at home. If you already have services assisting you at home, ask them about an extension of the service to meet your increasing needs. If you have the finances available think about employing a private nursing or domestic service agency to assist you both at home.

You may also need to consider medical equipment hire, for example a hospital bed, medication aides or oxygen. Discuss your medical requirements with your GP who will assist with the most appropriate referrals. Remember to ask about concessions and other entitlements you may be eligible to receive.

Keeping yourself safe and free from injury is vitally important. Ensure you are given adequate instruction on how to use and maintain the recommended aids and equipment.

When providing hands-on care it is a good idea to think about your own physical health status and ensure you are aware of the correct lifting and transfer techniques. Ask for advice from visiting health care professionals, alternatively the following resources contain instructions and pictures to help you learn more.

*The Carers Handbook: A practical Australian guide to caring for people who are sick, elderly or disabled* contains information on lifting and safe transfer techniques for carers and is available from Carers NSW telephone: 1800 242 636.

*Back to Basics* is a free resource booklet published by the Department of Veterans Affairs telephone: 133 254 is available to veterans and their carers it contains handy hints for carers to help prevent back injuries. The booklet is easy to read and uses photographs to illustrate safe techniques for lifting and transferring at home, into the car and in the community.

# Asking questions

Make sure you ask questions – if you don't ask, others will assume you already know or are not interested in knowing the answer at this time. Carers are not usually trained in their role. Even if you are a professional health provider nothing can prepare you in advance in all aspects of the caring role.

There is a lot to take in so do not be afraid to ask the same questions over again and clarify your understanding. You might find it useful to take notes when you talk to professionals. Using a diary or journal is an effective way of detailing advice given and keeping a record of conversations. Remember to include people's names, dates and a summary of any actions to follow up. Many carers develop a list of questions to take to appointments to make sure they ask all of the questions that are important at that time. Asking questions and clarifying confusion will relieve your anxiety and improve your ability to cope and care.

There may be questions you would prefer to ask when the person you care for is not in the same room. Make separate appointments to enable you to address your own health issues and your health related questions about the person you assist.

What follows is a list of prompt questions as a starting point for discussion with health providers.

## Prompt questions for health professionals

- What is my emergency after hours plan?
- What should I do if I have questions about medical issues that cannot wait to the next appointment? Who should I call, what is their number?
- How do I start talking about preferences around death without sounding negative?

### **Helpful hint: *Asking questions can help***

*"Asking Questions Can Help"* is a free resource from Palliative Care Australia that lists a series of questions to prompt discussions with health providers

**[www.palliativecare.org.au](http://www.palliativecare.org.au)**

## Considering palliative care

Specialist Palliative Care Services may be able to provide additional expert advice and support at this time. Palliative Care Services focus on providing comfort through symptom management (such as pain) as well as supportive care options. Discuss a possible referral with your General Practitioner.

## Considering residential care

Despite your best efforts there may come a time when you can no longer safely provide the level of care required at home and you might need to consider residential care. Your caring role may change whereby the residential care staff will take a lead role in personal care whilst you maintain the social and wellbeing aspects of care.

The decision to move to residential care should be discussed with the person you look after as well as the rest of the family. Many people prefer to take the time to explore residential care options well in advance of requiring residential care. It costs nothing to visit the facility and make enquiries about amenities, fees and available services.

Your local Aged Care Assessment Team (ACAT) telephone: 4304 0700 can also help you with planning for permanent residential care.

### **Helpful hint: *Surviving the Maze***

Carers Victoria has developed a resource for carers called *Surviving the Maze*, a series of easy to read information sheets covering residential care.

**[www.survivingthemaze.org.au](http://www.survivingthemaze.org.au)** or phone 1800 242 636 for more information.

## Money and benefits

Caring for someone can be expensive.

You might find you have extra costs, such as higher heating bills or extra petrol for travel to hospital or specialist appointments. Over time you might leave your job, or be required to cut the number of hours you can work.

In recognition of the costs of caring the Commonwealth government has approved several carer related entitlements paid by Centrelink, they are the Carer's Allowance, Carer Payment and annual Carer Supplement. You may be eligible for the carer benefits even if you are working or receive other pensions or allowances. It is best to make an appointment with the Centrelink Social Worker or Carer Section to discuss your individual circumstances telephone: 13 27 17.

# Work and caring

Juggling work and caring is not easy. You may feel that your only option is to give up work. It is important to think about how this will affect your life, such as your financial position, career development and superannuation. You may also miss the social aspect of work, or find that it gives you a break from caring.

## Talk to your employer

Tell your employer that you are looking after someone. Many employers will be sympathetic to your situation. Some workplaces even have policies to support employees who are carers. Think about your needs, and how your employer could support you. This might include;

- Days off for emergencies
- Time off for hospital or doctor's appointments
- Working part-time or flexible hours
- Having access to a mobile phone at work
- Having someone at work to talk over problems
- Working from home occasionally
- Taking a short break from work

You have the right to take a 'reasonable amount' of time off work to deal with an emergency involving a dependent – it is up to your employer whether this is paid or unpaid. Ask about your entitlements for carers and family leave.

It is important to think about your needs as a carer and the needs of the job, before making a request.

### **Helpful hint: *Working Carers Gateway***

Working Carers Gateway provides information, advice and support to help you achieve balance in your work and home life the website has many helpful ideas to assist your negotiate work-life balance –

**[www.workingcarers.org.au](http://www.workingcarers.org.au)**

# Legal & Financial matters

While you are focussing on day to day care it is easy to forget the need to consider the future financial and legal matters of the person. Thinking ahead and planning can help you avoid unforeseen difficulties.

Consider if there is another family member who can take over the financial planning and decision making while you focus on your personal caring role. Consider a discussion with your solicitor about property matters. Review all banking and investment details and ensure you have accurate information to assist with forward planning. To ensure savings are readily accessible, as the person's condition changes consider having all banking accounts in joint names where either yourself or the person you care for can sign to access funds.

Early access to superannuation funds may be possible in some circumstances. Contact the relevant superannuation fund for more information.

## **Helpful hint: *Planning Ahead Personal Checklist***

A checklist with all bank accounts, membership & registration details, insurance policy numbers and agencies will help you and the person you are caring for plan effectively.

An example Checklist can be found on page: 33-34

This is the time to consider legal matters and ensure that everyone is clear about the person's preferences for the future of their assets and healthcare decision making.

You may need to discuss and formalise the following:

- Making a Will
- Power of Attorney & Enduring Power of Attorney
- Guardianship & Enduring Guardianship
- Advance Care Directive/Advance Care Planning
- Funeral arrangements

More information about legal decision making can be found the following resources:

- ***Your Future Starts Now: A guide for over 50's*** – telephone: The Benevolent Society on (02) 9339 8000
- ***The Planning Ahead Kit*** telephone DADHC on (02) 8270 2000
- ***Guardianship Tribunal*** website: [www.gt.nsw.gov.au](http://www.gt.nsw.gov.au)



# Further Reading / Resources

*Advance Care Planning: A Family's Journey* – short DVD available from Hunter New England Health Service. Telephone: 4924 6003.  
[www.hnehealth.nsw.gov.au/advance\\_care\\_planning](http://www.hnehealth.nsw.gov.au/advance_care_planning)

*Advance Care Planning – It's all about talking, and making your voice heard!* – a free self paced workbook available from Carer Support Unit (NSCCAHS). Telephone: 4320 5556.

*Carers handbook: a practical Australian guide to caring for people who are sick, elderly or disabled* – available from Carers NSW telephone 1800 242 636

*Guardianship Tribunal – How to appoint an enduring guardian, or an enduring power of attorney.* See their website under “Publications – Plan for your future” Telephone: 1800 463 928; TTY: 9552 8534, [www.gt.nsw.gov.au](http://www.gt.nsw.gov.au)

*Helping you to care for a person with cancer: A self help guide for partners, family & friends* – a free resource available from the Cancer Council NSW. Telephone: 13 11 20.

*Respecting Patient Choices* provides a guidebook for the development of an Advance Care Plan to be used to make lifestyle decisions on your behalf should you be unable to communicate your wishes in the future. Telephone: 4924 6182. [www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

*The Planning Ahead Kit* – Ageing Disability & Homecare (ADAC) Information on enduring powers of attorney, enduring guardianship. Available to download from the website under “Publications and Policies – Relating to Ageing” (or telephone to request a copy be sent) Telephone (02) 8270 2000.  
[www.dadhc.nsw.gov.au](http://www.dadhc.nsw.gov.au)

*Your Future Starts Now: A guide for over 50's* – The Benevolent Society contains Information about planning for the future, wills, powers of attorney, enduring guardianship. Download a copy from the website under “Resources” and type in “Your future starts now: A guide for over 50's” Telephone: (02) 9339 8000.  
[www.bensoc.org.au](http://www.bensoc.org.au)

**For veterans and their carers the following free resources are available from DVA (133 254) or your local VAN (1300 551 918) office:**

- *Carers Booklet: Assistance for the veteran community*
- *Living with dementia: A guide for veterans, their families and carers*
- *Back to Basics – handy hints for carers to help prevent back injuries*
- *Planning Ahead: a guide to putting your affairs in order*

# PART TWO – End of Life Care

This section provides suggestions to support carers in the provision of care for someone nearing the end of life. During this time you may want to ensure that you have a clear understanding of the person's preferences for health care and medical treatment.

Based on the experience of others who have cared for a dying family member at home the following are seen as “essentials” to help you prepare for this phase of your caring role. They include:

- an agreed after-hours GP & after hours emergency plan,
- establishment of your network of care,
- the dying person's wishes clarified in an Advance Care Plan and/or Advance Care Directive,
- information on “what to expect” at time of death,
- preferences for place of death
- funeral details and wishes for celebration of life
- location of personal documents

An event is only an **emergency**  
when there is no plan

Talk to the person you are caring for about what they want to see and do in the last few months. They may want to visit a particular place or be involved in an event. Given the right level of help and support the person's wishes may be possible.

# Establishing your network of care

Caring for someone reaching the end of their life should not be left entirely to one person. Carers should consider accepting practical, medical and/or emotional support from a range of sources both within and outside of the family.

There will be some caring tasks that will come naturally while others are best undertaken by others. For some, the network of care may include any or all of the following: family and friends, allied health (eg physiotherapy, occupational speech pathology), alternative therapies (eg massage, aromatherapy, reflexology), nursing care, medical specialist and GP. Discuss your thoughts with family and health care professionals to develop a team approach to care.

Your GP is key to your success and should be readily accessible to you at home should you have any concerns about the medical needs of the person you care for. Ask your GP if they are available for home visits, ask for a mobile phone contact, make regular appointments – every two weeks is not unexpected at this time.

## **Helpful Hint: After Hours Plan for Carers (example)**

Should the patient's condition get worse, the patient wishes to be cared for at:

[ ] Home or [ ] Hospital or:

.....

Who do I contact should the patients condition get worse at home:

Office hours: ..... Telephone: .....

After hours: ..... Telephone: .....

Weekend: ..... Telephone: .....

In the event that a health crisis occurs and the GP cannot be contacted the following plan, as discussed with the GP, patient and myself (as well as other providers such as the palliative care team), will be followed:

.....

.....

Some carers seek out specialised private nursing services, allied health and community nursing through DVA or specific palliative care providers to support care at this time, while others rely on experienced family and friends.

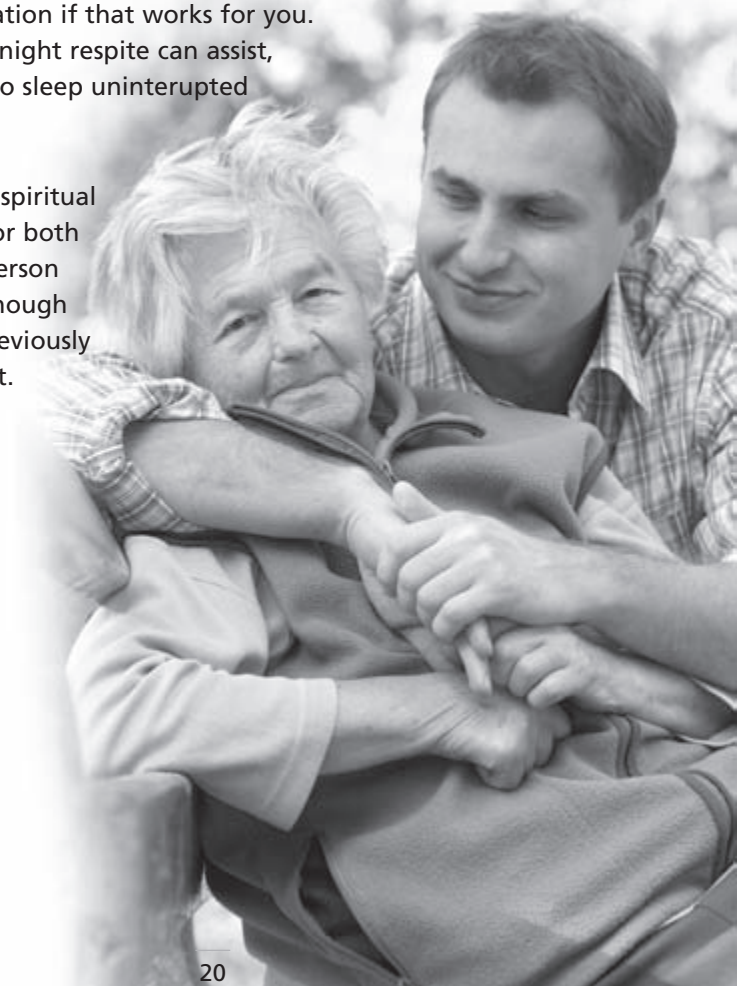
Carers may find comfort in support from experienced mentors, such as those provided through Home Hospice 1800 132 229 (see “Who’s Who” section for more details).

Do not feel guilty if you find the caring role difficult or if you find yourself wishing it would end. This is normal and expected.

Take regular breaks from the bedside to do things that are important to you, go for a walk, listen to music, “potter” in the garden, make time for relaxation and meditation if that works for you.

Some carers find overnight respite can assist, giving them a break to sleep uninterrupted for a few nights.

Many carers seek out spiritual or religious counsel for both themselves and the person requiring care even though they may not have previously relied on such support.



# Place of Care, Place of Death

Although many people say they would prefer to die at home for a range of reasons this may not be possible. Despite the best laid plans circumstances may change and the preferred place of death may also change. Given these realities there is a need to discuss the best place for care on an ongoing basis.

Home for some may be an aged care facility, hospice or for Aboriginal and Torres Strait Islanders going home to country is important.

Carer needs and their capacity to maintain care at home must be considered in determining the best place of care. Discuss your needs with your GP, palliative care nurse or trusted health care provider.

A carer may not feel comfortable discussing their needs in front of the person who is unwell. An opportunity for carers to express their needs and concerns should be sought without being judged (adapted from CareSearch website [www.caresearch.com.au](http://www.caresearch.com.au)).

Strategies to support end of life care may be individualised to respond to the needs of the dying person and their carer, only if their differing needs are explored and understood. Not everyone has the ability to provide end of life care at home. However with open discussion and effective planning the best possible care plan can be effectively negotiated.

*When the time came and Jack was getting close I kept thinking "I can't do this... I couldn't live with myself if he died at home"... I know that's what he wanted but I was petrified of being here alone at night and losing him. I spoke to the community nurse who was great; she sat down with Jack and we talked about it. Jack died peacefully in the hospice two days later, we were together at the end but I didn't feel alone.*

Carer of husband with terminal cancer

# Being prepared

You might choose to talk to the person you are caring for about what they want at their funeral:

- Whether they want to be buried or cremated
- Whether they want a religious or non-religious service
- The hymns, music or readings they would like
- How they would like to be dressed
- The sort of memorial they want

You might also want to ask about any other specific requests such as organ and tissue donation. It is less stressful for the whole family if the individual's wishes are known and discussed in advance.

If the person has discussed an Advance Care Plan or written an Advance Care Directive now is the time to ensure the information is still current.

You should have a copy of their wishes available and accessible for health care professionals to view and consider in planning medical care if required.

If the person has clearly detailed any medical treatments they do not want it is a good idea to have the GP confirm those wishes in writing so they are available to emergency medical staff and ambulance officers. It is one way you can ensure the person's voice is heard and their wishes understood.

# As death approaches

Talk to the person you are caring for about what they want as their death approaches. They might want music, candles, sunlight or a view of the garden.

Ask them to tell you about anyone in particular they would like to see again. Ask if they need help to write down messages or thoughts to give to another person. This may also be the time to say the things you have not had a chance to say before.

As death approaches, you may notice a day-to-day (even hour-to-hour) deterioration. People normally become weaker and increasingly drowsy, until they become bed bound and perhaps semi-conscious.

The person may refuse food or drink. Don't force them to eat as it may make them uncomfortable. There is normally a period of unconsciousness – lasting hours to days – before someone dies.

Swallowing may become difficult. Medicines may need to be given using a small pump called a syringe driver, to make sure that pain and other symptoms are controlled as well as possible. These are provided by the palliative care service.

Before death, it is normal for breathing patterns to change or for someone to sound 'chesty' – this does not usually cause distress to the person. However if you have any concerns about breathing talk them over with your GP or palliative care or community nurse. Extra medication may be given to assist.

Uncontrolled movements may occur, such as restlessness or twitching. Should these occur discuss them with your GP or palliative care nurse. You may also notice a change in their skin colour and body temperature.

Although there is some predictability with the process of dying not everyone will show the signs and symptoms listed above. It might help to talk to a doctor or nurse about your concerns and fears – these questions are expected – if you do not ask, health professionals may assume you have no concerns or don't want to know at this time.

# How will I know...

Many people have never seen another person die so do not know what to expect. You may be feeling apprehensive about what will occur but the moment of death is usually peaceful. It is expected you will need to ask questions and have more contact with health professionals as the time of death approaches.

*“While it is difficult to predict exactly how someone will die, there are some physical changes that are often experienced when a person is nearing death. It can be very difficult to watch a loved one go through these changes, but it is important to remember that they are a natural part of the dying process and do not mean that the person is in pain or distressed. How long the dying process takes varies from person to person. It may take just a few hours, or might take several days”.*

A useful resource for additional information on what happens in the final days of life can be found on the Cancer Connections website:

**[www.cancerconnections.com.au](http://www.cancerconnections.com.au)**

If something is worrying you... ask. Healthcare professionals cannot always anticipate your concerns and will sometimes only give you information in response to your direct questions. If asking directly is difficult, write down your questions.

Every person's death is unique. The process is usually a gradual winding down of the body over several days.

The person may appear to be unresponsive but may still be aware of your presence, feel your touch and hear your voice. Eventually the person's breathing will stop, pupils will be fixed, and there will be no heartbeat or pulse.



# When someone dies

## What now?

You do not have to do anything straightaway. It is okay to spend some quiet time with the person who has died, or take time for yourself. You may want to call a family member or friend to be with you.

If the person dies at home, the doctor is the first person to contact. However if the person dies during the night you may decide to wait until morning before calling the doctor. This is when your **after hours plan for carers** developed with your GP and Palliative Care team will be most useful as it will detail any specific steps you should take in advance.

The doctor will need to sign a certificate that confirms the death. Your funeral arrangements cannot begin until the doctor has signed and given you a copy of the certificate – generally called a “doctors certificate of cause of death” or “cause of death certificate”. This document is not the “death certificate” which is issued later by the Registrar of Births, Deaths & Marriages.

### Helpful hint: After someone dies

There is no need to hurry. If a decision has been made for the deceased to remain in the home it is a good idea to remove or turn off heaters & electric blankets. It is important to straighten the person in the bed as their arms and legs will stiffen, and replace their dentures.

You may want to bathe the person but this is not necessary. You can sponge away any perspiration or body fluids that worry you. Shaving a person after death requires special techniques and is best not done at home.

(adapted from the Palliative Care Victoria brochure “about – the process of Dying” June 2008)

If the person you are caring for dies in a hospital, you can have some quiet time alone with them, if you wish. The healthcare staff will discuss the specific arrangements for care of the person’s body until the funeral director takes over care.

If the death is sudden, or the cause is uncertain, an autopsy may be required. The healthcare staff or your doctor will explain to you what will happen and the reasons why.

# Registering the death

If you have arranged a funeral director to take charge of the funeral arrangements they will organise the necessary paperwork needed to register death and send it to the appropriate State or Territory authority called the Registrar of Births, Deaths and Marriages.

Some people decide to make their own private funeral arrangements and are required to lodge the doctor's certificate of cause of death with the Registrar who generates a Death Certificate and sends it to the next of kin.

# Organising the funeral

It is recommended that individuals & their families discuss their funeral wishes well in advance. Some may have discussed their preferences during their Advance Care Planning while others may have detailed their wishes as part of their will. If instructions have been detailed in the will, the Executor is responsible for carrying out the person's wishes, however they may not be responsible for arranging the ceremony. The deceased person may have made provisions for a funeral plan or funeral bonds to assist the family in planning. Again it is better for the family that funeral arrangements are discussed and understood before death.

# Who to notify after someone has died

Think about whom else in the family could assist you in this task of advising family & friends. Some carers organise in advance a telephone tree to share information about the person's condition rather than individually calling each family member, the same method could be used to share the news of someone's passing and funeral arrangements.

You may find the Planning Ahead Personal Checklist on pages 33-34 a useful place to start planning the notifications to services and agencies. Centrelink have prepared and published a very useful free resource to assist, called "Needing help after someone has died." The resource provides information to carers about bereavement entitlements, financial planning and emotional support as well as sample letters to organisations should you wish to provide advice in writing of the persons death.

# After someone dies

Feelings of grief and loss affect people in different ways and for different lengths of time. You may be feeling a mixture of the following – shock and disbelief, depression and apathy, relief, anger, and in time, signs of recovery.

Try not to be influenced by others telling you how you should be feeling. There is no right or wrong way to grieve.

## Talking about your feelings

Some people find that talking to others is one of the best ways to deal with these feelings. You may feel comfortable talking with family or close friends or someone you know who has been in a similar position. You may like to consider making time to talk to a spiritual or religious advisor. Consider writing down your thoughts in a journal or diary as a way of expressing how you feel.

If the Palliative Care Service has been involved they will automatically contact you and offer a range of bereavement support and counselling options. Please contact them if you want to discuss these earlier. If the Palliative Care Service has not been involved, then talk to your GP about referral to bereavement counselling for yourself or another family member. You may also have links to the community nurse or a social worker who can help you find appropriate support.

*“I was so busy being Fred’s carer that now he has gone I don’t know what to do with myself. It feels like I have nothing to do with my days... our friends have been marvellous but no-one warned me that I would be feeling so empty and lost”.*

Carer of veteran with dementia

In many communities there are local support groups to support grieving families. Carers NSW (freecall 1800 242 636) or Commonwealth Respite & Carelink Centre (freecall 1800 052 222) may be able to assist with information, or search the Central Coast Support Groups & Services Directory on the link below or call 4320 5556

<http://www.nscchah.health.nsw.gov.au/carersupport/cc/servicedirectory.shtml>

## Helpful Hint – What helps?

- ✓ **Be patient** – allow yourself as much time as possible to grieve – don't push yourself or be rushed by others.
- ✓ **Cry** when you feel the need
- ✓ **Recognise** that strong emotions are normal
- ✓ **Talk** about feelings, needs, and memories
- ✓ **Draw** on all your resources – family, friends, church and others
- ✓ **Allow** others to help you – being stoic is exhausting
- ✓ **Treasure** those who can grieve with you rather than attempt to take away your pain
- ✓ **Take care** of yourself physically, even if it's difficult, eat right, exercise and rest regularly
- ✓ **Trust yourself** – your instincts are your best guide

Copied with permission from Bereavement Support Service Mid North Coast AHS

## When to seek further help

Although grief can be painful, most people find that with the support of their family and friends and their own resources, they gradually find ways to learn to live with their loss, and they do not need to seek professional help. However, reach out for professional assistance if you feel the need, especially if some of the following occur:

- Over time you remain preoccupied and acutely distressed by your grief or there is total absence of grief
- You experience panic attacks or other serious anxiety or depression
- You have thoughts of self harm
- You find yourself unable to attend the tasks of daily life, such as going to work or looking after the children
- You do not have people who can listen to you and care for you

(Copied with permission from Palliative Care Services Mid North Coast AHS)

## Helpful Hint – As time goes on

Everyone will experience grief in his or her own way. It will last as long as it is supposed to last. Your memories, thoughts and experiences of life with your loved one will always be part of you, to recall whenever you choose. Share your feelings with someone who has some understanding of grief and who is willing to listen. Someone has died whom you feel deeply about and it hurts.

Try to allow yourself to experience the pain so that you may work through it. Grief demands time. Allow yourself as much time as you need to grieve.

### **REMEMBER:**

- Be patient with yourself
- Express your thoughts & feeling
- Take care of yourself even if you don't feel like it

Sources from "Early Grief" a booklet developed by Community Health Palliative Care Service  
Mid North Coast AHS



# Who's who?

The following is a list of the more common health workers supporting veterans and their carers in the community

**Personal Care Assistants or Care Workers** help with tasks at home, such as dressing, washing and housework etc. There are several funding sources for in-home assistance and support such as Commonwealth Funded Community Aged Care packages (CACAP) & Extended Aged Care in the Home (EACH); DVA funded Veterans Homecare (VHC) or community services via Home & Community Care (HACC).

**Community Palliative Care Nurses** are specialist clinical nurses, skilled in pain and symptom control. They give emotional support and practical advice to patients and their families, from diagnosis onwards.

**Community Nurse** provides regular nursing care and practical advice in the home.

**GP** (General Practitioner or family doctor) is responsible for all aspects of medical care at home, and can arrange help from other professionals or services.

**Home Hospice** offers a free program of one to one mentoring support to caregivers. Mentors focus upon carer needs, offering practical guidance and enabling carers to access the supports needed during this challenging time.

**Occupational Therapists** give advice on and provide equipment to help make daily life easier, eg help with the bath, toilet or the stairs.

**Oncologists** are doctors who specialise in treating cancer. A clinical oncologist treats cancer with drugs. They are often based at cancer centres, but they may also see you at your local hospital.

**Physicians, Surgeons and Hospital Doctors** are based in the hospital and specialise in a particular area of medicine.

**Physiotherapists** teach people special exercises to improve things or stop something getting worse. They will sometimes teach breathing exercises and passive exercise.

**Social Workers** can help you get emotional support, practical help and financial assistance. They are often employed by area health services. Some social workers work in hospices and hospitals. Some specialise in a particular area, such as working with children or bereavement support.

**Central Coast Palliative Care Service** health workers who only work in Palliative Care may include doctors, nurses, bereavement counsellors, volunteers, and others.

# State & National Contacts

## **Aged care contacts**

- Aged Care Assessment Team (ACAT) call CC&RC..... 1800 052 222  
Aged Care Information line ..... 1800 500 853  
[www.agedcareaustralia.gov.au](http://www.agedcareaustralia.gov.au)  
Aged Care Rights Service ..... 1800 424 079  
[www.tars.com.au](http://www.tars.com.au)

**Cancer Council Helpline** ..... 13 11 20  
[www.cancerCouncil.com.au](http://www.cancerCouncil.com.au)

**Carers NSW** ..... 1800 242 636  
[www.carersnsw.asn.au](http://www.carersnsw.asn.au)

**Centrelink Carers Line** ..... 13 27 17  
[www.centrelink.gov.au](http://www.centrelink.gov.au)

**Commonwealth Carelink & Respite Centre (CC&RC)** ..... 1800 052 222

**Department of Veterans Affairs (DVA)** ..... 133 254  
[www.dva.gov.au](http://www.dva.gov.au)

- Veterans' Affairs Network (VAN)..... 1300 551 918  
Veteran Homecare Assessment Agency (VHC)..... 1300 550 450  
Veterans & Veteran Families Counselling Service (VVCS) ..... 1800 011 046

**Home Hospice** ..... 1800 132 229  
[www.homehospice.com.au](http://www.homehospice.com.au)

## **Mental Health**

- Sane Mental Illness hotline ..... 1800 187 263  
[www.sane.org](http://www.sane.org)  
BeyondBlue Information line..... 1300 224 636  
[www.beyondblue.org.au](http://www.beyondblue.org.au)

**Motor Neurone Disease** ..... 1800 777 175  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au)

**Multiple Sclerosis** ..... 9646 0600  
[www.mssociety.org.au](http://www.mssociety.org.au)

**Muscular Dystrophy Assoc.** ..... 1800 635 109  
[www.mdansw.org](http://www.mdansw.org)

# State & National Contacts *(Continued)*

<b>NSW Cancer Council Helpline</b> .....	13 11 20
<a href="http://www.cancerCouncil.com.au">www.cancerCouncil.com.au</a>	
<b>Palliative Care NSW</b> .....	9206 2094
<a href="http://www.palliativecareNSW.org.au">www.palliativecareNSW.org.au</a>	
<b>Palliative Care Australia</b> .....	6232 4433
<a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a>	
<b>Parkinson's Disease</b> .....	1800 644 189
<a href="http://www.parkinsonsNSW.org.au">www.parkinsonsNSW.org.au</a>	
<b>Spinal Cord Injuries Australia</b> .....	1800 819 775
<a href="http://twwww.scia.org.au">twwww.scia.org.au</a>	
<b>Stroke Foundation</b> .....	1800 787 653
<a href="http://www.strokefoundation.com.au">www.strokefoundation.com.au</a>	
<b>Young Carers</b> .....	9280 4744
<a href="http://www.youngcarersNSW.asn.au">www.youngcarersNSW.asn.au</a>	

# Local Contacts

..... Phone .....

..... Phone .....

..... Phone .....

..... Phone .....

..... Phone .....

..... Phone .....

..... Phone .....



# PLANNING AHEAD PERSONAL CHECKLIST

Organisation	Contact details	Details (membership/ account number)	Notification
Accountant			
Australian Tax Office	132 861		
Australian Electoral Commission	132 326		
Bank/s			
Credit Union/s			
Centrelink	132 300		
Child Support/Child Care			
Clubs (sporting, RSL)			
Credit card/Dept Store credit			
Community Services (Homecare or Meals on Wheels)			
Department of Veteran Affairs (DVA)	133 254		
Doctor			
Electricity			
Employer/s			
Enduring Guardian			
Enduring Power of Attorney			
Executor of Will			
Funeral bond: Yes / No			

# PLANNING AHEAD PERSONAL CHECKLIST *continued*

Organisation	Contact details	Details (membership/ account number)	Notification
Funeral Insurance: Yes / No			
Gas			
Pharmacy			
Private Health Insurance			
Allied Health professionals (Physiotherapy, OT, Dentist)			
Hospital			
Insurance Companies: Personal & Property			
Investment/s			
Local Council (rates)			
Medical Specialists/ Surgeon			
Medicare	132 011		
Religious/Spiritual leader			
Preferred Funeral Service			
Pre-paid Funeral: Yes / No			
Telephone (home/mobile)			
Roads & Traffic Authority (RTA) Vehicle & Licence			
Solicitor			
Superannuation Fund			

Checklist based on Information contained in: Planning Ahead: a guide to putting you're affairs in order from DVA (2008) and Needing help after someone has died from Centrelink (2009)

# Notes

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A guidebook ...

# Supporting end of life care at home

