



LifeCircle Help Sheets

<http://www.lifecircle.org.au/resources-categories/helpsheets>

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Taking care of yourself

Caring for someone facing the end of life is challenging. But it can also be fulfilling. If you have not had any experience of caring for someone who is seriously ill you may feel overwhelmed, anxious or ill equipped to deal with their needs. You may be finding it difficult to cope with the changes to your own life. Even if you have had experience of caring you may not have cared for someone who is seriously ill or dying.

This help sheet is about some of the feelings you may have and how you might take care of yourself during this time. The old saying that you can really only care for others if you care for yourself is especially true as you care for someone who is seriously ill or dying.

Taking care of yourself

When you are caring for someone who is facing the end of their life you may be confronted by powerful thoughts and feelings. As the main carer you may feel others are relying on you to 'be strong' or 'to cope' and so you may try to ignore your own feelings. This is very common but it can have a harmful effect on your own health and wellbeing. When you take time to manage your own emotional needs you may find yourself better able to care for someone else and have greater confidence and clarity.

Building confidence and resilience

It is very important to remember that dying is a natural part of living. Building confidence can help you appreciate the journey you are sharing with the person you are caring for and help to make it more rewarding for both of you.

Feeling distressed, agitated or just plain exhausted is natural when caring for someone who is in the last few months or weeks of their life. It is challenging and you may have many questions and feelings of uncertainty. Taking time to clear your mind and find a little peace can help you think more clearly and can calm the thoughts and feelings you might have from time to time. This will help you be more resilient and able to maintain your own health and well-being while you focus on the tasks and responsibilities of caring.

The following relaxation techniques may help. They are just suggestions and you may have other ways of relaxing and calming yourself. If so think about what works for you and try to find the time and space to take care of yourself.

- Take a walk, even a short one, each day if you can. Walking can help lift your mood and calm you down at the same time
- Listen to your favourite music or pick something that suits your mood

- Take a few moments to write down your thoughts without judging the quality of the writing. This can help you clear your mind and lift your mood. No one needs to see what you have written; it is just for you.
- Take some time to breathe quietly and just be in the moment.
 - Move to a quiet place, close your eyes and make your body comfortable
 - Concentrate on breathing in and out at a comfortable pace
 - Try not to think about anything but the rhythm of your breath
 - Find a book, story, photo, or something in nature that will help lift your spirits.

Whatever technique you choose, try to do it each day. Taking the time to relax even for a few minutes each day can help you remain calm and able to care to the best of your ability.

You are not alone

It is important to realise that you are not alone. You may feel completely responsible for everything and think that you must 'cope' without asking for help. However there are community and health services that are there to support the person you are caring for and you as their carer. These are detailed in other LifeCircle help sheets.

Give yourself permission to call on family and friends; even though they may have busy lives they are usually very keen to help. Often you only have to ask. They know that what you are doing is difficult and for many it relieves their own feelings of helplessness to be able to do something useful for you and the person you are caring for.

The changing face of love

Your relationship with the person you are caring for will be changing in many ways as you both come to terms with their illness. You may be feeling uncomfortable about what this means. This is common and happens to many people at this time.

It can help to talk about and share what you both value and cherish in your relationship. Together you are on a journey of transformation and communicating openly can help you both.

Grief starts now

You may be experiencing the beginnings of grief already, a realisation that you have lost the person you used to know and the life you used to have. You may be grieving for:

- The loss of certainty in your own life
- The loss of your hopes and dreams
- The loss of familiar routines
- The loss of your own identity



- The loss of friendship, fun and laughter.

Whatever is causing you grief at this time give yourself a chance to feel it and to talk to someone about it. Your caring journey will be enhanced, not diminished, as you pay attention to your own emotional needs as well as those of your loved one. If you are feeling overwhelmed by grief it can help to speak with a trusted friend, someone from your community, place of worship or your LifeCircle mentor. Your GP or health clinic can also put you in touch with a professional counsellor if you need one.

Next steps

LifeCircle trained volunteer mentors are available to give you on-going support and guidance. They have all had experience of caring. They can answer your questions and provide information about local services; they can help you access the support you need and help you prepare for the future. Most importantly they can give you emotional support and be a sounding board for up to a year after the death of the person you are caring for. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Personal Care for Someone who is Seriously or Terminally Ill

If you have not had any experience of caring you may feel less equipped to deal with the needs of someone who is seriously ill. If you have had experience of caring you may not have ever cared for someone who is approaching the end of life.

Even without training you will be able to do a lot of personal care tasks and with practice you will develop a routine and a way of managing that is practical and suits your needs and needs of the person you are caring for.

What is personal care?

Personal care consists of tasks that someone would normally do for themselves but because of illness, disability or frailty they need another person to help them or to do them. Personal care tasks include:

- Help (or supervision) with bathing, showering, or washing
- Help with dressing and undressing
- Help with shaving, hair care and grooming
- Nail care
- Help with getting in bed and out of bed, sitting up, turning, standing and walking, sitting, transferring to the toilet or commode, wheelchair, regular chair or vehicle
- Help with eating and drinking including cooking and preparation of food and special diets
- Help with going to the toilet
- Help with doing exercises or therapy programs
- Help with hearing aids and communication devices
- Monitoring and sometimes giving medication.

This help sheet gives you tips to safely manage a number of personal care tasks for someone who can no longer do them for themselves.

Bathing

Safety is the priority when you are helping someone to bath, shower or wash. Getting a nurse or Occupational Therapist (OT) to help you set up the bathroom or sink area is the best way to ensure that it is safe and practical. You might need non-slip mats, a bench over the bath or handrails installed.

Bathing in bed - If you are bathing a person in bed, make sure you have all the equipment you need before you start: a bowl of warm water, soap, cloths, a couple of towels and some moisturising lotion. Make sure the bed is as high as it goes; this will reduce the strain on your back. Starting at the top of their body, work your way down, keeping the parts you aren't washing covered, perhaps with a sheet or towel. Wash genitals and bottom last from front to back between the legs.

This is a good time to check for any redness on the bony areas and gently massage the skin with some lotion. There is a section that explains more about skin care below. Waterproof creams are the best as they help protect skin that might be exposed to incontinence or moisture. This might be a good time for a gentle back rub or to massage the hands or feet.

Don't forget the finishing touches a person specifically prefers or asks for: shaving, cleaning nails, brushing hair and applying make-up. Or, if the person is quite tired after the bed bath, you might want to do this later on.

Hair care

For many people keeping their hair clean and well groomed can make a big difference to how they feel.

If the person you are caring for can't wash their own hair in the shower or bath, washing hair in bed can be challenging but it can be done. Some people use a plastic basin or an inflatable basin with a drain hose that is especially useful for long hair. Others use plastic liners and jugs of water. A visiting nurse can show you the best way and perhaps help you the first time.

Dry shampoo sprays or powders and special products such as a cap containing shampoo and conditioner that can be heated in the microwave and doesn't need rinsing are also available and you may be able to get the from a pharmacy or chemist shop.

A haircut might lift the spirits of the person you are caring for. You could ask their regular hairdresser if they provide an in-home service. If not, try the phone book or you could ask a hospice for a contact number.

Using the toilet

Safety is a big issue when using the toilet. An OT is the best person to advise on ways of making the bathroom safe for toileting. They can provide guidance on handrails and other aids as well as arranging for them to be provided. If significant adaptations need to be made to make the bathroom accessible and safe it is best to have an OT assessment before making any big changes.

If a person can still get to the toilet by themselves, you may need to install handrails for safety and make sure they can't slip on anything. Make sure they can reach the toilet paper easily. If they need help with wiping, make sure they feel comfortable with whoever is helping them.

If the person can't get to the bathroom, a commode chair can be useful. It has a toilet seat with a bowl underneath and is usually on wheels. Check that the brakes are locked on the wheels before use. Consider the person's privacy and dignity. It might be more practical to use the commode next to the bed but it may be more dignified for them to be wheeled to another, more private place.

If the commode is used in their bedroom, you may want to have sprays or oil burners around to help mask any unpleasant odours.

Using a bedpan can feel strange and uncomfortable and generally takes some getting used to. Warming up the pan with hot water can take the chill off a plastic or metal one. Be sure to dry it before using it. Sprinkling some talcum powder around the rim can help stop the buttocks sticking to the pan. A 'slipper pan' that has a thin edge at the back, is often easier to manoeuvre under larger people. You might want to place a protective sheet under the buttocks before placing the bedpan under the person you are caring for.

Ask a nurse to show you how to best position the person and place and remove the bedpan to prevent spills and ensure as much comfort as possible.

Portable urinal jugs make it more convenient for men to urinate in a chair or in bed. Take care when removing a full urinal from the bed so that it doesn't spill. Again a nurse will be able to help you learn how to do this.

Mouth care

Keeping the mouth clean can help prevent infection and also make eating and drinking more enjoyable. Cleaning teeth might be one of a few activities a person can manage on their own or with a little help.

Cleaning someone else's teeth can be a bit awkward. Sitting up is the best position if possible and a **soft** toothbrush might be best if there are sore areas in the mouth. Warm water helps soften the brush. If toothpaste is too strong on the gums, using bicarbonate of soda on the toothbrush may be much less abrasive.

Special **mouth swabs** like large cotton buds and mouth-rinsing **liquids** can be used to clean the mouth. Take care not to get the swabs too wet, as they could break off inside the mouth. Avoid alcohol-based mouthwashes as they can dry the mouth. Some people find sucking on small pieces of ice, gauze or swabs soaked in ice water, sugar free lollies or lozenges, special mouth sprays or chewing special gum helps relieve a **dry mouth**. All of these products are available at pharmacies.

Don't forget the lips. A mild balm like lanolin or pawpaw ointment adds moisture and helps prevent chapping.

Skin and pressure care

If someone spends a lot of time in one position lying in bed or sitting in a chair their skin may be at risk of tearing or deteriorating and forming a pressure sore. Pressure sores may develop wherever the weight of the body presses the skin onto a surface especially on bony areas. Sores usually start as a reddened or tender area and can develop into a raw open wound. For people with fragile skin and those who have lost a lot of weight just moving arms or legs across sheets can sometimes tear the skin.

Painful pressure sores can be prevented using a few techniques:

- Limit the amount of time in one position. This may mean turning or moving every couple of hours.
- Elevate any bony areas so that they are not resting on anything for too long. Make sure that this doesn't affect the person's circulation in any way.
- Place something soft under the heels, elbows, buttocks and between the knees. Materials with soft ripple surfaces such as lambs' wool are gentler than a sheet or blanket. Special egg crate mattress overlays placed under sheets lift and protect the area slightly and help the air circulate, reducing the pressure between the two surfaces. Electric air-filled mattresses ripple waves of air along the bed under the sheet.
- Make sure nothing is pressing against the body and that the body is not leaning or pressing onto anything like catheter tubing or the hard bed or chair edges.
- Gently massage the limbs, back, hands, fingers and ears with a gentle moisturising lotion to help keep the blood circulating. Back rubs after bathing are often comforting.
- Keep the sheets as smooth and dry as possible as wrinkles and wetness can affect the skin.

Check the skin regularly, every day if possible. Bath time is often a good time. If the skin is very red or has broken, great care must be taken to protect the area and you may want to get professional advice. If you think pressure sores are likely to become a problem it is best to get specialist advice before they develop. The palliative care team or specialist community nurses can make sure that you are doing everything you can to prevent them and can treat them if they develop.

Preventing infection

You may need to think about ways to protect the person you are caring for from infection and germs as it is likely their immune system won't be working very well. This is especially important if they have lots of visitors particularly in the cold and flu season. There are a few simple precautions you can take:

- Wash your hands after helping with personal care, especially if you've come into contact with body fluids. Warm soapy water is best or a disinfecting liquid available in pharmacies and supermarkets more practical. Keep your nails short as long ones could scratch or get caught.
- Use disposable latex gloves when you're handling any body fluids. Anything that has been in contact with blood or body should be put into two bags before going into the garbage. Disposable plastic aprons may help to protect your clothing or you might just want to have a supply of old comfortable clothes that can be quickly and easily washed and dried.
- Some people wear a surgical mask if they have a cold. While practical, this might be uncomfortable or seem too clinical.
- Reschedule visitors who are not well or coming down with flu or a cold.

Tips for staying safe around the house

If a person is mobile it's important to take some basic safety precautions at home to prevent falls and other injuries. Remember that an OT can assess your home, recommend and in most cases organise any modifications needed.

- Remove throw rugs and scatter mats to prevent slips, especially if the person you care for uses a walker, cane, or crutches
- If rugs interfere with a wheelchair, remove or cover them with plastic runners
- Tape rug edges to the floor
- Check floors for raised nails and loose boards or tiles that could cause tripping
- Keep electrical cords, furniture, plants, children's toys, and pet toys out of the person's path
- Make sure that the person's clothes don't drag on the floor. Turn up hems on long clothing a few inches. Avoid or alter long, loose sleeves that can catch on things
- Encourage the use of non-skid slippers or shoes for standing or moving about the house
- Use bed rails to prevent falls from bed. You may only need them at certain times of the day or at night depending on the level of alertness of the person you are caring for
- Install banisters or gates on stairwells
- Use handrails in the bathroom and the toilet. Do not use towel racks, these easily pull out of the wall
- Place non-skid strips or a non-skid bathmat on the floor of the bathtub or shower
- Keep a bedpan or commode within reach of the bed. You might want to disguise them with a sheet or towel when you have visitors.
- When helping the person out of bed, let them sit upright for a minute or two to help prevent dizziness.
- If the person is using a hospital type bed make sure the brakes on the wheels are on before you help them out of bed to prevent the bed from rolling
- Discourage the person from smoking, especially in bed. If they do smoke provide them with safety lighters and ashtrays and use non-flammable clothing and bedding.

Helpful personal care products

If someone is able to manage some of their own personal care some of these products might help:

- toothbrush or denture brush, comb and hair brush with built-up handles
- finger ring brush that slides onto the finger instead of being held
- hair brush that slides over the back of the hand instead of being held
- toothbrush that slides onto the finger instead of being held
- toothpaste tube squeezer
- electric razor that slides over the hand instead of being held
- goose neck mirror that stands on a table

- long tongs that can be used to pick up items out of reach
- skirt aids, pant aids, stocking aids, and sock aids to help with dressing
- elastic shoelaces so shoes can be pulled on and off
- raised toilet seat or portable commode that can be kept near the bed
- bath or shower bench or chair
- hand-held shower with a wall mount at hand level
- hand rails near the toilet, sink and bath.

To find out more about what's available you can ask pharmacies, suppliers of specialist equipment, an OT, physiotherapist, palliative care service or a community nurse.

Next steps

A **LifeCircle** Mentor can help you find ways of learning the skills and managing the personal care of a person dying at home. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Services for People Caring for Someone at the End of Life

You may have been caring for someone for a long time or you might have been thrown into the caring role quite suddenly. Either way it can be helpful to know about the services designed to support you in your caring role. These include palliative care, respite care and a range of other options detailed in this help sheet.

Palliative Care

Palliative care is the specialised, multi-disciplinary and holistic care of someone living with a terminal illness and their family. The aim is to make sure that the person who is ill or dying receives the best care possible. This is done by coordinating and delivering a range of specialist services to meet their needs and the needs of their family.

If the person you are caring for is in hospital and you are planning to bring them home it is important that a referral is made to the local palliative care service before they are discharged; this can be done by either the hospital doctor or the person's GP.

Palliative care can be provided by a number of different health professionals, who often work together in teams. These include:

- specialist palliative care doctors and nurses
- general practitioners (GPs)
- other medical specialists such as oncologists, cardiologists, neurologists, respiratory physicians
- allied health professionals such as pharmacists, occupational therapists, physiotherapists, speech pathologists, dieticians etc
- social workers
- grief and bereavement counsellors
- pastoral care workers
- volunteers.

Palliative care services vary from area to area. However, services can offer:

- expertise in managing pain and other symptoms
- help with financial, employment, parenting and other issues which arise as a consequence of being diagnosed with a terminal illness
- emotional support for patients, families and carers
- care in hospital or a specialist palliative care unit
- bereavement counselling for family and

- referral to local community services such as home care, delivered meals, community transport and home-based respite care.

If you are caring for someone at home, *community* palliative care services can provide support through home visits. If the person you are caring for is well enough to get around on their own they may also visit specialist palliative care clinics.

Many palliative care services have volunteer programs where trained volunteers offer support to families affected by terminal illness. In the home, the role of the volunteer can include:

- providing companionship and support to both the patient and their carers
- respite for the carers while they attend to other matters or take a break or help with simple tasks such as shopping or transport for medical appointments.

A range of fact sheets and other information is available from Palliative Care Australia at: www.palliativecare.org.au or by calling 02 6232 4433.

Respite Care

Respite care gives you and the person you care for a break. This can be:

- in your own home with care ranging from a few hours a week to overnight care
- in a Day Centre which provides full or half day care
- in a residential aged care facility for a few days to one or two weeks
- in a palliative care in-patient unit.

Under the National Respite for Carers Program, a network of Commonwealth Respite and Carelink Centres has been established around Australia. These Centres can assist carers to take a break through short-term and emergency respite services. They can also provide advice on and coordinate access to a range of services in a carer's local area. You can contact your nearest **Commonwealth Respite and Carelink Centre** on **1800 052 222**.

Home and Community Care (HACC) Programs

The Home and Community Care (HACC) Program is a joint Australian, State and Territory Government initiative which provides a range of basic maintenance and support services for frail older people, people with a disability and their carers. HACC services help people to live independently in their own home and the community for as long as possible. The range of services varies from place to place.

Information about what services are available in your area can be found in the local telephone directory or by phoning the Commonwealth Respite and Carelink Centre on 1800 052 222. Services provided through the HACC Program include:

- **Home modifications or maintenance** – assistance to maintain a person’s home, garden or yard to make it safe
- **Social support** – assistance to meet a person’s need for social contact and participation in community life
- **Transport** – practical assistance with group or individual transport needs
- **Domestic assistance and personal care** – help with cooking, cleaning, washing, ironing, bathing and dressing
- **Nursing care** – support in the management of health problems such as incontinence
- **Case management** – a process for managing support to people with chronic, ongoing or complex conditions or situations
- **Meals and other food services** – the preparation and delivery of meals
- **Centre-based day care** – group activities and regular respite
- **Respite care** – support to carers through the provision of respite care
- **Linen services** – the provision and laundering of linen
- **Goods and equipment** – loan or purchase of goods and equipment that help the person with their mobility, communication, personal or health care
- **Allied health services** – such as podiatry, physiotherapy, occupational therapy, speech pathology and nutrition
- **Assessment** – to establish eligibility needs and gain access to services
- **Client care coordination** – professional coordination of HACC services.

Local Government, community and voluntary organisations, religious and charitable organisations, commercial organisation as well as State and Territory Government agencies may provide HACC services. Sometimes charges are made for HACC services but any fees will be discussed with the person and carer before services are provided. A person will never be refused access to services due to an inability to pay.

HACC Case Management

The Home and Community Care Program (HACC) provides funding for Case Management services to be delivered in the community. Case management is a process designed to assess and manage the support, care and social health needs of frail aged people or people with a disability with chronic or complex conditions or situations, and their carers. A Case Manager helps to coordinate what can be a confusing range of different service providers. HACC funded Case Management services specifically support the following people:

- those who have a range of interacting physical/medical, social and emotional needs, usually regarded as complex needs, and who require comprehensive assessment and formal case management
- those who need short term, ongoing or periodic assistance from a Case Manager to organise and co-ordinate community care services



Next steps

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How to talk about dying and death

This help sheet supports family and friends of someone who has been diagnosed with a terminal illness or whose health has deteriorated to the point that there is no more curative treatment available. Once the initial shock of the news has passed, it can be difficult to think clearly about the future and what will happen next to both you and them. You may feel too overwhelmed to put your feelings into words or your thoughts into actions.

This help sheet offers suggestions to help you overcome the fear, reluctance or uncertainty that you may feel about talking about dying and death. It encourages you to consider the idea that having that conversation may be the first step in a journey that can be as rewarding as it is difficult. It suggests that talking about dying and death could possibly ease some of difficulties you now face.

Who do you want to talk to?

- The person who is dying
- Your partner, husband or wife
- Your parents, children, brothers, sisters or other close family members and relatives
- Close friends
- Work colleagues
- Spiritual or religious colleagues.

What concerns you about dying and death?

- Are you frightened about caring for or being with someone who is dying
- Are you frightened of losing them
- How will you cope with the changes in your life after they are gone
- How are you supposed to behave now
- How are you supposed to feel now
- What are you supposed to know about now
- Should you talk about what's happening or carry on as though they aren't dying? As though they are going to get better
- Will you be able to cope with the grief
- Is it okay to feel as though grieving has already started.

What might concern your loved one about dying and death?

- Fear of dying or death
- Place of death if choice is possible
- Whether donation of organs or tissues is possible

- Options for a celebration or ceremony
- Choices about their body after death such as burial or cremation
- Where to place remains: cemetery, under a tree, scattered on a beach, in a garden
- What would they like people to remember about them: their family's story, their own life story, their work, their house, garden or a special interest, passion or hobby.

How do you start talking about dying and death?

If you've thought about some of the things you want to talk about or feel you need to talk about and you have someone in mind that you would like to talk to, the next step is to make the time to have this important conversation.

A conversation with your loved one might be about personal things like how you might cope, or details such as their arrangements, what they want to have happen as death approaches, (Will, Advanced Care Directive, Power of Attorney, etc) and how they want to be remembered after their death (such as funeral or other ceremony).

Hopefully this will be the first of many conversations and each one will get easier as you become more comfortable with this inescapable part of living and with the emotions that arise when you talk about dying and death.

Try not to be afraid or embarrassed by your emotions when you plan a conversation about dying and death. This is a difficult time for all of you and it is important that you try to make the time to talk before it is too late. You may want to talk to someone close to you before you first talk with the person dying and you may want to keep talking with them as the person moves closer and closer to death.

If you are talking with the person dying you both may get emotional and though that may feel distressing try to keep going, even if you need to take your time or get some tissues and a glass of water. It may be best to have several short conversations talking about one thing at a time. Pick a time when you are both well rested and a place where you are both comfortable. Consider asking someone to be with you if you need extra support.

Here are some suggestions for starting a conversation with a person dying or someone else affected by the illness or prospective death of someone:

- Could we make a time to talk about what is happening to [you / person]? I feel really uncomfortable, but I think it's time to start thinking about what's going to happen.
- I know that no one wants to talk about what is happening or that [you / person] is dying, but I so much want to talk about how I'm feeling and I'd really appreciate just getting some things off my chest.



- I know that we are all going along as if this isn't happening, but [you are] / [person is] going to die and I would feel so much better if we can accept that and start talking about it.

Some of your questions will need to be asked of medical or other professionals who are caring for the person dying. Don't be afraid to make a list of questions or ask for information to be repeated or written down. Remember that no question is the wrong or a silly question.

Next Steps

A **LifeCircle** Mentor is trained to talk with carers about any aspect of dying and death. They have experience of caring for someone and can help you feel more comfortable about these conversations. A mentor can support you before or after these conversations. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Fear and how to deal with it

Dying and death are frightening and final concepts and most of us struggle with them. When you are caring for a family member or friend who is dying, fear may be a constant companion or it may be an unexpected or sudden visitor from time to time.

Why are you afraid?

Being with someone or actively caring for someone at the end of life is an experience most of us will have at some stage but these days we don't know much about dying or what is normal. We are familiar with images from TV and movies but they often give us unhelpful ideas about what actually happens when someone dies. We hear stories from friends and families about how difficult and emotionally painful death can be. So many of us are afraid and reluctant to talk or even think about dying and death.

The reality is that death is a normal part of life and it happens to all of us. By learning about what happens when someone is in the final days or weeks of life we can become more comfortable with it.

You may be afraid because

- *You are confused by some of the things that have been said or not said by doctors, nurses or others.*

Do you have questions or are there words that you don't understand? Make a list and take them to your doctor for an explanation. Sometimes it can help to take a friend or family member with you to be an extra "ear", take notes or to write down what the doctor says. Don't be afraid to ask the doctor to clarify anything you don't understand.

- *You may feel that you can't talk to anyone about how frightened you are.*

Think about someone you could tell and then make the time to tell them how you are feeling.

- *You may feel that you need to be strong because others around you are frightened.*

Your fears are valid too so consider who you can talk to about what frightens you. Voicing your own fears may actually be helpful for those close to you as well as you allow yourself to be more open about what is happening.

How does fear affect you?

- *You may feel guilty about being frightened.*

Dying well at home

Information for people caring for someone who is dying

Someone close to you is living through their final months, weeks or days. This may be an experience you have never encountered before.

This help sheet will help you to be aware of some of the changes which may take place as the dying person moves through the final stages of living. Being aware of what happens in these stages can help you and your family and friends live each day more fully with the person who is dying; it can relieve some of your fears and give you comfort when you know that the person you are caring for is progressing in a normal way towards their final moment. Finally this awareness can give you some ideas about how to respond to the changes that are taking place in the person you are caring for.

People die well in hospitals, hospices and in their own homes. Wherever the person you are caring for is dying, we hope this help sheet will make it possible for you and your family to surround the dying person with time, conversation, laughter, tears and love. It is written with dying at home in mind but we hope it will help you wherever you and the person you are caring for is living.

The final couple of months

The effects of dying on both the mental and physical state of each person are unique as they live their last few months, weeks and days. However there are some typical changes that might take place.

- **Withdrawing:** A person may start to withdraw from the wider world and become more preoccupied with personal and family matters, including reflections and memories. For example, a person who had been very interested in current affairs may no longer be interested in the daily news.
- **Finding busy activity or a group of people no longer easy to manage:** For example a large family gathering may be overwhelming despite evident pleasure in the event.
- **Irritability over daily busyness:** A person may feel that they need to take more time over each step in the day rather than rushing through a list of what used to be manageable tasks.
- **Anxiety and agitation:** A person may feel that they are running out of time to complete whatever has become important to them or they are fearful about what is ahead of them.
- **Sleepiness:** As the body's mental and physical functions deteriorate a person may need or may want to spend more time dozing or sleeping. Talking and being with others as well as eating and drinking may be exhausting.
- **Eating and Drinking:** The body's gentle process of shutting down means that a person may want less to eat and drink.

What can you do at this time?

For yourself

- Try not to respond to or be upset by unexpected irritability or frustration on the part of the person dying. You may have done nothing to cause it.
- Plan each day at the pace that is comfortable for the person dying and for you. It might be a very different schedule than you are all used to so give yourself permission to go with what seems to be important now rather than what you are used to achieving or expecting to happen.
- Be ready to abandon your daily plan and just enjoy the moment with the other person and all the important people in your life.
- Say “Yes!” to every offer of help from people who can support you at this time and enable you to prioritise what has become important in these final months. You will have plenty of time later to say thank you and to reciprocate. If you are having difficulty saying “Yes” it might help to reflect on how good you feel when someone lets you help them! Allow the people around you to enjoy that good feeling too.
- Find time to talk to whoever can help you if you are feeling unsure about how to cope from day to day or how to manage overwhelming emotions. A family member or friend, a LifeCircle mentor, a counsellor, religious leader or your GP can all support you on this journey.
- Don’t be afraid of talking about dying and death with whoever you need to including the person dying. It’s time to talk freely about what is happening and it feels good to allow laughter as well as tears. Don’t be afraid to include children—they need to understand and to feel that they are part of these momentous events.
- Do whatever you need to do to ensure that you are getting some sleep
 - Get help in overnight or respite care
 - Get help with the early morning routine of children and daily transport to day care, school, sport etc
 - Prepare a thermos, small snacks or lay out whatever you might need to find in the night so it is accessible and minimises disruption for you and your household.

For the person you are caring for

- Manage visitors (or allocate that task to someone else) at a pace which isn’t too tiring or too many at once. A visit may now consist of sitting and chatting around the bed while the person dozes and enjoys the companionship without participating very much in the conversation.
- Ensure that the person is able to sleep as much as they want to and prioritise other activities according to what each day brings.
- Small snacks and sips of liquid throughout the day may be more palatable than set meals at the usual times. Tastes may change or some foods may be easier to eat and preferred now.

- Reading to the person rather than expecting them to find the energy to hold a book or a magazine might become an important part of their day. They might prefer to listen to music. Bring household activities such as meal times into the person's room or move them into a living room even if they don't want to sit up and eat with the family.
- Provide extra pillows wherever the person is sitting or lying to ease sore or stiff spots. Pillows may also enable the person to enjoy watching the daily round without having to sit upright.

The final few weeks

As the body and brain prepare for death, more changes may be observed during the final weeks.

- **Withdrawing:** Social activity may now be impossible as the person dying is too exhausted or drowsy to participate in any social activities. They may still enjoy the sense of movement and chatter around them as they drift in and out so don't feel you should leave them alone or keep the house quiet. Ensure that they have a sense of movement and normality in the household remembering that the ebb and flow of daily routine is the reason you and your person want to be at home during these remarkable days.
- **Activity:** As the body and brain steadily shut down, the person may not be active in any way. There is information below about how to maintain comfort and hygiene at this time.
- **Anxiety, agitation and restlessness:** Chemical changes in the brain can affect thinking, awareness and emotion. The person might be confused and disoriented at this time. They may be unable to recognise their surroundings or familiar faces. This can be frightening for the person and upsetting for family and friends. They may also be restless or agitated at this time.
- **Sleep and consciousness:** The person may now be drifting in and out of consciousness and gradually becoming unable to respond even though they can probably hear what you are saying. They may dream vividly or be incoherent in what they say. Your presence can be of great comfort to them.
- **Eating and Drinking:** Your loved one may now refuse most or all food and drink. This is a natural change, as the body no longer needs nutrients. However the mouth and throat might be uncomfortably dry so sips of water or juice, sucking ice or gently moist mouth swabs can relieve those feelings. Cream for dry or cracked lips might also be very soothing.
- **Incontinence:** Sometimes people who are dying lose control of bladder and bowel because the muscles in those areas relax and no longer function normally. This can be both embarrassing and uncomfortable but can be managed with advice and perhaps equipment from a community or palliative care nurse. As less fluid is drunk, urine becomes stronger and darker in colour and there may be little faeces in these final few weeks as very little food is eaten.
- **Breathing:** Breathing patterns change as death approaches. Breathing may become rapid at times, or irregular with pauses between breaths. Moaning noises may sound disturbing but can simply be caused by air moving across weak vocal cords.

- **Skin and circulation;** As the body's circulation slows down the face, hands and feet in particular usually become cooler and sometimes more sensitive when touched. They may look bluish. A person's back may become mottled, as blood flow moves away from non-vital areas to protect vital organs for as long as necessary. Temperature may fluctuate between being too cold or too warm.

What can you do at this time?

For yourself

- Do whatever you need to do to ensure that you are getting some sleep
 - Get help in overnight so you can sleep knowing you will miss nothing momentous
 - Get help with the early morning routine of children and daily transport to day care, school, sport etc
 - Prepare a thermos, small snacks or lay out whatever you might need to find in the night so it is accessible and disruption for you and your loved one is minimised.
- Plan for what an emergency will look like for you and the dying person and think through the necessary steps and the implications of any emergency medical emergency intervention such as calling an ambulance and being moved to hospital. Take into account the dying person's wishes if you know what they are.
- Get all the information you need to help allay your fears and give you a feeling of control and calm in the face of the profound events awaiting you.
- Say everything you need to say to everyone important to you at this time and listen to whatever they need to say to you.
- Provide opportunities for all the important people to be involved to whatever extent is comfortable and appropriate.
- Don't feel guilty or neglectful about the person eating and drinking little or nothing at this stage. While providing food is a very powerful way to show love and concern, the refusal to eat and drink is a natural part of the dying process and is not uncomfortable for a dying person.

For the person you are caring for

- Comfort and rest will be priorities now, so plan visits and any activity, however small, according to what the person wants and needs.
- Settle agitation or distress with familiar surroundings, calm reassurance and stroking or gentle touch or massage. You may need to remind the person of your own name and assure them of your presence.
- Keep talking with the person, even if they appear to be sleeping or drifting in and out of consciousness. Assume they can hear you even if they can't respond. Bedside chat with family and friends can be comforting for everyone.

- Even though the person may be eating and drinking little or nothing now, make sure that cracked lips are soothed with lip cream and mouth is kept moist and fresh. Mouth care can be very important to the comfort of the person now.
- If incontinence is a problem, there are bed and personal products available to help you manage this. A community or palliative nurse or a pharmacist will be able to advise you. However, as food and fluid intake reduces this may now become less of a problem.
- Breathing may be increasingly erratic and noisy. This might sound alarming but once again this is probably normal and caused either by slack vocal cords or secretions collecting at the back of the throat that the dying person is no longer able to cough away. Propping up the bed head with pillows or laying a person on their side can help to drain secretions. A cool mist humidifier in the room may also help. Snoring and snuffling may also increase as jaw and throat muscles weaken and the tongue drops further back. In general the person is not lacking oxygen but just going through a natural process as the lungs and breathing shut down.
- Breathing distress (which may be due to confusion or agitation) is uncommon but can be aided by slow steady breathing together with the person in a rhythmic and calm way. A fan or airflow can also help as long as it doesn't make the person cold or shiver.

The final few days

What can you do at this time?

For yourself

- You, your family and friend may want to be constantly near the person dying now. This might mean enlisting help with anything and everything to keep the household running. It might also mean letting go of all other daily priorities or having alternate arrangements in place.
- Give yourself permission to radically change your priorities and your focus so that you can make the most of this precious time with and for whoever is now part of this journey towards death.
- Ask for the help you need so you can be free to do, feel and say exactly what is right for you at this time.
- Plan to sit with the dying person in shifts, if possible, so that everyone can both be involved and get some rest. Alternatively, rest or get some sleep near the dying person's bed.
- Be bold in saying what you want to say and doing what you want to do with and for the person dying. This is a time when powerful memories can be created which will form a cornerstone of the legacy that is being built for you and yours.
- Assume that what is said to and near the person can still be heard even if they are barely conscious or apparently unconscious.

For the person you are caring for

- There may be brief surges of energy with requests for particular meals or to get up and dressed. There may be a feeling of contentment as soon as the request is acknowledged without it having to be acted upon.
- Restlessness may increase and can be addressed in the same way as discussed earlier. It may be due to lack of oxygen or it may be due to confusion and disorientation. Calming reassurance and gentle stroking may work equally well to settle the person irrespective of what is causing the restlessness.
- There may be a sense that the person is waiting to complete unfinished business or for the arrival of someone special in their lives. You may be able to provide closure and encourage the person to let go when they are ready without having to wait unnecessarily.
- The skin may feel quite cold now and may be very sensitive to even the gentlest touch.
- Speak with the person as though they can hear and understand all that is said.
- Eyes may be partially closed and mouth may be open as muscles completely relax just before death.

The final breath

The final breaths a person takes can be intermittent with seemingly endless gaps between them. They can be surprisingly loud if fluid has been accumulating in the lungs. This is sometimes known as the death rattle. Do not be alarmed; this is often a normal part of the process.

Eventually the person will stop breathing altogether. There will be no pulse as the heart also stops beating. There may be a few muscle twitches, but that will stop quite quickly. The face will relax and the pupils will be large and still.

After death, the body goes through some more changes. As muscles are completely relaxed, body fluids may be expelled from the rectum, bladder or mouth, which can be upsetting if not expected.

What can you do at this time?

For yourself

- Remember that there is no hurry to do anything at all.
- Take the time you need to say goodbye, share this moment with the people around you and complete the journey of caring on which you embarked with the person who has just died.
- You may want to touch or hold the person or you may prefer not to. Make your own decisions about how you would like to spend this time and let others also make their own choices without impacting on each other.

For the person you are caring for

- You have just completed the enormous task of doing everything possible for the person who has just died. Allow yourself and your family to become the focus of concern and connectedness now.
- There is nothing more you need to do.

Immediately after death

There is no hurry to have the person's body taken out of the home. If the weather is very warm, keep the room as cool as possible. Muscles won't start to stiffen for some hours, so take your time. You might want to arrange the person's body straight on the bed and tidy any fluids away or place towels or pads underneath the body. If the person's mouth is slack and open, roll a small towel under their chin.

You may want to wash the person's body, comb or tidy hair or change their clothes. You may want to do nothing but sit or you may need to be outside or in the fresh air. Choose what is right for you and give yourself permission to do just that. Family, friends and especially children may want to be near the person, touching, stroking and holding them in order to make death and the nature of this farewell meaningful for them as well.

When you are ready, a doctor who has seen the person within the last 3 months can arrange a death certificate. You will need to advise them of the time of death. If a funeral director is taking the person's body, they will be able to remove the person's body after the death certificate is available. You can look at one of our other help sheets about planning a funeral if you are unsure about what happens next.

Once the person who has died has been taken out of the home, emotions may flood and overwhelm you and yours. You may be both exhausted and unable to sleep. Give yourself permission to feel proud of the ways in which you have accomplished a unique task. You have shared the gift of living well and dying well with the person who has just died and with everyone who has been a part of that person's life and death.

Next Steps

A **LifeCircle** Mentor has experience of caring for someone at the end of life. They help carers through these final months, weeks and days by staying in contact as a supportive listener with ideas to help carers on their journey of caring for someone who is dying. . If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Adapting Your Home Environment

Managing change at home and in the community

If you are caring for someone with a serious illness some aspects of life may have become more challenging to manage. These might include showering, getting in and out of bed, moving around the house or picking things up from the floor. These changes can have an impact on you and the person you are caring for.

Changes may happen suddenly, such as after an admission to hospital or a fall, or gradually. Sometimes changes happen so gradually that you might not be aware that you've both adapted or you may begin to struggle with managing everyday life. It's important that you and the person you are caring for continue to do as many of the activities you need and would like to do safely and for as long as possible.

This help sheet outlines practical tips to help you and the person you are caring for manage the changes and ensure that you both can live safely at home maintaining your independence for as long as you can.

Occupational Therapists – help with advice and equipment

An Occupational therapist (OT) is trained to help you care for someone ill or disabled safely at home and make it possible for you and the person you are caring for to keep doing the things you like to do.

OT's can be involved before someone comes home from hospital as part of the discharge planning process. They can do an assessment of your home and will be able to advise on equipment such as up/down beds, commodes and how to do things safely.

A home assessment can be organised before discharge from hospital or through your local community health service if the person you are caring for hasn't been in hospital. You can also engage an OT privately and you do not need a doctor's referral to hire one yourself.

What does the Occupational Therapy assessment involve?

The OT will come to your home and have a look at and advise on:

- the **tasks** you need to do
- the **layout** of your house
- any **equipment** you might need to make things easier and safer
- **advice** about other activities like getting in/out of the car.

After the assessment the OT will give you information about where to get the aids, equipment and home modifications that they have recommended. These can often be obtained at a subsidised rate, through such services as a hospital equipment loan pool, community health centres, the Program of Appliances for Disabled People (PADP), disease specific organisations such as the Motor Neurone Disease Association and local government funded home modification and maintenance services.

If you hired a private OT you can hire or purchase appropriate aids and equipment from retail outlets like pharmacies and specialist disability equipment suppliers. You can also privately engage the services of a qualified tradesman (including builders) to modify your home.

You do not need a doctor's referral to contact an OT, but **you should always seek the advice of a professional before modifying your home, and before buying specialised equipment.**

Aids and equipment

Ideally access to aids and equipment should be arranged prior to discharge from hospital so that you can set up a safe home environment. These may include:

- **mobility aids** to help with getting about
- **personal care aids** to help with activities such as showering and dressing
- **personal safety devices** to let someone know if your loved one is in trouble
- **home safety aids** to help with day-to-day activities in and around the home
- **bedding, seating and lifting equipment** to minimise pressure sores, skin problems and help with lifting
- **communication aids** to help people who find it difficult to talk or communicate their needs.

Safety

The OT will also give you advice about how to eliminate potential safety hazards in your home. They may suggest that you re-arrange your furniture and get rid of excess clutter and/or remove loose rugs and seal carpet edges. Lifting and transferring a person for example from a chair to bed can be a complex task. Talk to the OT about the safest ways to do this without hurting yourself.

Home modifications

Home and Community Care (HACC) funded Home Modification and Maintenance services are there to make the changes and repairs to the homes, gardens and yards of frail older people, younger people with a disability or their carers to help them live independently and safely in their own home. These range from replacing cabinet doorknobs with pull handles to installing wheelchair ramps, widening doorways or bathroom modifications.



Your OT can provide you with details of your local Home Modification and Maintenance service. Commonwealth Respite & Carelink Centre on **1800 052 222** is the best source of information about local community services of all kinds including the HACC funded Home Modification and Maintenance service.

Next steps

A **LifeCircle** Mentor can support you to find what you need to know and who you need to be in touch with when you are making decisions about caring for someone at home. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Creating memories and legacy

Talking about the future

The prospect of losing someone you love can sometimes feel unbearable. Especially if you know they are dying. So many emotions threaten to overwhelm you that it can be difficult and painful to think clearly ahead to a time without them. However, if you can find some quiet space to think about that future time it can be a good way to:

- Spend time together right now
- Make memories which will be a comfort for you after the person you love has gone
- Provide a wealth of information and learning for you and your family
- Create tangible mementos of the person you love and your times together
- Resolve conflict or confusion about past events
- Strengthen ties with family and friends
- Provide opportunities for people to come to terms with death in a helpful way
- Help those left behind to manage feelings of grief and loss.

Sharing and gathering memories

The hardest part of making records, notes, memories or mementos can be getting starting. In order to start taking stock of life and deciding what parts you want to preserve, you may need to acknowledge that death is going to come soon.

You and your family and friends may be struggling to come to terms with the idea of dying and death, but try not to let that get in the way of having those important conversations. And don't forget to include and involve children. Participating in sharing memories can help children come to terms with what they see happening around them.

Once you've had that first conversation, it becomes easier to talk about your memories of both the good and the not so good times and to share the laughter and the tears that come as you remember the past.

Gathering memories

You might talk about what is important to remember, what needs resolving and what should be set aside. You might want to find ways to capture and preserve your time together as well as the memories you have shared.

Here are some ideas for recording memories and legacy:

- Make notes and/or a scrapbook
- Record conversations on film or tape
- Go through old photographs and share stories about them
- Choose jewellery, books, recipes, menus, plants, jokes, furniture, pictures or ornaments to give to particular people as mementos
- Record and share the stories which go with each of these gifts
- Choose a favourite prayer, spiritual reading or religious occasion by which to be remembered
- Make a note of favourite novels, movies, celebrities, momentous occasions, family stories and characters
- Scan photos and documents to create a powerpoint presentation, printed photo book or internet site
- Make a film of and with your loved one.

A time to be with loved ones

Think about who can be involved and how to spend the time available.

- Get family and friends together to share good memories and resolve anything outstanding or let go of past disagreements
- Do one of those things which you or the person dying has always wanted to do and take film or photos to record the outing or the event
- Even if a person is too weak to join in social occasions, they may want to listen to what's going on from their bed, or lie comfortably somewhere and soak up the atmosphere
- Talk about funeral plans and what the dying person would like.

Creating legacy

We tend to think that legacy is what we leave behind after we are gone. But creating legacy is something that can be started at any time and before the person you love dies. Taking time to think about how or what you both want to be remembered can help you prepare for death and can relieve some of the fear of what lies ahead.



Next steps

A **LifeCircle** Mentor can encourage a family to create wonderful memories and legacies when someone they love is dying. . If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Funeral services and Ceremonies

A funeral is for those who are living. It is a celebration and thanksgiving of the life of the person who has died. Consequently it is important that everyone who has been touched by the person has the opportunity to share in a celebration of their life.

Four basic needs fulfilled by the funeral or ceremony

- **Physical** The disposal of the deceased's body is controlled by State Laws and is usually by way of burial or cremation.
- **Emotional** A funeral allows family and friends to share their memories of a loved one, to grieve and cry together and to provide vital support to each other in facing their loss.
- **Social** It is a social event shared with family and friends that acknowledges the life of the person who has died and gives comfort to those left behind in the weeks and months following the death.
- **Spiritual** For those with a spiritual or religious belief it enables the life and death of an individual to be recognised within that context.

The funeral service or ceremony

The funeral service or ceremony can be a key part of the grieving process that helps people on the road to working through their loss. In order to fulfil that role, it must meet the needs of the family and friends and their community. The following aspects help to meet these needs:

- Some sort of service or ceremony in which all mourners can share. Some people choose not to have a service or ceremony and this is an option too. It can be held in a church, a funeral home or chapel, at the graveside or the crematorium or any other place that was special to the deceased.
- People are encouraged to select their own venue, their own music, readings or poetry. They can choose to have a religious or non-religious ceremony.
- The order, content and style of service can all be varied to suit the family's needs. A personal tribute from a family member or close friend or perhaps the inclusion of appropriate cultural traditions may make the service more meaningful.
- The presence of the body of the person who has died at the funeral or ceremony can be an important way of helping family and friends through their grief. It may be painful to witness the removal of the body at the end of the ceremony but including this step may help those left behind to accept the reality of their loved one's death.

Arranging a funeral service or ceremony

Most people have little or no experience of organising a funeral or ceremony following the death of a loved one. If there has been time to talk about what the person who died wanted, some of the planning may have already been done.

All reputable funeral directors can provide a wide range of services to suit the needs of the family. They can help make the funeral simple or elaborate and the cost will be reflected accordingly. The funeral director is there to guide and advise on the many matters that may need to be considered.

Initial interviews with the funeral director can be at their offices or in the home. While some people may have fairly clear plan for the arrangements they want to make, others may want to consider a variety of alternatives before making any final decisions.

The choices to be made

- When and where the funeral or ceremony is to be held
- What type of service or ceremony is appropriate
- Who is to be involved in the service or ceremony
- Will burial or cremation follow the service (for many people this decision may reflect religious or ethnic attitudes and family traditions)
- Which coffin or casket and clothing is appropriate
- Details about any viewing of the deceased
- What floral arrangements are preferred
- What motor vehicles would be appropriate
- Who is to conduct the service or ceremony
- Preparation of an order of service with readings and/or poems of special meaning
- What type of music will be played
- Any audio visual presentation, preparation and planning
- Is there a favourite charity for donations in memory of the deceased
- Mementos to be displayed at the service or placed in the coffin
- Booking and planning a reception after the service, including catering
- The wording of press notices
- Are there any special requests or needs.



Next steps

A **LifeCircle** Mentor can help you find the information you need to make decisions about the funeral service or ceremony you or the person you are caring for would like to have. They will continue to support you for up to one year after the person you have been caring for has died. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

There are other help sheets in this series. They are all on the **LifeCircle** website **www.lifecircle.org.au**.

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Hospital to Home

Coming home from hospital after a hospital admission can be a relief but also a little daunting, with changes and adjustments often to be made. The information contained in this fact sheet will support you and your loved one in the planning process when coming home from hospital.

Discharge Planning

The aim of discharge planning is to ensure a safe and smooth transition from hospital for those who wish to return home and who still need care and support. Planning should always involve the patient, their carer, family and any professional staff involved in the patient's care to make sure that their care and support needs will be met once they are back home.

Typically, the professional staff involved include, the doctor in charge of the treatment of the person you are caring for, the Nurse Unit Manager (NUM), occupational therapist, social worker, physiotherapist and pharmacist. Be sure to ask about discharge planning as soon as mention is made of the patient returning home.

Palliative Care

Palliative care is specialist care for people living with, and often dying from, a serious illness. The main goal of palliative care is to ensure a good quality of life for the person who is ill and their family.

Seeking palliative care isn't about admitting defeat or giving up. Palliative care aims to provide access to expert support to alleviate pain and suffering and to integrate medical with spiritual, emotional and psychological aspects of care. It may begin at any time. Early (and even late) involvement of the palliative care team can greatly improve how a person lives with and ultimately dies from serious illness.

If your loved one is coming to the end of their life it is important that a referral is made to the local palliative care service before they are discharged from hospital; this can be done by either the hospital doctor or the person's GP.

Palliative care services vary from area to area. Most services offer *help with pain and symptom* management. They can also provide *emotional support* for patients, families and carers, *inpatient and respite care*, *referral* to local community services such as home care, delivered meals, community transport and home-based respite care.

GP Care

You and the person you are caring for need to have a GP who is available after hours, and who is prepared to conduct home visits.

Ensure that you have the GP's surgery and after-hours contact details. When the person is discharged from hospital, the person in charge of their discharge should send the GP a discharge summary recording the reason for the hospital admission, any investigations done, the treatment provided, any new medications prescribed and monitoring requirements. It may be useful to organise a follow-up visit with the GP in the week or two after discharge particularly if things have changed significantly.

Community Care Services

Be sure to ask the hospital discharge planner or social worker to provide you with information about local support services, and if necessary ask them to make referrals on your behalf. It can sometimes be easier to put these services in place while still in hospital. However, most community care services accept self-referrals, so contact services directly if you aren't sure a referral has been made.

To find out about community care services in your local area, contact the Commonwealth Respite & Carelink Centre on 1800 052 222.

Aged Care Assessment Team

Aged Care Assessment Teams (ACAT) help older people and their carers work out what kind of care will best meet their needs when they are no longer able to manage at home without assistance. The hospital discharge planner can make a referral but if you aren't sure they have contact the Commonwealth Respite & Carelink Centre on 1800 052 222 to get the contacts for your local ACAT and make the referral yourself.

Family, Friends and Neighbour Support

Planned and regular support from your family and friends can add to the professional community support services make it easier for you to cope with caring in the long term. Prior to discharge from hospital, it is a good idea to get your family and friends together

or if that isn't possible to find a way to discuss your needs and challenges so that you can all plan around them.

Practical Tips for Communicating with Family and Friends:

This is a really important part of managing the care of your loved one. If you burn out, get sick or are injured, it will make caring for them at home much harder.

- Before meeting with or talking to family and/or friends make a list of the tasks that need doing. List what you can manage, what you need help with, and what you can't manage.
- If you're worried about burdening your family or how the family will respond, consider asking one of them or a trusted family friend to speak on your behalf.
- Remember, you can't manage the care of a dying person on our own – it's a family and community effort. Your needs are important too. By involving family and friends you are giving them a precious opportunity to share this special time with you both. And they often want to do whatever they can to help.

If there is a family member or a friend who is really good at organising ask them if they will make a list of practical things people can do to help, when that help is needed and those who are willing and able to help. They can then draw up a roster of who will do what and when and make a back-up plan for days when things may go wrong.

Other Practical Tips

- Before your loved one comes home, make sure the grocery shopping is done and stock up on supplies you will need
- Pre-prepare meals and freeze them prior to the discharge date. Even better – ask a friend or neighbour to help out with some meals!
- Make sure an initial supply of medication is provided by the hospital pharmacy
- Buy an answering machine or set up voicemail so you don't have to answer the phone every time it rings
- If your loved one is bed-bound, find a way they can communicate with you when you are out of hearing range. The hospital's speech therapist or occupational therapist may be able to help you with this
- Contact **LifeCircle** to talk about your situation and get linked with a mentor who can help and support you during this time.

Next steps

If you need emotional support or a listening ear please call the **LifeCircle HOPELINE®** on **1300 364 673** to talk to one of our telephone counsellors.

If you want to want to be know more about being matched with a mentor please call our **LifeCircle** enquiry line **1800 132 229**.

If you want further information about community education or volunteering please call our **LifeCircle** enquiry line **1800 132 229**.



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Coping with Grief and Bereavement

Grief is both a physical and emotional reaction to a loss. When you lose someone you love or have been caring for you grieve. The depth of your grief is directly related to the depth of your relationship with the person, how long you've known them, how close you were to them, the nature of your relationship and sometimes for the manner in which they died.

What is a usual response to the loss of a loved one?

Physical

- Feelings of panic, shortness of breath, tightness in the chest
- Difficulty sleeping, interrupted sleep
- Weeping
- Lack of appetite, nausea, feelings of physical illness
- Tiredness
- Lack of interest in daily life and normal activities such as cooking, cleaning, going to work, seeing friends or family.

Emotional

- Overwhelming feelings of sadness and/or distress
- Lack of concentration
- Lack of motivation
- Uncertainty and difficulty in making decisions
- Fear and anxiety
- Shock sometimes accompanied by confusion
- Anger at yourself or the person who has died or friends and family
- Emptiness and extreme loneliness.

Sometimes you may feel that you cannot go on without the person you have lost. You may be afraid and unsure of how you will be able to face the future especially if the person's death has been unexpected.

How long does grief last?

There is an expectation that people will "get on" with their lives and "get over" their loss within a matter of weeks. Grief is an individual process that sometimes feels chaotic and it can go on for what can seem like a long time. Each person's experience and reaction is different and it is important that you remember that you can take as long as you need to take in coming to terms with your loss.

Everyone's grief is different depending on your personality, whether you are male or female and

sometimes on your previous experience of death or loss. It may be helpful to reflect on your previous experiences in coping with loss to give you some guidance to deal with the current one.

Dealing with grief and loss

You may want to start by asking yourself some questions:

- How have I dealt with loss in the past?
- How do I usually handle a loss or crisis?
- What steps do I usually take to deal with things that occur that are out of my control?

Thinking about the way you have coped in the past can give you some ideas about what strategies might be useful now.

- Take small steps
- Don't make any big life changing decisions in the first 12 months
- Give yourself time and space
- Consider talking with somebody who may be able to help you if it feels like you are not coping.

When you have lost someone with whom you shared your life or a part of your life you will never be the same. It is normal to feel that you have lost not only the person and their presence but also yourself. Building a "new" life takes time. The following may help you in the early stages of grief:

- Finding people who will listen to you without making judgments; people who are comfortable around you and your grief, respectful of your feelings, constructive and have a sense of humor
- Keeping photos of the person who died around you or
- Putting the photos away until you feel you can have them around you again
- Playing music or watching films or TV programs that you enjoyed together
- Keeping those things of theirs that are meaningful to you or
- Disposing of their things if you want to and when you are ready to
- Doing what is meaningful to you and what YOU need to do to manage your grief.

Do not worry that how you feel now is how you'll feel forever. Time does not really heal but it does help you to get used to your loss. You do not get over the loss but you do get through it. Take small steps and be kind to yourself.



Next Steps

A **LifeCircle** Mentor has experience of caring for someone and dealing with their loss. They are there to support you for up to a year after the death of your loved one. If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

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Olsens Funerals provides a Bereavement Support Service to all families in our care. A member of the Bereavement Support Team follows each family up after the funeral and arrangements can be made for the bereaved person to speak with one of the team individually. They are able to put you in touch with community organisations that could be of help.

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Website Resources Page

CARERS & COMMUNITY SUPPORT

Healthdirect Australia

Ph: 1800 022 222

Free 24-hour telephone health advice line staffed by Registered Nurses to provide expert health advice about any health issue and what to do next. Also help with general health information and can direct people to local health services.

Carers Australia - National Carer Counselling Program

Ph: 1800 242 636 (Also Carer Advisory Service)
<http://national.carersaustralia.com.au>

The National Carer Counselling Program (NCCP) is designed to meet the needs of carers in terms of counselling and support, with assistance being provided on a one-off basis or over several counselling sessions. The NCCP Service can be provided in a location to suit the carer, eg. in-home or at the counselling service. For carers in rural and remote areas, counselling may be via telephone services or face to face counselling through a local service provider.

Centrelink

Disability, Sickness and Carers:

Ph: 132 717

www.centrelink.gov.au

Commonwealth Respite and Carelink Centres

Ph: 1800 052 222

<http://www9.health.gov.au/ccsd/>

These information centres are for older people, people with disabilities and those who provide care and services. Centres provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia

Living Caring Working

www.livingcaringworking.com

Provides online information and resources for those living with a terminal illness, carers and their work colleagues.

Working Carers Gateway

www.workingcarers.org.au

Online resource providing information and resources to those who are juggling work and caring roles.

Young Carers

Ph: 1800 242 636

<http://youngcarers.net.au>

Information, resources and support (including camps) for young people, under 25yrs, who help to care for someone with an illness, a disability, a mental health issue or who has an alcohol or other drug problem.

PALLIATIVE CARE

Palliative Care Australia

Ph: 1800 660 055

<http://www.palliativecare.org.au>

Provides information and resources for carers, families and those receiving palliative care.

Care Search

<http://www.caresearch.com.au>

Online resource of palliative care information and evidence for patients and families provided as part of the National Palliative Care Program.

AGED CARE

Aged Care Australia

<http://www.agedcareaustralia.gov.au>

Provides online information about care options for those who are frail aged, health conditions and support for carers.

Aged Care Information Line

Ph: 1800 500 853

Provides information about Australian Government-funded residential aged care and community care options.

FUTURE PLANNING

Australian Public Trustees

Please see the office in your home state

Provides a range of information and resources related to power of attorney, will making, trusts and financial management.

NSW Health

www.health.nsw.gov.au/patient_care/planning

Information about Advance Care Planning

Respecting Patient Choices: Advance Care Planning

<http://www.respectingpatientchoices.org.au/>

Respecting Patient Choices is an Australian model of Advance Care Planning that can address questions of care ahead of time. For example, if you became really sick, or had a serious accident and might die, how much medical treatment would you want? Would your answer change if you were not going to return to your previous state of health? Who would you like to make medical decisions for you if there came a time that you could not speak for yourself? Advance Care Planning helps you answer these questions.

Wrapping Up

www.wrappingup.com

A website for people who are seeking advice about estate planning and who need bereavement support.

COUNSELLING / GRIEF & LOSS SUPPORT AND INFORMATION

See also 'National Carer Counselling Program' in the Carers section

Australian Health Directory – Bereavement / Dying Support

<http://www.healthdirectory.com.au/Bereavement:Dying/Support/Search>

Listing professional counsellors, pastoral and religious support providers, companions and support groups who can assist the dying person to stay in control over treatment and care decisions, and for emotional support. Bereavement service providers also specialise in assisting the bereaved to deal with grief from the loss of a loved one.

GriefLink

<http://grieflink.org.au>

GriefLink is an information resource for the bereaved and grieving, their carers, friends & colleagues, and for health & welfare workers.

Kids Helpline

Ph: 1800 551 800

<http://www.kidshelp.com.au>

Kids Helpline is a private and confidential, telephone and online counselling service specifically for young people aged between 5 and 25.

Lifeline

Ph: 13 11 14

<http://www.lifeline.org.au>

24hr telephone counselling service.

MensLine Australia

Ph: 1300 78 99 78

<http://www.crisissupport.org.au/Mensline.aspx>

Telephone support, information and referral service for men specialising in family and relationship concerns. The service is available from anywhere in Australia for the cost of a local call, 24 hours a day, 7 days a week. Staffed by paid professional counsellors experienced in men's issues.

Relationships Australia

Ph: 1300 364 277

<http://www.relationships.org.au/>

Community-based, not-for-profit relationship support services for individuals, families and communities aiming to achieve positive, respectful relationships.

Wrapping Up

www.wrappingup.com

A website for people who are seeking support for bereavement and grief and estate planning.

Dying Matters

www.dyingmatters.org

Dying Matters is a broad based and inclusive UK coalition of more than 15,000 members, which aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement.

The Groundswell Project

www.thegroundswellproject.com

A community organization that uses creativity to promote resilience and well being through all phases of life

DISEASE SPECIFIC ORGANISATIONS

The Cancer Council

Helpline: 13 11 20

<http://www.cancercouncil.com.au>

Helpline staff are experienced cancer health professionals. They provide detailed information about all types of cancer as well as information about support services and emotional support. In addition a range of services are offered such as counseling, financial assistance, telephone support groups, regional transport and practical support services.

Cystic Fibrosis

Ph: 1800 232 823

<http://www.cysticfibrosis.org.au>

Provide a range of support services, information and education service and an advocacy service. Service include equipment hire, financial assistance, Mother's Respite Weekends, Peer Support Program and Country Outreach.

All Enquiries 1800 132 229 • **HOPELINE® Counselling** 1300 364 673 www.lifecircle.org.au ABN 95 267 224 727
Sydney, 153 Dowling Street Woolloomooloo NSW 2011 Australia T +61 2 9334 1393 F +61 2 8302 3520
Melbourne, 11/473 Bourke Street Melbourne VIC 3000 Australia T +61 3 8629 1125 E info@lifecircle.org.au

Huntington's Disease Association

Ph: 1800 244 735

<http://huntingtonsaustralia.asn.au>

Provides support to those living with Huntington's disease, carers and families including information and education, social program and Carer Support Service.

Leukaemia Foundation

Ph: 1800 620 420

www.leukaemia.org.au

Provides personalised and practical support for those living with leukaemia and their families, including information and education, emotional support/counselling, transport, accommodation and financial assistance.

Motor Neurone Disease Association

Info Line: 1800 777 175

www.mndaust.asn.au

Provides support and information to people with motor neurone disease, their families and carers, including support groups, regional advisors, equipment loans, respite and education.

Multiple Sclerosis Society NSW/ACT/VIC

MS Connect: 1800 042 138

<http://www.msociety.org.au>

Provides specialist programs to people with MS, their families, carers, friends and health care professionals, including support groups, respite, education and information, and medical services. MS Connect is an information service that answers questions about Multiple Sclerosis, and offers advice on symptom management and lifestyle issues.

Muscular Dystrophy Association

Ph: 1800 656 632

<http://mda.org.au>

MDA is committed to providing a range of services and support addressing social, educational, medical and financial needs. Services include information and education, support groups, respite, social activities, Carers Program, equipment funding and Home Support program.

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Melbourne, 11/4/73 Bourke Street Melbourne VIC 3000 Australia T +61 3 8629 1125 E info@lifecircle.org.au

Parkinson's

Info Line: 1800 644 189

<http://www.parkinsonsnsw.org.au>

This incorporated, non-profit, community-based organisation provides information, counselling and support to people living with Parkinson's disease, their partners, carers and families.

RADIO AND TV

ABC TV and Radio

www.abc.net.au

06 June 2011 - Jon Faine hosts the End of Life Forum; with Bill Sylvester, Andrew & Josie Chapman, Molly Carlile

www.abc.net.au/local/audio/2011/06/06/3236820.htm

27 May 2011 – In the National Interest with Peter Mearns; the more you talk about death the less you fear it

www.abc.net.au/rn/nationalinterest/stories/2011/3229031

18 May 2006 – Let's Talk About Death

www.abc.net.au/science/articles/2006/05/18/2809176.htm

Slow TV

www.themonthly.com.au

Helen Garner interviewed by Caroline Baum at the Live, Talk, Die Conference, March 2011

Simon Longstaff speaks at the Live, Talk, Die Conference, March 2011

Yew Tree Films

In the End – a documentary about dying with Dr Charlie Corke, and intensive care physician

www.in-the-end.com

ARTICLES

The Home Hospice Where the Heart Is; Helen Garner, *The Monthly*, June 2011

www.themonthly.com.au

Regrets of the Dying by Bonnie Ware

www.inspirationandchai.com

RESEARCH

Dying to know, Bringing death to life; Andrew Anastasios, pub. Pilotlight, 2010

Bring Our Dying Home; Dr Deborah Horstfall, Kerrie Noonan, Prof. Rosemary Leonard; University of Western Sydney, Cancer Council NSW, Home Hospice, May 2011

Dying for Change; Charles Leadbeater & Jake Garber, Demos Publishing, 2010

There's no place like home: Challenges for palliative care; Cancer Council NSW Issues Paper, October 2006

BOOKS

Living On, A guide to living on in the thoughts and memories of those you love; Jill Margo and Emily Margo; pub. Brandl & Schlesinger, 2008

The Intimacy of Death and Dying; Claire Leimback, Tryphena McShane, Zenith Virago; pub. Inspired Living, 2009

What to do when they say "It's cancer" - a Survivor's Guide; Joel Nathan OAM; pub. Allen & Unwin, 1998

Time of my Life; Joel Nathan OAM; pub. Penguin, 1994