



Supporting a Person Who Needs Palliative Care

A GUIDE FOR FAMILY AND FRIENDS

PETER HUDSON PhD

ROSALIE HUDSON PhD



2nd Edition

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To obtain additional copies of this guidebook please contact:

Palliative Care Victoria Inc.
Level 2, 182 Victoria Parade
East Melbourne
VIC 3002
Australia

Tel: +61 (0) 3 9662 9644

Fax: +61 (0) 3 9662 9722

Email: info@pallcarevic.asn.au

Web: www.pallcarevic.asn.au

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Supporting a Person Who Needs Palliative Care

A Guide For Family And Friends

PETER HUDSON PhD

ROSALIE HUDSON PhD

Foreword

This guidebook provides a comprehensive and practical resource for family carers of people diagnosed with a life threatening illness who require palliative care. It provides strategies to support them in what can be a very difficult but often rewarding experience.

Providing the best support to a person who needs palliative care can be made easier by getting appropriate information and finding the relevant resources. This means knowing what questions to ask, when and who to ask, and importantly how to look after oneself.

This guidebook has been written by experts, informed by the latest research. Most notably, it includes information from past family carers, who have been in a similar situation. We can learn from them, and the book contains valuable insights from their firsthand knowledge.

I am delighted to whole-heartedly recommend this carers' handbook to all family and friends who are about to, or those that already are, supporting someone living with a life-threatening illness. I am confident that this significant resource will help, whether you are reading it just in case, or in those moments when the road ahead seems just a little too difficult to find.

Dr Brian Le

Head, Department of Palliative Care, The Royal Melbourne Hospital,
Australia & Clinical Associate Professor, Department of Medicine,
The University of Melbourne

Guidebook Development

The development of this guidebook involved extensive research incorporating a comprehensive literature review and feedback from senior clinicians and academics from a variety of disciplines including nursing, medicine, psychology, social work, and pastoral care. Importantly, the guidebook development process sought the input of families who were supporting a person in need of palliative care and families who had been in a caring role in the past. Family carers contributed to the guidebook by attending focus group meetings, providing written feedback on draft versions and completing a survey. The use of the guidebook has also been evaluated in several research studies as part of a broader strategy aimed at enhancing family carer support.

While the initial guidebook development involved carers of adults with cancer being cared for at home, most of the content remains relevant for people in a variety of settings and for those who are confronted by other life threatening illnesses. This new edition includes updated information about these broader contexts for palliative care, including those in aged care homes (also known as aged care facilities).

For specific information about caring for a child with a life threatening illness or additional information about caring for adults confronted by a specific life threatening illness other than cancer please contact your local palliative care service or state/territory palliative care organisation.

If you would like more information about the guidebook development process please contact Peter Hudson: phudson@unimelb.edu.au.

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Introduction

This guidebook provides information that will help you assist a relative or friend who needs palliative care. There are some tips to help you in your caring role and suggestions to assist you to look after yourself.

The guidebook contains eight chapters:

1. Being a family carer: what's it all about?
2. Caring for yourself and your relationships
3. Caring for your relative at home
4. Practical care
5. Caring for your relative in hospital, hospice or aged care home
6. Advance care planning, legal issues and funerals
7. Care as death approaches and bereavement
8. What resources are available?

You do not need to read the guidebook from beginning to end. There are a number of topics within each of the main chapters, so you can choose those areas that are of particular interest to you. The table of contents at the front will help you choose. You may need to read some parts more than once.

You don't need to have the entire book 'under your belt' before you can care properly. At the end of each chapter, there is also a section that highlights the main tips.

You can share this guidebook with the person you are caring for, or with other relatives or friends.

If there is something you do not understand, or would like more information about, please contact your local palliative care service, the nursing home manager or your doctor.

Please note that this guidebook reflects the current situation regarding the provision of palliative care services in Victoria. This situation may change and may be different in other States and Territories.

Chapter One

Being a family carer – *what's it all about?*

This chapter provides information about palliative care, who it's for, and who are the palliative care specialists. It also describes who can be a family carer and provides some common reactions when a relative requires palliative care.

What is palliative care and who is it for?

Palliative care aims to help people with a life threatening illness. The World Health Organisation emphasises that palliative care seeks to relieve suffering by aiming to meet physical, psychosocial and spiritual concerns. The focus of care is on managing symptoms, providing comfort and helping to support the person who has the illness and their relatives and friends. Hence, this guidebook has been designed to help care for you and your relative.

Palliative care is not confined to cancer care; it includes care for people with any life-threatening illness. Life-threatening means there is no cure for the disease; so a palliative approach replaces cure with care. Common life-threatening illnesses (apart from cancer) include heart disease, lung disease, motor neurone disease, renal disease, and dementia. While many people live with these serious illnesses for many years, there comes a time when a person may require additional support. Palliative care aims to relieve suffering by carefully addressing any painful or distressing symptoms; and by supporting the family.

Many people have mistaken ideas about palliative care, so it's important to understand what palliative care is *not*.

Palliative care is

- *not* the end of all active treatment
- *not* confined to the last hours or days of life
- *not* the withdrawal of food and fluids
- *not* the 'default' position when all else fails
- *not* hastening death by use of drugs
- *not* artificially prolonging life

Being a family carer – what's it all about?

The focus of palliative care is on the quality of life that is to be lived; making sure the person is as comfortable as possible, free from all avoidable pain and suffering. When the disease has finally run its course, death occurs naturally, ideally without unwanted or burdensome interventions. No matter how long or short the illness, palliative care offers support to the patient and the carers, preferably early in the disease process.

Who are the palliative care specialists?

Palliative care teams include health professionals who are qualified and experienced in caring for people with life-threatening disease. Australia has regional palliative care services, each one differing slightly from the others in the services they provide. Some include specially trained palliative care doctors, nurses, social workers, psychologists, physiotherapists, other therapists (such as speech/music/reminiscence), pastoral care workers, dieticians, bereavement counsellors, volunteers and coordinators of volunteers.

Who are palliative care volunteers?

Palliative care volunteers provide their service free of charge. They offer support to carers so the patient can remain at home for as long as possible. Volunteer services vary but can include being able to stay with your relative while you go out; taking your relative for a drive or to an appointment; they can mind children, write down someone's life story, play music, answer the phone, provide simple beauty treatments or gentle massage, and offer companionship. If you would like a volunteer to assist you, please ask the palliative care service. Please be mindful however that the volunteer availability does vary.

Being a family carer – what's it all about?

Who is a family carer?

The term family carer in this context refers to someone who is giving support to a person who needs palliative care. A carer may be a relative, husband/wife, partner or friend of the person who requires assistance. The term 'relative' will be used in this guidebook to refer to the person you are caring for. In some cases there may be more than one carer involved. Often, there is one person who is seen as the primary or main carer.

When do you become a carer? The point at which a person becomes a carer varies. Some people may have been in a caring role for some time before their relative requires palliative care. Others may have decided to take an active caring role when they realised that their relative's condition was not improving. Some carers find themselves 'thrown into' the caring role without much warning. Many people do not think of themselves as a 'carer' at all and you do not need to be called a 'carer' in order to get support in your caring role.

People become carers or remain carers for different reasons. Some do it because they want to, some because they feel they should, some because others expect that they should, and others because they know it's what their relative wants. No matter how you start being a carer, the most important thing to realise is you are not on your own. The person you are caring for requires palliative care and that means there are a number of different people, organisations and services you can call on for guidance and help.

Common reactions when a relative requires palliative care

When you first found out that your relative needed palliative care you may have experienced a number of emotional reactions. Whether or not it came as a surprise, you may have felt, and may still feel, overwhelmed, worried, angry, anxious, downhearted or confused. The future may be uncertain and you may feel a sense of hopelessness or that everything is out of control. These are very normal reactions to what can be a very upsetting and unsettling time.

Being a family carer – what's it all about?

You may have many questions and concerns but simple answers may not always be possible. It's a good idea to write your questions down, so you can ask someone from the palliative care team. They can listen to your concerns and provide ways to help you lessen the load. As one carer said, *'I felt overwhelmed and confused at first, but the palliative care team helped me to see the situation more clearly.'*

Main tips from Chapter One

- Palliative care is available to patients with diseases other than cancer.
- Palliative care is not confined to the very end of life.
- Palliative care aims at comfort when cure is not possible.
- The palliative care team's aim is to support you as well as your relative.
- Volunteers are available to assist you in a variety of ways.
- The care roles you take on depend on you and your relationship with your relative.
- You may feel a range of different emotions; they are all okay because they are your feelings.
- Write down your questions; things often settle down when your questions are answered.

Chapter Two

Caring for yourself

If you are supporting a person who needs palliative care at home, in hospital, in a hospice or in an aged care home, you will need a variety of internal and external resources to assist you in this role. This chapter offers some suggestions about how to look after yourself.

How do I look after myself?

Looking after yourself is important, so you should take time to do something for yourself everyday. Don't feel guilty caring for yourself – you are important and deserve to be looked after. Your relative will also benefit if you are feeling a bit better about yourself. Even if it feels selfish to you, many patients feel less of a burden if they can see that the person caring for them is getting some enjoyment and rest. It may not be possible to take away all the stress but here are some things that might help:

- Get some exercise. Do something physical. Go for a walk and/or do some bending and stretching. There are exercise videos, DVDs and podcasts available for you to use at home if you find it difficult to leave the house. Exercise will help you maintain your energy. Try and choose an exercise you enjoy.
- Get enough sleep. It is common for carers to have some trouble sleeping. Limit coffee and alcohol in the evening. Consider herbal teas, a warm bath and/or some relaxing music to help you get off to sleep. If you can't fall asleep, get up for a little while, try to do something relaxing and then attempt to fall asleep again. If your night time sleep is disturbed, try to get a brief rest during the day. Most of us can manage with less sleep from time to time, but if you are finding it hard to sleep on a regular basis, discuss this with your nurse or doctor.
- Maintain a healthy diet. This can be hard at times, particularly if your relative has lost their appetite. However, you need your strength, so eat a balanced diet and don't forget to 'treat' yourself from time to time with food you enjoy.

Caring for yourself & your relationships

- Do something just for yourself everyday. Make a list of 10 things you enjoy that would give you a short break and replenish your energy. Do at least one of these things each day. You may feel as though you are managing quite well; however, looking after yourself also helps prevent stress.
- Try and remain in contact with your friends as much as possible.
- Depending on your religious or spiritual beliefs and practices, you may find help in prayer, meditation, or discussion with a trusted pastoral counsellor. It may also be important for you to continue your involvement with your religious community or other community involvement.

How do I maintain hope when the situation seems hopeless?

Maintaining hope while expecting the worst is a 'tough call' and your feelings of hopefulness and hopelessness may change many times. Some people have found help in hoping for small things, even in the face of death and loss.

'I know I can't hope for him to be cured, but I can hope that he will have a good day today.'

'I hope I can keep my sense of humour even when things get pretty bad.'

'I hope he knows I'm here even though he's not able to talk.'

Accepting help

Some former carers did not seek help for themselves because they felt that their relative's needs were more important or that the palliative care team was too busy to offer additional assistance. Remember that your well-being is a vital part of being able to support your relative. It is the palliative care team's responsibility to help you, so don't be afraid to let them know if you need more support.

Caring for yourself & your relationships

If you have relatives or friends who are willing to help, use them! Their assistance may take some of the strain off you. Keep handy a list of things that other people could do for you, such as preparing a meal, being with your relative while you go to an appointment or do some shopping, making phone calls or taking messages. That way, if you are talking to someone and they offer to help, you can make suggestions from your list.

Asking for help does not mean that you have failed or that you are not coping; it means that you are being smart, sensible and acting on your feelings.

Family meetings

A family meeting may be arranged by the palliative care team and usually involves the patient (if well enough to attend), family carer(s) and relevant health care professionals. The purpose of a family meeting is to involve you in developing a 'care plan' for your relative and clarifying the 'goals of care'. The care plan is based on your relative's specific needs and includes your own needs. The care plan is regularly reviewed by the team, especially when your needs change, or your relative's needs change. Having a plan can help you to 'keep on track'.

Juggling your needs, your relative's needs and life's usual duties

Some days you may feel as though all you have done is provide care and had no time for other things. Despite your relative's needs, life goes on around you and you may find it hard to manage. You may feel as though you are not in control. These are normal responses. You are reacting to a great deal of change and having to try and adapt very quickly. Here are some suggestions that may help you gain a greater sense of control of the situation:

- *Prioritise tasks into lists: 'must do', 'would like to do', 'if I get a chance I'll do'.* You may like to write down a list of things you would 'like to' achieve today, but don't make the list too long. Remind yourself that it is okay if you don't get everything done. At the end of the day think about the things you did achieve rather than the things you didn't.

Caring for yourself & your relationships

- *Take one day at a time.* It is normal to think about the future but try to take the challenges of caring one day at a time.
- *Consider writing care related issues down in a diary.* You can keep track of things as they occur and you can use it as a reminder when asking questions or giving details to the palliative care team or other carers.
- *Keep all written information about your relative in one place.* For example place medication charts, palliative care team information, useful phone numbers and this guidebook all in one place.
- *Get an answering machine.* You don't have to pick up the phone if you are busy or having some time to yourself. Use this opportunity to have private time with your relative, time for an uninterrupted meal or just for time out.
- *Get a mobile phone* if finances permit. You can go out of the house knowing that if there is an urgent issue with your relative then you can be contacted.
- *Make a list of friends/relatives you know you can ask for help.* If there is no-one willing to help, speak with the palliative care team about a volunteer or see the social worker.
- *Consider asking a friend/relative to stay overnight.* This may allow you to get a good night's sleep and you might appreciate the extra company.
- *Get someone else to do the household chores* (unless you find these chores relaxing). Access the local council, private services in your local newspaper or ask a friend or relative to help.
- *Ask your relatives/friends to bring over some prepared meals* (soups, casseroles etc). If this is difficult, consider 'meals on wheels' or other home delivery food services.
- *Ask one of your relatives/friends to phone or accept calls from 'others'* who need or want to know the latest information related to your relative. This saves you repeating the story over and over.

Caring for yourself & your relationships

- *If your work outside the home is making it stressful trying to juggle both roles, discuss the issue with your employer (or other people involved) to see how much flexibility you can have. You may also need to consider taking special leave.*
- *Consider sending a regular email to friends and families to keep them updated.* This allows you to ensure relevant people are aware of how things are but saves you making lots of phone calls.
- *Control the number of visitors.* Relatives/friends may want to visit often; however, it is okay to say that the person you are caring for is very tired. You could put a note on the front door to say they are resting. If required, ask visitors to please always phone first. It may help to set up visiting hours to avoid a constant stream of visitors. Don't feel as though you always need to be the host. Ask others to make a cup of tea for you.
- *If there is more than one person caring.* Try and set up a roster system to share the load. Get family and friends together and ask what they would prefer to do, for example one person may prefer to offer emotional support rather than physical care. Another may want to act as the key contact with health professionals.
- *Give yourself regular rewards.* Take a break, have some nice food, do something special for yourself that makes you feel good and lifts your spirits.

Remember, if things are getting on top of you, help is available from the National Carer Counselling Service (see Resources section).

Caring for yourself & your relationships

Caring for your relationships

Your relationship with the person you are caring for

During palliative care there may be changes in your relationship with the person you are caring for. At times it may be strained, at other times it may feel strengthened. The effects on your relationship depend on many things including your past, your emotional attachment, your reason for caring and how you usually manage difficult issues. Your relative's condition is also an important factor. Here are some thoughts from a carer's experience.

'The hardest thing for me to accept was the way he dealt with it emotionally, he seemed to seize up, to try and deny what lay ahead, he refused to even acknowledge that he was deteriorating physically. He just didn't want to open up to me.'

You may find it hard at times to talk with the person you are caring for, particularly when it's about an emotional subject such as dying, so here are some suggestions:

- Try to keep communication open and honest.
- Where possible try and balance the situation with some humour.
- Ask your relative what's most important to them.
- Be sensitive to signs of a bad day or a bad mood.
- Test the waters before launching into complex discussion.
- Try and work at things together. Be a team – things will be easier.
- Consider showing this guidebook to your relative. It may help them better understand some of the issues that you are facing.

It may be hard to talk openly if you appear to have different thoughts about the illness and what it means. Some people who are receiving palliative care choose to believe that they will definitely be cured, or their carers may think this. Consider talking with your palliative care nurse, doctor or social worker if this issue is causing concern. You may experience feelings of guilt because of something you have done or not done in the past. This is a common feeling and it may help to talk it over with your relative or with someone you trust, possibly someone outside the family.

Caring for yourself & your relationships

You may also feel that your caring is not appreciated. Your relative may not always express gratitude for what you are doing and may in fact appear to take it out on the person closest to them. Your relative may feel concerned if you take 'time out' to be away from them. They may not like you spending time with others. Again, it may help to discuss this issue with a trusted person.

People who are diagnosed with a life threatening illness are sometimes confronted with physical changes, which affect their self-esteem and how attractive they feel. When people believe they are unattractive, they may expect rejection, so they tend to avoid physical contact with the people they are closest to. If your relative is unhappy with the way they look remind them that it is not only outward appearance that makes them attractive, but many other qualities such as their sense of humour, their unique habits and their nature. Try and encourage touch between you and the person you care for if this is appropriate for your situation. Touch is a very powerful way of not only gaining pleasure, but also reducing worry and communicating how you feel, without words.

If your relative is feeling well enough, consider taking a trip somewhere pleasurable. If you are able to take a holiday, the palliative care team may be able to arrange support from health professionals in that area.

You may feel as though you need to show your relative that you are in control and are coping well. This is a normal feeling, but no one can be free from strain at all times. Expressing and sharing your feelings, both good and bad, can promote better ways of dealing with current and future issues.

Involve your relative in day-to-day activities to prevent them from feeling isolated. You may like to play cards, listen to some music or watch a video together. Think of things that have given you both pleasure in the past. Try to do as many things as you can together. If you have a close intimate or sexual relationship with the person you are caring for, it is important to continue whatever activities that provide pleasure for you both.

Caring for yourself & your relationships

In some cases, it may be advisable to discuss intimate relationships with a member of the palliative care team, depending on the nature of your relative's illness and current condition. Close bodily contact, in appropriate circumstances, can provide immense satisfaction both for the person who is ill, and for the carer. A warm embrace can overcome feelings of loneliness and isolation; expressions of love can overcome fear and despair. Other simple pleasures can provide lasting memories.

This carer's comments highlight the value of trying to enjoy things together.

'I could still take him out in the wheelchair. We went to see a movie. We would go and look at the beach. As often as we could we'd go for a drive or even a short stroll to the local park. If he was not feeling well enough to go out we'd get the photo albums out, listen to music or I would read to him. We lived each day as if it was special. Those memories are treasured.'

Involving children

Depending on the age of the children in the family, or other children who are visiting, some explanation may be needed as to what they may expect. However, most children are very 'matter-of-fact' and can surprise us with their level of understanding. It's best to be open with children, rather than to have an air of secrecy. It's okay to say your relative is very sick and may not get better. It's also good to talk with children about what your relative might enjoy. Children are often very creative and their gifts of poems, drawings, flowers, or an affectionate hug can make a visit very special. (See also Chapter 7 on involving children at the time of death).

Your relationship with family and friends

Your relationship with family and friends may also alter. Some people, who you thought would be contacting you often, may not do so. Try not to take this personally.

Caring for yourself & your relationships

Some people find it quite difficult to visit people who are very sick or to discuss issues about dying. Consider phoning them from time to time to ask them to help you with some practical things, such as providing a meal or assistance with transport. They may appreciate being asked and feel that at least they are 'doing something' to help. Or you may find that there are many family and friends offering help, visiting, phoning and offering advice.

Sometimes family and friends want to give you advice based on their own feelings and reactions. This is usually done out of concern for you. However, if the advice doesn't feel right you may simply say, 'Thanks, I'll think about that.' Remember, you need to do what feels right for you, regardless of what other people think you should do or feel!

Whatever your situation you may find that you develop deeper and longer friendships with people who choose to support you in your caring role.

Feeling overwhelmed? It's time to relax!

People respond to caring in different ways. Please understand it is very common to feel any or many of the following: anxious, down, angry, upset, grumpy, guilty or confused. Don't ignore how you are feeling. Some carers also feel the strain physically; they might get very tired or get headaches from time to time. People deal with tension in different ways. There is no right or wrong way of managing the difficult emotions that arise. Here are some things that may help:

- *Plan to do something you enjoy* within the next few hours.
- *Discuss your feelings* with someone you feel comfortable with (a relative/friend, religious/spiritual professional or someone from the palliative care team).
- *Look for the positive* and find some benefits within your situation.
- *Plan to give yourself a big reward* in the next couple of days, for all your hard work so far.
- *Maintain hope* – that, even in the context of serious illness, things can get better.

Caring for yourself & your relationships

- *Think of something funny* that you have experienced or heard, or tell some jokes.
- *Listen to a relaxation tape*
- *Remind yourself that:*
 - You are doing the best you can.
 - There are options (even if you can't see them clearly at the moment).
 - You are not alone.
 - Your feelings are normal.
 - There is help available.
 - You will feel better.
- *Try this relaxation exercise: '10 steps to feeling calm'.*
It may take some practice, but it gets easier.
 - (1) Find yourself somewhere where you know you can have peace and quiet for at least 20 minutes.
 - (2) Take 10 deep breaths.
 - (3) Find a comfortable place: lie down on the floor. You may need to put something soft underneath you.
 - (4) Loosen your clothes and take your shoes off.
 - (5) Close your eyes.
 - (6) Take a deep breath and slowly breathe out.
 - (7) Tense all your body muscles; count to five and then slowly release (do this 3 times).
 - (8) Begin tensing then relaxing muscles at the top of your head and work your way to your toes (take your time).
 - (9) Keep your eyes closed and imagine a real or fantasised place, which is peaceful. Imagine pleasant sounds or sights. Stay in this place until you feel ready to return.
 - (10) Count from 1–10 slowly, open your eyes. When you are ready stand up slowly.

Caring for yourself & your relationships

Do this exercise as often as you like, you may want to use aromatherapy (special burning oils) and/or relaxing music to make the environment even more peaceful.

If you feel anxious or depressed it is best to speak with the palliative care service or your own doctor. In some situations you may need additional professional help, particularly if other strategies haven't worked.

Taking a break

You may decide that you need to take a break from some of the caring tasks. This is fine; caring can be really hard work, so regular short breaks are highly recommended. *Taking a break is not a sign that you are not coping, or that you are a failure.* It does not mean you have stopped caring, or stopped loving. Rather, it shows you are being sensible and looking after yourself. Here are some options you may want to consider:

- Ask the palliative care service to arrange a volunteer to be with your relative while you go out and do something you enjoy. This may be provided on a regular basis and will allow you to have frequent breaks. You might also think about asking a friend or family member to do this for you.
- You may decide that you need a longer break, that is, a few days or weeks. This is often referred to as respite and the palliative care team can arrange for your relative (with his/her approval) to be admitted to a hospital, palliative care unit or other facility for the period of time you need. This time in hospital or the palliative care unit can also be an opportunity to reassess symptoms or review medications and will also provide you with a rest.

Main tips from Chapter Two

- Take time each day to do something for you. Don't feel guilty about looking after yourself. It will help you to be a better carer.
- Get enough sleep.
- Exercise regularly.
- Eat a healthy diet.
- Accept help from others, you deserve it!
- Caring can make life very busy. Making lists may help.
- A family meeting can help with planning the care your relative needs.
- Look after your relationships, both with your relative and with others.
- Accept help for those practical things which can lessen your load.
- Perform a relaxation exercise a few times each week.
- Take regular breaks: get a friend or volunteer to stay with your relative while you do something for yourself.
- If you are feeling overwhelmed; talk to someone (a friend or someone from the palliative care team). Remind yourself that you are doing your best and that you are not alone. Your feelings are normal, there is help available, and you will feel better.
- Deal kindly with yourself, give yourself plenty of rewards and maintain a sense of humour.
- Look for the positive in all situations - it may take some practice but it's worth it!

Chapter Three

Caring for your relative at home

Many people in need of palliative care choose to remain at home where they know their surroundings, they have more privacy and more freedom to do as they like. However, for some people this is not the case and people should not be 'persuaded' into home care if it is not suitable for them. Palliative care services can provide you and your relative with home-based support. Palliative care services vary in terms of their costs, waiting lists, referral procedures and what specific support they can offer. To find out about your nearest palliative care service please contact your state/territory palliative care organisation (refer Resources section).

Palliative care services can usually provide 24-hour access to telephone advice and if needed, in very urgent situations, a nurse can visit during the day or night. The number of visits by the palliative care service varies. Palliative care nurses are not able to stay in the home for lengthy periods; however, this is seldom required. When several hours of care are required in the one day or night, some people choose to pay for more nursing services or extra 'hands on' care through a private agency or the local council. Sometimes people need extra 'in home' nursing support overnight for 'respite care' (a break from caring) or to help treat particular problems your relative may be experiencing. This type of care may cost extra, depending upon your level of income. The palliative care service can assist in making these arrangements if required.

Despite the amount and quality of services available to support a person and their carers at home, the demands on carers may at times be overwhelming. You may be the person who spends the most time with your relative.

Remember, no matter how much you care for that person you may get tired, frustrated, down, angry, and unsure or upset at times. This is normal. You are probably trying to provide good care as well as managing everything else in your life. You need to be as healthy as possible and to feel supported, in order to provide the best care. If things are getting on top of you it is important that you seek some advice on how to try and lessen the burden. The palliative care service will be able to help and advise you.

Caring for your relative at home

What do family carers at home usually do?

This depends on your relative's needs, your relationship and what you feel comfortable doing. Some carers provide emotional support – by being there to listen and to comfort their relative. Other carers provide help with meals, medications and transporting their relative to medical and other appointments. Some carers want to be involved in some of the more intimate aspects of care such as personal hygiene/bathing, grooming and skin care.

You are not required to take on any of these roles unless you feel comfortable in doing so. If you are not sure, ask the nurse for some guidance. People learn in different ways and sometimes it is hard to understand all the information you have been given. Please ask if you need something explained or need more advice. If you want a health professional to show you a particular skill or observe you while doing it, just say so. It's a good idea to practice a new task a few times. You may also ask for more written information on any issue that concerns you. The amount and type of care varies from person to person and may change over time, as shown by the following examples.

'When the nurse first asked me if I was willing to give mum a hand in the shower, I thought: no way! But I decided to give it a go after some guidance from the nurses. I'm glad I did. Mum used to say I was better than the nurses. Believe it or not it turned out to be a special time for us, we would remember and laugh at old times.'

'I used to do all that for my husband, but now I'm totally exhausted. I was so relieved when the nurse said someone else could help bathe him at least a couple of times a week. I think he likes the change, too.'

Caring for your relative at home

Some practical tips for improving your relative's appearance and therefore helping them to feel better include:

- A visit to a beautician or stylist (or ask them to visit you at home)
- A facial massage (for male and female patients) and removal of facial hair if desired
- Soft, flowing, comfortable garments for day and night, including vibrant colours according to taste

What care can I provide if my relative is unable to be at home?

For many people with a life threatening illness care may need to be provided in hospital, a hospice or an aged care home. For some people this might only be for a short period of time while for others it might be several weeks or months. If your relative is in hospital or elsewhere you can still take on a caring role if you wish. For example you may like to continue helping your relative with meals or with hygiene care when you visit. The best thing to do is to talk with the nurse about how you can contribute to your relative's care. (These issues are dealt with in more detail in chapter 5)

Your options as a carer

It is important that you are aware of your rights and some of the things that you can do as a carer. You can:

- access information to assist you to care
- seek financial help
- access palliative care support and advice
- arrange for respite, a break from full time caring
- say 'no' to things you don't feel comfortable doing
- decide that you can't go on with your caring role
- complain about the services if they are unsatisfactory

Caring for your relative at home

- seek advice on making decisions, financial and/or medical, on behalf of your relative
- obtain information about all the services offered by the palliative care team
- access additional supports e.g. house cleaning, meals on wheels, extra nursing assistance
- seek further opinions
- ask any question you like.

As you step into this caring role for the first time, and as you continue in this role you may feel all kinds of emotions: frustration, joy, denial, despair, guilt, uncertainty, sadness, strangeness, confusion, fear, tearfulness, resentment, happiness, anger, or confidence and hope. You may feel a mixture of emotions all in one day, or even all in one hour! Remember other carers have felt these emotions too. They are all legitimate because they are *your* emotions. You have no need to be overly concerned at feeling any of these responses. However, if they are troubling you all the time you may like to talk to a health professional about your feelings.

What if I have questions?

Write down questions or issues that are important to you.

- Ask yourself, do I want to contact the palliative care team for help with this issue? If so, think about whom you might ask. For example, if it is a medical concern you may ask a doctor or a nurse. If it is an issue related to finances you may wish to speak with a social worker. If you are unsure whom to ask, that's fine, just ask one of the nurses and they can help find the best person to respond to your query.
- You may decide to tackle the issue yourself, but remember, if you get stuck, the palliative care team is usually available 24 hours per day. You may think your question is a bit silly, or you're not sure how to express it. Don't be concerned, the palliative care team is used to hearing and responding to all types of questions, that is part of their job.

Caring for your relative at home

- It may help to have a plan of action to deal with the issue(s) of concern. That way you can look back to see if the plans you have put in place have been helpful. First you will need to think about what you want to achieve. Then think about the ways in which you might try and achieve those aims. If your plan works – great – if not, consider getting some help from one of the palliative care team or a relative in order to adjust the plan. Don't feel disappointed if you need to keep changing your plan. This is very common.
- Sometimes your questions may not be answered with absolute certainty by health professionals. Unfortunately, supporting someone who requires palliative care can be complex and sometimes different approaches need to be tried to work out what's best. This may cause frustration as you may be searching for definite answers. In these circumstances you can expect to have your questions answered honestly by the palliative care team.
- Don't worry if you need to ask the same question a few times. When we are tired or a bit anxious it is difficult to digest and retain information. No one will mind if you ask the same question again.
- Remember, asking for help is not a sign of weakness or failure. It can be a sign of strength to admit that you need some help. It shows you are able to work out that you need some support before things get on top of you. This shows that you are thinking ahead and acting in the best interests of yourself and your relative.

When should I call the palliative care service?

You can usually phone the palliative care team at any time of the day. It does not have to be an emergency situation. However, 'after hours' calls are usually limited to more urgent matters. The person you are caring for may be feeling worse or something might have changed or you may be unsure of what to do. When you phone ask to speak to a nurse. The nurse will ask some questions to assess the situation and provide you with some guidance. In some cases the nurse will arrange a home visit. Again, no question is a silly question.

Caring for your relative at home

If there is something you are not sure about, which relates to the care of your relative, or if you feel concerned about yourself, please phone for help. Remember that the palliative care service exists to support you and the person you are caring for, so don't delay in getting further advice. An early phone call may save you hours of worry, and help you get a good night's sleep. It's a good idea to keep the palliative care service phone number in a prominent place e.g. by the phone or on the fridge.

While the aim of the palliative care team is to support you in all the ways mentioned, they may not be able to respond immediately. For example, the palliative care nurse may not be able to visit as soon as you call, you may not have the same nurse visit each day, and you may not be able to receive visits as often, or for as long, as you would wish. You may also find some health professionals easier to talk to than others. The palliative care service will make every attempt to meet your needs; however, they may not be able to respond to every situation. The best way to avoid disappointment and frustration is to discuss your expectations openly with a member of the palliative care service.

Making a complaint

If you feel your expectations are reasonable and for some reason, are not being met, the best approach is to contact a senior person from the palliative care service and express your concerns. If the issue is not dealt with you can, as a last resort, make a specific, formal complaint about the service. Before taking such action it is wise to write down the specific concerns you have, check it out with a friend or family member and leave some time for the matter to 'settle' in your mind. Then, when you are clear about the issue, you may consider contacting the manager of the service or if unresolved, the Department of Health or the Health Services Commissioner in your State/Territory.

Caring for your relative at home

Do we need a general practitioner?

In most cases, your relative's local doctor, also known as a general practitioner (GP), is the person who manages day-to-day medical care at home. However, their availability varies. Some are happy to provide you with an 'out of hours' contact number. Some GPs use a 'locum' service when the usual GP is not available. This simply means that another doctor, often a doctor you haven't met before, acts on their behalf. Some GPs offer home visits, where necessary. Home visits are helpful, as sometimes people in need of palliative care may find it difficult to visit the GP at their practice.

Ideally your relative should feel confident in the GP's decision making. If your relative does not have a regular GP, or if they want to change, you may be able to assist in making the choice. The following questions might help you decide:

- What is the GP's availability, especially after hours and at weekends?
- Will the GP do home visits?
- What doctor does the GP use when they are not available?
- What is the GP's palliative care experience?
- Is the GP willing to refer to a palliative care specialist if required?

Don't forget that seeing your GP for your own health and wellbeing is just as important. If you need to cancel an appointment due to your caring role, make sure you make another one.

When should I call the doctor?

You should phone the doctor if there is a medical issue concerning your relative. Deciding whether it is a medical issue can be difficult, so if you are unsure phone the palliative care team and speak to a nurse, who will help decide if the doctor needs to be contacted. Sometimes there may be more than one doctor involved in your relative's care. As well as the GP there may be a specialist, for example an oncologist or palliative care consultant. The specialist may also provide you with a phone number. In this case, you may be unsure whether to phone the specialist, GP, or both.

Caring for your relative at home

Again, don't hesitate to use the palliative care team to assist you with this issue. The specialist, GP and palliative care team should be working together to provide the best care for you and your relative.

How will being a family carer affect you?

Caring for someone requiring palliative care can be very hard. Carers have said that they feel as if they are on a roller coaster with the ride having highs and lows. Occasionally there is time to get off and have a break, but at other times the ride takes off again just when you think you are going to pull up at the platform. Some carers feel as though they get little time for themselves and may feel quite tired. Former carers have said that they found it hard to get enough sleep and at times felt quite overwhelmed. These are all normal responses. Caring for someone who is very ill can be physically and emotionally draining at times. These comments from carers who supported a relative at home highlight some of the common challenges.

There is free time but it only comes in snippets, for example, 30 minutes here, 30 minutes there, but not enough time to do anything of substance.

I don't feel as though I can leave the home.

I'm afraid to go to sleep for fear of something happening.

These demands can cause a certain amount of stress. Stress is one way we may respond when we are adapting to change. The effect of caring varies greatly. You may have other concerns, which have not been mentioned, or you may have very few concerns. In fact, some carers have expressed that although caring at times was challenging, overall they found it very rewarding and it helped them to be a bit wiser about life.

Caring for your relative at home

Positive aspects of caring

Carers often experience very positive outcomes from helping a relative requiring palliative care. Some carers have said that they benefited personally from the caring experience. Research has shown that many carers may feel better when they 'look for the positive' in difficult times. This can be hard when things are not going so well. The following carer comments show some of the positive things that can result from caring.

'No one had told me of the potential benefits of caring for Lisa. In the tough times, it was certainly hard to see any positives, but they were there, they were just a bit difficult to find. Looking back on the experience, I have definitely benefited greatly. Not only do I feel good about being able to have provided support to Lisa but I also feel as though I have learnt much more about life and myself in general. Caring for Lisa has been the most powerful experience of my life.'

'My partner and I have become closer through this experience.'

'The closeness - lying with my husband when he's in pain, trying to comfort him - I get a lot out of that, even though it was almost killing me watching him in pain.'

'I feel like I am a stronger person now.'

Look for the positive by reminding yourself:

- your support is helping your relative
- you are taking on a very difficult role, so it is natural to feel overwhelmed at times
- there are people to help you
- you can arrange to do something that makes you feel good
- to think of pleasant past experiences
- you are doing the best you can

Main tips from Chapter Three

- Make sure you have all the options explained to you, about where you can care for your relative.
- Be assured that you can ask for extra support if and when you need it.
- The palliative care service can teach you ways to help your relative.
- There are alternatives to caring for your relative at home if things 'get on top of you'.
- You only need to do caregiving tasks that you are comfortable with and you can ask for assistance when needed.
- You can seek financial support or other practical assistance by asking your palliative care service.
- Respite care can be arranged if you need a break from your caregiving role.
- Talk openly with your relative about what's best for you both at any given time.
- You can seek advice and support at any time by ringing the palliative care service.
- If you are not satisfied with the service you can make a formal complaint.
- Give careful thought to selecting a GP who can support you and your relative at home.
- If you have questions about caring or your relative's well being, write them down and discuss them with a member of the palliative care team.
- Remember that, although the caregiving can be very difficult at times, there are also many positive things to focus on.
- The palliative care team may be available by phone 24 hours per day.

Chapter Four

Practical care

This chapter provides tips on helping you to give practical care, how to deal with common symptoms and how to deal with your relative's emotions.

Information about your relative's illness

A person's medical history is often a private matter. However, usually there are a couple of people in our lives that we don't mind sharing this information with. If possible, get your relative to write down the people who they will allow access to this medical information, and ask them to sign it and have someone sign as a witness. If you think that you are going to be a main carer for your relative, having their written permission to give and receive information about their medical situation may make it easier for you. This will make communication easier when you need to speak to nurses, doctors and other health professionals about your relative's condition from time to time.

Providing practical care

Your relative may be quite independent with some tasks, or may require assistance. You will find it helps if you have some knowledge of these tasks, so you can assist when necessary. Remember, only do things you feel comfortable with. If you are unsure at any time, seek guidance from the palliative care team.

Helping with medications

- Always double-check the label on containers to ensure that you are giving the right medicine at the right time. Not all medicines are taken orally (by mouth), so check first. Not all medicines are in tablet form, some may be liquid and others may need to be given by injection or via a skin patch.
- Sometimes people are given a list, from the hospital or GP, of what medicines are for and when to take them. If you haven't got a list and you would like one, speak with the GP or palliative care team.
- Some medicines need to be given at certain times; others are given 'as

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required'. For example, some pain medications should be taken only when the person gets pain, whilst other pain medications are given regularly at specific times of the day or night.

- Medicines should only be taken 'as directed'. If your relative is not sure about this, speak to the doctor or nurse.
- If there are many tablets to be taken, consider using a dosette box, which allows tablets to be put into special compartments so that it is easier to remember which ones need to be given when. Dosette boxes are available at most chemists and can be filled by you, or the chemist. Or speak with your chemist, palliative care team or GP about a 'webster' pack. This is a weekly pack, made up by your chemist, of all the medicines being taken.
- If syringes and needles are being used, ask about safe disposal via a 'sharps disposal' container available from chemist or local council.
- It is quite common for medicines to change. When a medicine is no longer needed, it should be discarded to avoid accidental use. Unused medicines should be returned to the chemist for safe disposal. If there is a chance that a medicine may need to be used again in the future, store it in a safe, cool and dry place, away from the medicines that are being used every day.
- If you have only a few tablets (or other medicines) left, phone the GP to arrange for another prescription. Try not to leave this too late. Where possible, avoid having to arrange this on a weekend. Some chemists provide home prescription delivery services.
- If swallowing is difficult, some tablets can be crushed and given with food or fluids. Check first, with the doctor or nurse, as some tablets should not be crushed, and an alternative form of the medication may need to be prescribed

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- Some people may need to take strong pain medicines, such as morphine. If a strong pain medicine is required, the doctor, chemist or palliative care team can explain why, how and when to use it. Written information is also available.
- In many cases the palliative care team may arrange for some medicines, in the form of injections, to be left in a safe place within the home. These are sometimes referred to as ‘emergency medications’ and are prescribed ‘just in case’ your relative has discomfort that isn’t relieved by medicines taken by mouth. For example, if a person has nausea and can’t take their pain medicine by mouth, the nurse or doctor may need to visit to give an injection to stop the nausea or to prevent the pain.
- Many drugs (medicines) given to relieve pain also have unwanted side effects. Speak with your nurse about this, so you know what to look for. Most side effects wear off within 24 or 48 hours as the body gets used to the drug. However, it’s much better to *prevent* the side effects where possible; for example, by giving laxatives regularly to prevent constipation or having anti-nausea medications on hand to prevent vomiting.
- Some patients and families worry about the use of strong pain medicines (opioids such as morphine). They worry that the person may become addicted, or that the prolonged use of these powerful drugs may hasten death. You can rest assured that palliative care is based on the latest evidence. This shows that when given for pain, opioids do not cause addiction; and when used in prescribed doses, do not hasten death. In fact, many patients feel so much better when their pain is relieved; their appetite improves, they can move about more freely and can often resume pleasurable activities.

Providing hygiene care

- Assisting with hygiene care may be done in different ways: you might just be nearby to ‘lend a hand’, you may offer to wash your relative’s face and hands, or you may want to assist with a complete shower or bed bath. Your relative may also need help to move out of bed and to the bathroom. The nurse can guide you with any of these tasks. If preferred, a nurse can provide the hygiene care and/or you can do it together.

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- Safety is important. Consider having rails installed in the bathroom, and where there are steps. Talk to your palliative care team about hiring a shower/bath chair so that your relative does not have to stand. A hand held shower hose may also make things easier. A health professional can assess the bathroom set up in your home to improve safety. There are several other devices that help people move safely if they are unsteady on their feet (see page 40).
- If incontinence, that is, loss of control over passing urine or faeces, is an issue there are a number of aids or products that can help your relative feel clean and comfortable. Don't be afraid to talk to one of the palliative care team or your GP about this.

Assisting with eating and drinking

- Many people with a life threatening illness lose their appetite This may be caused by the disease or a side effect of treatment and/or medications or through feeling sick, downhearted, constipated, tired or having a sore or dry mouth. Unrelieved pain can also result in loss of appetite.
- Despite the reason, caring for a person who is not interested in food and is losing weight can be very hard. Here are some suggestions you can offer:
 - Smaller meals, more often, rather than three big meals. Serve food on smaller plates and don't fill drinks to the top of the glass.
 - New types of foods. People's desire for certain food tastes may also change. For example, people may no longer like sweet tastes and may now prefer spicy food.
 - Nutritious drinks. These can be bought from chemists and some supermarkets. You can also make your own juices or smoothies. If a person is not interested in solid food, offer drinks regularly.
 - A glass of wine or other alcohol before a meal can help stimulate appetite. Alcohol should not be taken with some medicines so check with the doctor to see if it is okay.
 - Good mouth care. Keep the mouth moist by encouraging regular teeth cleaning, drinks and mouth rinses. If you notice white 'flaky' spots in the mouth let the doctor or nurse know. This is common and is usually easily treated with a special medication.

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- As your relative's illness progresses, you may notice they are eating less. It may not be so important at this stage to have 'well balanced meals' every day. It may be more important to concentrate on what your relative *enjoys*, as the following example shows.

'I've always been so careful to give auntie her vegetables each day. Now that I have to feed her myself I see that she's constantly spitting them out. When I give her some ice cream or some chocolate, her eyes light up and she swallows the lot. The dietician told me it's better for her to have food she enjoys rather than no food at all!'

Help with other 'technical' care

Some patients cared for at home require special management of various tubes, wounds, drainage systems, injections, etc. Many relatives develop significant skills at managing this complex care. However, others are not so comfortable. As one carer said,

'I can do everything else, but I get all jittery with this technical equipment.'

If you are concerned with any of this care, discuss it with the visiting nurse. You may want to take time to learn some new skills, or you may prefer to leave all the technical care to the nurses.

Use of special equipment

The equipment you need depends on your situation. The use of equipment can increase your relative's independence, make it easier for you and promote a safer environment.

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The following types of equipment may need to be used in the home:

- Shower chair – enables a person to safely sit down in the shower.
- Commode – portable toilet, looks like a chair
- Bath/shower hand rails – provides support for standing/sitting in a bath/shower
- Bath board – enables a person to safely get into and out of the bath
- Slipper pan/urinal – devices to allow toileting in bed
- Absorbent and plastic sheets – used on a bed or chair where incontinence (uncontrolled bladder or bowels) is an issue
- Dosette box – special medicine container that helps people to take the correct tablets at the right time
- Syringe driver – a device used to deliver medications under the skin rather than by mouth
- Sharps container for used syringes and needles
- Call bell or intercom
- Disposable gloves
- Hospital bed – a bed that can be raised or lowered and has sides to prevent falls.
- Bed stick – helps the person to sit up and get in or out of bed
- Urinary catheter – tube into the bladder to assist passing of urine
- Pressure relieving devices – special mattresses, sheepskins or cushions used for comfort in bed or a chair and to prevent bed sores
- Walking frame – a device used to help with walking
- Wheelchair – allows a person to be mobile if they are unable to walk easily
- Slide sheets – slippery sheets that make it easier to move your relative around when they are in bed

If you think you need any of the above the palliative care team can assist you in choosing what is required. They can also help you obtain the equipment and show you how to use it. There may be some safety tips that you need to know. A hire charge usually applies.

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Dealing with common symptoms

The word symptom is used to describe an issue related to an illness. When a person has a serious illness, and where curative treatment has stopped, the focus of care is on relieving symptoms that may arise. Every person is different and so are the symptoms that might occur. It is important to highlight the common symptoms (pain, constipation, nausea, tiredness, breathlessness) and some basic ways of relieving them. Symptoms may not disappear completely, but in most cases symptoms can be controlled to a level that is comfortable. Your role in helping to recognise and manage the symptoms will depend on how independent your relative is, your relationship and what you feel comfortable doing. Remember that relief of symptoms is one of the major aims of the palliative care team, so help is available. If a symptom arises that is not mentioned here then speak with the palliative care team and they will provide you with more information. It may help to keep a diary or a daily journal to jot down the time and the words used by your relative to describe a particular symptom.

Pain

Many carers worry about the comfort of their relative. This is very understandable. The first thing to be aware of is that not all people who need palliative care suffer ongoing pain. It is also important to realise that a person's level of comfort is a very personal feeling. We all feel discomfort in different ways and at different levels. People often associate discomfort with pain; however, we may also feel uncomfortable if we feel sick, tired, worried or restless. The important thing is that if your relative says they are in pain then the palliative care team can help. Despite advances in treatment, pain may not always be completely removed. The palliative care team will help you with various strategies to reduce the pain as much as possible.

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The ways of dealing with pain vary from person to person. Here are some common things you could do if your relative is in pain:

- Assess the pain. You may want to ask your relative these questions, and write down the answers. This will help you to describe the pain to the nurse or doctor and assist in the choice of treatment.
 - (1) Where is the pain? (sometimes the pain may be more than one area).
 - (2) What does the pain feel like? (e.g. sharp, throbbing, burning).
 - (3) How long has the pain has been there?
 - (4) Is this a new type of pain?
 - (5) How would you rate the pain on a scale of one to ten? (1 being 'no pain' through to 10 being 'excruciating pain'). If the answer is 7 or 8 out of 10 this would be regarded as a considerable amount of pain).
 - (6) Do you feel like vomiting?
 - (7) When did you last have your bowels open?
(constipation can cause pain)

Alternatively, the palliative care nurse may give you a pain chart which either you or your relative can fill in. If your relative has dementia, or is unable to understand or answer the questions, it is important that you ask the nurse how to look for signs of pain (e.g., when your relative is moving from bed to chair, eating, walking, or being assisted to move in bed).

- Managing the pain:
 - (1) Ask your relative to lie on the bed or to sit down.
 - (2) Ask your relative to take 10 deep breaths.
 - (3) If your relative has been given some medicines to take (which are for the pain they are feeling) give the medicine as directed on the container. Check first to see what pain medicines have already been taken that day. If your relative has had as much as they are allowed phone the palliative care service.
 - (4) Ask your relative to try to take their mind off the pain by reading, watching TV or listening to some music.
 - (5) Offer a massage of feet, hands or shoulders.

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- (6) If nausea (feeling like vomiting) or constipation (no bowel action for several days) is an issue, this may be a possible cause of the pain (refer to sections on nausea and constipation below).
- (7) If the discomfort has not eased after 30 minutes phone the palliative care team. They will be able to review the problem and suggest other ways to reduce the pain.

Concern about opioids and hastening death

Opioids are very strong pain killers which will only be prescribed if the pain is not managed with milder medicines. Some patients and relatives fear the use of opioids (like morphine for example) because they think it might hasten death. It's important to remember that *what causes death is the underlying disease, not the drug*. The doctor will carefully reduce the medication if it is causing serious side effects. However, it is important that you know about the effect of these drugs and why they are used. Ask your palliative care nurse for a brochure which explains all about opioids.

Nausea

This is the term used when someone feels the urge to vomit or feels sick at the thought or sight of food. The cause of nausea can be related to the disease, medications, chemotherapy, radiotherapy, constipation or an imbalance of chemicals within the body.

If your relative has nausea:

- (1) Ensure a bowl or bucket is within easy reach in case they vomit.
- (2) Ask how they rate the nausea on a scale from 1 to 5 (1 being 'very little' nausea and 5 being 'extreme' nausea).
- (3) If anti-nausea medicines are prescribed check to see if they have been taken as directed. If the prescription allows, give the anti-nausea medication, unless the thought of trying to take a tablet makes your relative feel worse.

Practical care

- (4) Some people prefer not to eat or drink anything until the nausea passes; others find small amounts of food or drinks helpful.
- (5) Ask when was the last time your relative had a good bowel motion. If it is longer than two days follow directions under the 'constipation' symptom below.
- (6) Encourage your relative to rest. Suggest deep breathing. Play some soft music. Offer a foot or neck massage. If your relative feels up to it, a bath or shower may help.
- (7) If nausea is not relieved after one hour or if it gets worse, phone the palliative care team.

Constipation

Constipation occurs when a person does not open their bowels for several days. This symptom can cause nausea, pain and tiredness. The cause of constipation can be related to decreased fluid intake, limited mobility, poor diet or the person's illness. Constipation is also related to side effects of strong pain medicines. In most cases constipation can be prevented.

To prevent constipation:

- (1) Encourage drinks such as water and juices.
- (2) If possible, have foods high in fibre, as well as plenty of drinks.
- (3) Suggest that your relative has a short walk each day if they feel up to it.
- (4) Take note of the bowel actions: are they hard, soft, small, or liquid?
- (5) Keep a record of when bowel actions occur.
- (6) If your relative is prescribed strong pain medicines (such as morphine), make sure that laxatives have been ordered.
- (7) There are many natural remedies for constipation that can be used in conjunction with prescribed medicines. Ask a member of the palliative care team for suggestions.

Practical care

- (8) If there is no bowel action for 2 days, speak with the palliative care team who will set up a plan specific to your relative's needs.
- (9) Do not assume that if your relative is not eating that they do not need to use their bowels – constipation can still occur even when little food is eaten.

Breathlessness

Breathlessness or difficulty breathing can be an unpleasant symptom. It is usually caused by disease of the lung, or asthma, emphysema, chest infection, pressure from other body organs, or anxiety. While the specific treatment depends on the cause, here are some general tips which may help:

- (1) Encourage your relative to sit in the upright position and stay with them.
- (2) Put on a fan and/or open a window.
- (3) Suggest that your relative wear loose fitting clothing.
- (4) Put on some calming music, maintain a gentle, reassuring presence, offer a foot, hand or shoulder massage.
- (5) If medicines for breathlessness have been prescribed, ensure they have been taken as directed.
- (6) Oxygen via a mask or nasal prongs is not routinely needed and requires a doctor's order to be used.
- (7) If breathlessness is not relieved and is causing distress, phone the palliative care team.

Fatigue

Fatigue is very common in people with life threatening illness. It is a feeling of extreme tiredness that can be quite frustrating (or debilitating). There are a number of possible causes of fatigue. These include lack of sleep, low oxygen in the blood, poor diet, depression, effect of chemotherapy or radiotherapy, infection, or the effects of the disease itself.

Practical care

Fatigue can be (not always) quite hard to manage. The following strategies may help:

- (1) Encourage short naps during the day.
- (2) Suggest regular gentle exercise.
- (3) Encourage nutritious food and drinks.
- (4) Plan to do the most energetic tasks (eg shower or bath) when energy levels are higher.
- (5) Encourage your relative to take up a hobby that does not require a lot of energy. For example: board games, talking books, listening to the radio and/or watching television or videos.
- (6) If you think that fatigue has become worse, speak with the palliative care team.

Delirium

This is a change in a person's thinking, memory and behaviour and is common in patients who are receiving palliative care. The changes are caused by a disturbance in brain function due to illness or sometimes medication.

Patients receiving palliative care either in hospital or at home are often sicker than other patients; and are taking a variety of medicines. We know that patients who are seriously ill, taking several different medicines, and who may have infections or have had recent surgery may develop delirium. Also patients who are older, or who already have some memory problems are more likely to develop delirium.

Delirium can be very distressing for the person who has it, and for their family. People with delirium have difficulty remembering new information, trouble concentrating and paying attention, and sometimes have difficulty telling day from night. The person with delirium may be confused and not recognise familiar people, or they may become fixated on one thing, or become suspicious. Sometimes delirium causes hallucinations when people see things that are not there.

Practical care

The doctors and nurses looking after your relative will look for causes and try to treat the cause so that the delirium will settle. Sometimes the patient may be prescribed tranquillising medicine to help them to feel calmer and to make sure they are safe.

The changes in the person's thinking and behaviour when they have delirium are not usually permanent and do not mean that the person has an ongoing mental health problem. However it must be pointed out that patients in a palliative care setting may be very ill and close to death, and in this situation the thinking, memory and behaviour problems of delirium may not settle completely.

The best way of helping your relative with delirium is to make sure you have eye contact with them, speak slowly and calmly and remind them who you are, where they are and that you are there to help. If your relative is in hospital or another care facility it is very helpful for staff if family and friends can stay with the patient whenever possible, as patients with delirium respond better to familiar people than strangers.

It is best for the person with delirium not to have too many visitors at once, nor to have too much stimulation such as loud music or TV. It is also important to encourage them to drink fluids as they may get dry, especially if they are restless and not wanting to eat and drink.

Please advise health professionals if you think there are changes in your relative that might mean they are developing delirium. It is also helpful to give the staff as much information as you can about your relative's previous history as this may be important in diagnosing the cause of the delirium, and preventing delirium recurring.

Practical care

Complementary therapies

Complementary therapies are treatments used together with conventional medicine. *Alternative* treatments are often considered to be those used in place of conventional medicine and are sometimes referred to as unproven remedies.

Complementary physical and psychological therapies include massage, acupuncture, reiki, hypnosis and guided imagery. Complementary therapies can have beneficial outcomes in some circumstances. However, it is strongly recommended that you speak with a health professional for further information about what complementary therapy(s) might be suitable for your relative or for you. Other examples include aromatherapy, music therapy, art therapy, pet therapy. If you would like to find out more, ask the palliative care team. Here are two examples of complementary therapy:

'I had no idea what music therapy was until the palliative care nurse asked whether I found music helpful in relaxing me and helping the pain. Within two days I had a visit from this beautiful harpist, and in one hour the pain just melted away.'

'The art therapist brought some paper and paints to help George express his feelings in ways other than words. One day he expressed his anger by painting the cancer cells invading his body. Another day he painted a soothing sunset.'

It is quite common for people with life threatening illness to consider other medical treatments that are not routinely used by doctors. This is because people often want to explore all possible treatment options. It is highly recommended that before your relative uses alternative treatments that you discuss these options with your relative's GP or medical specialist. While some of these alternative treatments may be promoted as being beneficial some might in fact be harmful. It is wise to talk with a medical specialist about the benefits of any alternative treatments.

Practical care

Emotional care

It is very hard to provide precise tips on dealing with your relative's emotions, as every relationship is different. It may help to be aware that your relative will have 'highs and lows' throughout the illness. At times they might feel angry, upset, grumpy or irritable and may even blame you for some of their emotions. However, sometimes they may even feel very positive.

Your relative may be thinking about a number of major issues about death and dying. Some of these things may be easier to talk about with someone else, perhaps someone from the palliative care team. The point is, you do not have to have all the answers.

Some things which may help include:

- (1) Providing some time alone each day, if desired.
- (2) Asking if there is anything that you can do to make things easier.
- (3) Suggest some enjoyable things to do together.
- (4) Asking if there is anything that they have a particular desire for.
- (5) Remember that it is normal for your relative to feel downhearted from time to time.
- (6) Encourage involvement in 'day to day' things such as the news and social activities.
- (7) Remind your relative of the skills and different roles of the palliative care team.
- (8) Tell them how much you care for them and want to help them.

In some instances patients and/or their carers become so worried about what is happening that they become depressed or anxious. Everyone has times where they feel a bit low or 'flat'. *Depression* usually means the person experiences the following symptoms for more than two weeks: feeling sad, down or miserable most of the time, lost interest or pleasure in most of their usual activities. While there are many types of *anxiety disorders* and the symptoms for each disorder are different, some general signs and symptoms include:

- feeling very worried or anxious most of the time
- finding it difficult to calm down

Practical care

- feeling overwhelmed or frightened by sudden feelings of intense panic anxiety
- experiencing recurring thoughts that cause anxiety, but may seem silly to others
- avoiding situations or things which cause anxiety (e.g. social events or crowded places)
- experiencing ongoing difficulties (e.g. nightmares/flashbacks) after a traumatic event.

If you or your relative have these feelings please make the doctor or nurses aware. Then, a thorough assessment can be undertaken so that appropriate strategies can be used to try and lessen the depression and/or anxiety. Information can be found at 'beyondblue' www.beyondblue.org.au or 1300 22 4636.

Palliative care patients rarely speak about or make a request for suicide. If this does occur, contact your palliative care service, doctor or the 'beyondblue' helpline. Some patients might make remarks such as "I've had enough" or "no- one should have to be in this situation". These types of comments are not usually linked to a specific or sustained request for suicide. However, they do require discussion to find out why the comment was made and to see if the situation may be improved.

Spiritual care at the end of life

Spiritual care is much broader than formal religious practices. It refers to any support related to questions about life's meaning, depending on the person's values and beliefs. The kind of spiritual care required will differ for every person. If you are unsure of your relative's spiritual needs, you (or someone else) can open up a conversation with questions such as:

'Is there any particular person, place, or object that gives you hope and strength at this stage of your illness?'

'Is there a particular religious ritual you would like assistance with?'

'Do you have any particular concerns as death is approaching?'

'Is there anyone you would like to talk to about spiritual matters?'

Practical care

If your relative is in the habit of attending religious services, and this is no longer possible, discuss the matter with the local minister, priest, rabbi, or other religious representative. For example, someone from the religious community may arrange to come to your home. It is important for these religious contacts to be maintained, as well as any familiar rituals. These visits may help you and your relative to feel less isolated, and to feel that you remain an important part of the religious community. Opportunities to receive Holy Communion or to participate in other rituals, to make confession or to seek religious 'counsel' are all a part of spiritual care, depending on your relative's wishes and familiar practices. In times of crisis spiritual care can be very helpful, as in the following example.

June was devastated when she learned there was no more curative treatment for her cancer. She had several operations and now the oncologist suggested ceasing the chemotherapy. June and her family felt the situation was hopeless. The palliative care chaplain suggested June and her family might like a brief ritual to mark the transition from hospital to home. A prayer was offered, giving thanks for medical skills and acknowledging a different form of care would now be required to maintain June's comfort.

Other spiritual matters may include reminiscing or conducting a 'life review', with you and/or with another family member or friend. This provides opportunity to 'tie up loose ends', to laugh and to cry, and to tap into the 'spirit' of your relative. Some people choose to write the life review down so that it can be available as a memoir. Other ways of tapping into the 'spirit' or the 'whole person' may be through music, art, literature, photos or conversation. A way into this 'spiritual realm' may be to ask your relative: 'What's the most important issue for you at this time?' Or 'If you had one wish, what would it be?'

Practical care

Remember, even if your relative has never been particularly 'religious' or 'spiritual' these issues may arise at some stage of the palliative care journey. You can request assistance from the palliative care team at any time. For some people the formal services of a chaplain or pastoral care worker might be appropriate; for others, a friend or family member may become their 'spiritual companion'. It is important for you, especially if you are the primary carer, to remember you may not be able to provide all the emotional and spiritual care as well as the physical care. It's okay to seek help from others. (Refer also to 'spiritual care' in chapter 7 and 'Care as death approaches' and 'Advance Care Planning' in chapter 6).

Cultural care

We all have certain values, beliefs and customs and these are usually associated with our cultural backgrounds. It is important that you let the palliative care team know about any specific cultural practices that are important for you and your relative. These may include matters of diet, personal hygiene, clothing, special national or holy days, or other important rituals.

If you or your relative has difficulty understanding English the palliative care service can arrange for an interpreter. Although there might be family or friends who can help with interpreting from time to time it is recommended that a professional health interpreter be used when discussing important information about health care.

If you or your relative would prefer not to discuss issues of death and dying, because of your cultural beliefs, please let the palliative care team know, so that no offence or embarrassment is caused.

Practical care

How much should patients be told about their illness?

Your relative might have chosen not to be told of their serious illness, leaving you to obtain all the information and to make the decisions. Even though your relative may in fact 'know' that they have a life threatening illness, they may avoid any discussion on the subject. This may place a great burden on you, and seeking help from the palliative care team is essential. Depending on your relationship with your relative, and the way you have communicated difficult issues in the past, you may ask, 'Can we have a chat about this with someone else here?' A member of the palliative care team can help you with this discussion. Remember also, that some patients who have previously refused to speak about their terminal illness change their mind, so be prepared for the unexpected!

On some occasions family carers think that their relative should not be informed about their diagnosis. This may be because they think that their relative will not be able to cope with such news. Or, there may be specific cultural reasons why it is not appropriate to talk about death and dying. However, people with a life threatening illness commonly want to plan and make decisions about their place of care, put their affairs in order, say their good-byes and be protected from unnecessary medical interventions. It is very difficult to keep information from relatives. As one person put it: *"Truth may hurt but deceit hurts more."* The palliative care team are very experienced in having open discussions and answering family and patient queries about the impact of the illness.

Practical care

Forgoing medical treatment

Many patients and carers are keen to pursue 'just one more treatment' in the hope of a cure, or in the desire to postpone the person's death. Others think that 'stopping treatment' is 'giving up' or hastening the person's death. You may find reassurance in the palliative care principle that treatments should only be offered if they are going to improve the person's quality of life.

That's why treatment such as pain management will remain right until the end. Remember also, that palliative care focuses on comfort when cure is no longer possible. When no more specific medical treatment is likely to improve the person's condition, all aspects of palliative care (physical, psychological, spiritual, cultural and emotional) will continue, together with support for you and your relative.

Main tips from Chapter Four

- Only take on tasks that you feel comfortable in doing.
- The palliative care team can guide you if you would like to try and take on new care related activities.
- Don't be surprised if you need to be shown how to do something a few times.
- You may find it difficult to retain information so try and write things down.
- Ask as many questions as you like.
- Sometimes people needing palliative care may have pain or other symptoms; there are ways that you can help.
- Care at home is not always possible; you may be finding care too difficult and/or your relative may need close supervision by health professionals to assess symptoms.
- Consider your relative's spiritual and emotional needs.
- Tell the palliative care team of any particular cultural needs.
- If you are unsure about what your relative should be told, speak to a member of the palliative care team.
- If you or your relative are unsure about continuing or stopping treatments, the palliative care team can help you.
- The palliative care team has a lot of experience and are used to answering difficult questions.
- Speak with the palliative care team if you are worried about your relative or yourself.

Caring for your relative in hospital, hospice or aged care home

You can have a ‘hands on’ role with your relative’s care even if they are in hospital, a nursing home or a palliative care unit. Just speak with a nurse about the involvement you want to have. You can also play a key role in making the area home-like by bringing in some of your relative’s favourite things. It will also help the health care team if they can work with one or two key family or friends for most aspects of your relative’s care. So think about whether or not you wish to take on or continue with this role. It is important to let the health care team know about any cultural or spiritual wishes that need to be respected. Ideally the facility where your relative is receiving care should have a quiet area where you and family/friends can talk in private. Health care professionals should also try and use a private area if they are discussing your relative’s care with you.

If your relative is at home and quite unwell or if you are feeling worn out and finding it too difficult to provide care, the best thing for your relative might be a hospital admission. This decision can be hard, but it can also be in the best interests of your relative. You may feel guilty or ashamed if you cannot care for your relative at home, but your health is important too. What follows is a brief outline of some of the options if care cannot be provided at home.

Caring for your relative in hospital, hospice or aged care home

Palliative care unit (the hospice)

These are places designed to support people who require palliative care when care at home is no longer possible. People are admitted to palliative care units for one or more of the following reasons:

- *Symptom management*: In some cases it may be difficult to completely relieve symptoms such as nausea or pain. The advantage of an admission may be to allow for 24-hour health professional assessment and monitoring. The length of the admission may vary from days to weeks, depending on the situation.
- *Care as death approaches*. Some carers or relatives may decide that death at home is not appropriate for them. In this case an admission to the palliative care unit is arranged to care for the person as death approaches.
- *Respite*. This is where a person is admitted, for a few days to several weeks, in order for the carer(s) at home to have some time to themselves.

Palliative care units are designed not only for the care of the person who is ill but also to provide support for carers. Access to similar health care professionals that you had at home will also be available (e.g. pastoral care counsellor, social worker, nurses) within the palliative care unit. The units have their own specialist palliative care doctors who manage the medical care and work with the GP.

Palliative care units usually have open visiting hours and carers are encouraged to phone at any time of the day or night. Some units have facilities for primary (main) carers to stay over night from time to time. Patients are usually advised that they can bring in photos, music or other personal items. Palliative care units vary in style and layout (a single room may not be assured) but they all strive to uphold the same philosophy of care, which focuses on trying to enhance quality of life. Carers and their relatives are encouraged to make a time with the palliative care unit in their region (just ask the doctor or nurse to advise you of the contact details) to go and see for yourself what the unit is like. If you or your relative think that an admission to the palliative care unit may be appropriate just ask the nurse or doctor involved in assessing your situation and if necessary they can arrange the admission.

Caring for your relative in hospital, hospice or aged care home

Hospital

Your relative may have been (or still is) receiving some type of medical care from a hospital. Many major public hospitals have specialist palliative care staff who can assist in assessing and coordinating care needs. They work closely with the community palliative care service. A decision to remain in hospital or to be readmitted from home will vary according to your circumstances, medical advice and your preferences. Some people may prefer to use a private hospital, because their specialist works there, and/or they find the environment comfortable. Some private hospitals have specialist palliative care staff. The private hospital can also work with the community palliative care service. It is also important to speak with the health insurance representative.

Residential aged care homes

Some people who need palliative care live in or may be referred to an aged care home, otherwise known as a residential aged care facility, nursing home or hostel. Referral to an aged care home may be required when your relative cannot be at home but is not expected to die in the near future. This provides an option for longer term care. The type of aged care home available will depend on your relative's needs. An assessment is needed by an Aged Care Assessment Team. For people with lower level needs the aged care home will have staff to assist the person with activities of daily living such as meals and bathing. There may not be a registered nurse available 24 hours per day. People with greater needs may require care in an aged care home where there is 24-hour nursing care provided. Aged care homes have no resident doctor, so the person's GP manages any medical issues. The community palliative care service may be able to provide extra advice or resources to assist residential aged care facilities to provide palliative care.

The choice of staying at home or going to one of the facilities mentioned above may be a tough one. However, you and your relative don't have to make a decision until you are ready.

Caring for your relative in hospital, hospice or aged care home

Also, if you make a decision and for whatever reason it doesn't feel right, you can change it. For example, if your relative decides to stay at home but it's not working out so well, a re-admission can be arranged. Or, if you and your relative decide an admission to an aged care home is best but it's not what you expected, you can arrange to return home with support. It is also important to be aware that if your relative needs to be admitted to another facility and you would like to continue providing some aspects of care, you are free to do so. Short term respite care may also be available in some aged care homes.

It's important to remind yourself that making this decision is not a sign of failure or 'giving over' the care to someone else. It means you will continue caring, but in a different place and in a different way.

Who do I ask?

Aged care homes are staffed by a variety of workers ranging from qualified nurses to personal care workers who may have very little training. If you have a question it's best to ask the person in charge, and this will vary from day to day and within the day, depending who's on the current 'shift'. As you develop a relationship of trust with the aged care team, you will get to know the best time to phone or have a face to face discussion about your relative's care.

What if more complex care is needed?

Aged care staff work with the specialist palliative care team in their particular region. Similar to the service offered in their own home, the palliative care team can be called on for advice on physical symptoms; for assistance with psychological, emotional, or spiritual care; and for family support. The GP attending your relative may also seek advice from the specialist palliative care team for issues such as complex pain management.

Caring for your relative in hospital, hospice or aged care home

Main tips from Chapter Five

- You need to have all options clearly explained to you so you and your relative can decide which option suits you best.
- You can ask for a family meeting soon after your relative is admitted to hospital, hospice or aged care home.
- You can change your mind if things don't work out.
- It's best to discuss your concerns with the person in charge at the time.
- In aged care homes the treating doctor will be your relative's GP so it may be helpful for you to arrange an appointment with the GP to discuss your relative's care.
- In an aged care home you are free to discuss your relative's care plan with the person in charge, and to ask for a review at any time.
- If you believe your relative would benefit from additional specialist palliative care support (e.g., for pain management) feel free to ask.
- If your relative is approaching the time of death make sure your relative's wishes are respected regarding hospitalisation or suggested new treatments.
- If you are unsure about the care as death approaches, you can request a meeting with the doctor and/or senior staff.
- Your presence at the bedside will in most cases be welcomed and appreciated and there is no restriction on visiting hours in a hospice or aged care home.

Advance care planning, legal matters and funerals

In this chapter some of the practical issues involving important ‘paper work’ are discussed, to help you and your relative plan for the future.

Advance care planning (ACP)

Death can happen to any of us at any time. When we are healthy and well we don’t like to think about making a will, or deciding how and where we would like to die, or who should act on our behalf if we are unable to speak for ourselves. These are the questions at the heart of ACP which is different from any of the other issues discussed so far, but it is a vitally important component of palliative care. ACP gives power and control to your relative over questions like going to hospital, or having unwanted medical interventions at the end of their life. It is important that you know what your relative would want, particularly if they are unable to speak for themselves. If an ACP form or discussion has not been provided you may request a meeting on this important issue. ACP is designed to avoid situations such as this one:

‘Dad had an angina attack in the middle of the night, so I got this phone call from the aged care home at 1 a.m. to ask if I wanted him sent to hospital. I was only half awake, but I said ‘No’, knowing dad would not want that. But then I spent the rest of the night lying awake wondering if I’d made the right decision.’

Advance care planning, legal matters and funerals

ACP can also be used to overcome family disagreement as in the following case:

Mrs A was being cared for at home with regular visits from the palliative care nurses. She was close to death and developed severe breathing difficulties. One daughter wanted to call the ambulance and send her to hospital; the other daughter found the ACP form which stated Mrs A would prefer to die at home. An emergency visit was arranged by the palliative care nurse who, in consultation with the doctor, was able to give Mrs A drugs to calm her anxiety and alleviate her breathlessness. She died peacefully; her wish to die at home was respected.

Advance care planning gives you the option of 'allowing natural death' rather than death with intrusive treatments in hospital, if that is preferred. You do not need to complete the ACP form on your own. It should be part of a private, unhurried discussion with a trusted, skilled health professional, your relative (if able) and yourself. Remember also, what is recorded on an ACP can be changed at any time.

You can complete an ACP for yourself too. Discussion about what your relative wants can help you to think about your own wishes when the time comes. If your family needs further assistance, counselling can be arranged through the specialist palliative care service.

A more detailed description of ACP can be found in *Affirming life: a guide for family and friends with loved ones in aged care* (refer Resources section).

Preparing a will

Although preparing a will may appear to be a daunting task it can be satisfying as you and your relative may feel better knowing that financial affairs are in order. In most cases wills are fairly easy to prepare. There are 'do it yourself kits' available or if you need some help, contact a solicitor. The palliative care team can refer you to a social worker if you need further assistance.

Advance care planning, legal matters and funerals

Making decisions on behalf of your relative

In some cases, if the person who is ill cannot clearly express their wishes, the carer may seek more formal legal permission to make decisions on their behalf. Many carers prefer to think ahead and arrange this option before their relative becomes too unwell. This is often referred to as advance care planning (discussed above). If you are concerned about medical or legal matters you can consider applying for a 'medical power of attorney' and/or 'enduring power of attorney' (the forms vary in different states). Some people also like to write down their medical care choices in advance. For example, people may express a wish not to be resuscitated, or not to be placed on a mechanical ventilator. It may help if you talk to your relative about any medical preferences they have. It is best if they write their preferences down and have them witnessed, dated and signed. The palliative care service, legal service or a social worker can assist you with more information about these and other options.

When should funeral arrangements be made?

Some people commence funeral planning prior to their death or the death of a relative. Such planning is considered a helpful way of preparing for the inevitable and is often advocated as something we all should do. In the case of a carer, advance planning can prevent rushed decision-making at the time of death: it can also be one less thing to have to do. Some dying people wish to be involved in funeral planning, while others avoid this issue. It is, however, helpful to know what your relative prefers, particularly in relation to cremation or burial. For others, there are decisions to be made regarding the funeral ceremony, music preferences, location, etc. Some people choose to arrange for a pre-paid funeral.

Funeral companies vary in cost and style. Funeral companies need details about full names and birth dates as well as specific information about the funeral format. The palliative care team can assist you in identifying the questions you may like to ask when choosing a funeral service. They can also provide written information. If preparing for a funeral is not something you feel able to do yourself, ask a friend or relative to help you.

Advance care planning, legal matters and funerals

Main tips from Chapter Six

- If your relative does not have a formally appointed attorney (differently named in each state) you can obtain a form from your local newsagent.
- If your relative has not completed an Advance Care Plan (ACP) ask the person in charge for a copy of the form, to be completed as soon as possible.
- You may seek a solicitor's advice if your relative is unsure about arrangements for a will.
- Funeral arrangements are best made in advance, where possible, to avoid making a decision at a stressful time.
- As death approaches and if you are unsure about your relative's wishes, or how to make decisions on their behalf you can request a meeting with a chaplain, a social worker or one of the palliative care team.

Care as death approaches & bereavement

This chapter provides information on what to expect when someone is close to death, suggesting ways of preparing for and coping with this extremely difficult time. It may be quite hard to read this section as it contains information that may stir up deep emotions. Take your time and be sure to ask the palliative care service if you have any questions.

Talking about and understanding death and dying

Talking about death and dying can be hard. It is a subject we are not used to talking about. Unlike other major events such the birth of a child, a job promotion or the purchase of a new house, death is often not openly discussed. Also, many things about death are unknown. There are no right or wrong ways of dealing with death and dying as circumstances differ from person to person. The way you go about trying to understand death will depend on your past experiences, your relationship with your relative and your own belief systems, culture and values.

Spiritual care at the end of life

We have discussed some spiritual aspects of care in Chapter 4; however, these issues may become more important as death approaches. Some carers find that thinking about the death of a relative makes them confront their own mortality. 'I know we all have to die some time but this brings it very close to home.' Some people look for spiritual guidance to help them. Questions such as 'why me?' or 'what happens after death?' are often raised. Depending on what's right for you, you may want to seek advice within a church or other religious community. However, you may not feel the need to speak with a 'religious' person; you may find help among friends or other community groups.

Care as death approaches & bereavement

If spiritual issues become a concern, consider seeking some guidance. You can refer to books or you may want to ask the pastoral/spiritual counsellor from the palliative care team to come and see you. If you think that death may be near, you might like to consider whether your relative has any spiritual needs that should be addressed. While these factors are usually intensely personal, the philosophy of palliative care regards spiritual issues as important as physical matters.

As death approaches, it is important to ask your relative if they wish to receive a visit from a priest or minister even if this has not been a familiar practice. Religious rituals and symbols can also be very important for some people as they are close to death. If you are finding religious or spiritual matters difficult to talk about, ask one of the palliative care team to help you.

Waiting for death to occur

For some people waiting for death can be very difficult. There may be times when you feel you've 'had enough'. You will see from the following example that these thoughts are not uncommon.

'I just wanted it to be over. I was tired to the bone and to be honest I was fed up; I had had enough. Its bloody hard work doing what I did - washing, medicines, the house, doctors' appointments and helping him shower. You name it – I did it. But then I felt bad I shouldn't have thought that way.'

Alternatively, you may be thinking 'I don't want them to die'. You may be feeling as though it's not fair to be left without that person as part of your life. You may feel that you don't deserve to be in this situation. If you feel guilty about these feelings, remember these thoughts are quite normal.

Care as death approaches & bereavement

Occasionally people with a life-threatening illness feel that they are bored, that they are a burden, that they are isolated, that they don't have control, that they are depressed, or they might feel guilty about something. As a result of these issues carers are often faced by comments from their relatives such as 'I just want it all to end'. Such comments can cause concern and confusion for carers as they may be uncertain about how to respond. Carers may also be concerned that their relative might be very depressed or even suicidal; they may be asking for help to hasten their death; or they may be extremely worried about something.

The first thing to realise is that comments like this are quite common. Often it is a result of the person expressing that they have times where it all gets a bit too much. Some questions you may want to ask are:

"Is there something in particular that is bothering you?"

"What is your greatest concern?"

"Can I or the health care team do something to help?"

Sometimes just acknowledging your relative's feelings can be very helpful. Consider comments like:

"I can tell you're really upset." Or "I know this must be awful for you."

"I can assure you I will do everything I can to help you." Or "I promise to do everything I possibly can, to help you."

However, if your relative expresses major concerns that are very worrying seek their permission to ask a health care professional from the palliative care team to come and talk with them. Health care professionals have particular skills in assessing distress and planning strategies.

Care as death approaches & bereavement

Where will the death occur?

If you and your relative both wish for death to occur at home then the palliative care team will support you. About half the people needing palliative care choose to die at home. In some cases people aim for a death at home; however this may not always occur. For example, the person who is very ill (or dying) may need to be admitted to a hospital or a palliative care unit because they have symptoms that are difficult to control. Or you may be finding some things are too difficult to manage at home.

Some carers and their relatives do not make a decision about where the death should occur until death is very close. You may find it helpful to talk about where your relative would ideally prefer to die. This is a sensitive issue and your ability to talk about it very much depends on your relationship. You may have to rely on your own 'gut feelings' but if you can, it's worth trying to talk about it, when the time feels right. If this issue is worrying you and you are finding it hard to talk to your relative please speak with a member of the palliative care team. The important thing to realise is that you don't have to know way in advance about the place of death. Some people think one way to begin with and then change their minds. Try to avoid making promises about where death will occur; it may not be possible to keep your promise.

Should children be involved?

If there are children in the family, ensure that they have a chance to see, talk to, touch and say goodbye to their relative. We know the benefits of involving children at this time. However, children should not be forced. They should be told about what is likely to occur and prepared for what they might see and hear. The palliative care team can provide you with reading materials and strategies related to children in this situation. The following example shows the importance of treating death as 'normal' as possible.

Care as death approaches & bereavement

'It was Friday night and the family knew their father's death was near. Knowing how their dad loved their Friday night ritual of fish and chips, they brought the grandchildren in, sat around the bed, played favourite music, ate their fish and chips and chatted normally about their day. The patient opened his eyes, smiled approvingly at each one, and died a few minutes later.'

How will I know when death is near?

A common question for carers to ask when they find out that a relative requires palliative care is: 'How long will it be?' Unfortunately, no one will be able to give you an accurate answer. The doctor involved may provide you with an estimate, but there are many stories of people dying well before or after the estimated time. The estimates are usually based on people who have had similar medical conditions. Try not to dwell on the exact detail of 'how long?' Instead, use this precious time to express feelings and share moments that can be cherished always. This carer's comment provides a helpful example.

'We were told months ago it may only be a matter of months and for some reason I had October or November in my head. And now it's January and she's still doing ok. Sometimes I laugh about it and sometimes I don't know what to think. But most times I think, just enjoy.'

There are some common indications that death may be near, that is, within days or weeks. Usually, if more than half of the following signs are present it may indicate that death is near.

- Spending large portions of the day in bed.
- Unable to move from bed to chair without help.
- Difficulty swallowing solid food.
- Sleeping for many hours.
- Not talking very much.
- Occasional confusion with time, the past and people.
- Restlessness.
- Unable to express the need to go to the toilet.
- Changes in breathing.

Care as death approaches & bereavement

If any of these issues arise talk to your palliative care nurse who can assist you, and there are some more details in the next section. It is also important to realise that death sometimes occurs without much warning, some or many of the common signs may not be present. However, in most situations signs as described above usually provide an indication that death may not be too far away. Your doctor or nurse can help identify when death seems to be close.

Care as death approaches

Prepare the environment

If your relative is at home:

- Arrange the bed (or couch) so that your relative can look out a window or at a favourite picture. If you share a bed with your relative, you may choose to continue using the double bed. However, a single bed may be easier for providing physical care, such as hygiene. Depending on the circumstances, a hospital bed may be recommended as the safest option. Place a radio or television in the room, if desired.
- Try and use a room that has easy access to the toilet and bathroom.
- Place an armchair in the room for yourself and visitors.
- Have a table in easy reach of your relative where you can put common items such as drinks or tissues.
- Consider using aromatherapy oils.

Care as death approaches & bereavement

Common changes and how you can help

Once it seems that death is near, that is, within days or weeks, the following advice may help you to provide care. Please remember that just as every birth is different so is every death. The following issues may or may not occur in your case. The amount and type of care that you provide is up to you. Don't forget the palliative care team is there to help, guide and support you.

Before looking at some practical caring tips for physical symptoms you may wish to discuss with your relative whether they have particular expectations, wishes, dreams, projects they wish to fulfil while there is 'still time'. Asking 'Is there anything you would like to do today?' might help you and your relative focus on what can be achieved. Setting a goal, even if it's a very small goal such as writing a card or making a phone call, can provide satisfaction. For others, it might be the completion of a project such as sorting personal belongings. Setting and achieving goals for each day will of course depend on the person's physical condition, so it's important to make adjustments accordingly.

Problems with swallowing food and fluids. The nurse or doctor can help decide if it is safe to continue to provide sips of drinks. Do not try and force solid food as this may make the person choke. Watching someone not eating or drinking can be very hard to deal with. However, this may be the body's way of saying 'I'm slowing down'. It is important to keep your relative's mouth and lips moist by applying moisturisers to the lips and placing small amounts of water in the mouth via a teaspoon. Some patients find that sucking a flavoured icy-pole is very refreshing. In a few cases, a special device that provides fluid under the skin may be tried. This device ('subcutaneous hydration') is usually only needed if there is a specific additional medical need.

Giving medications. If necessary, certain medications, such as those used for pain or nausea that were previously taken by mouth, can be given in other ways or by a 'syringe driver'. This small machine gives medication via a tube, with a small needle under the skin. The syringe in the machine is changed every day (sometimes less often) by the nurse. Some carers choose to be involved in this process.

Care as death approaches & bereavement

The machine is simple and safe. If it is needed the nurse will make sure that its use is fully explained. Some medicines may be stopped all together; e.g., those for heart or blood pressure that have been used for a long time. If you are concerned about why some medicines have been stopped, talk with your relative's doctor or the palliative care nurse.

Maintaining comfort. Comfort is really important. Your relative may not be able to tell you whether they are uncomfortable. If groaning or facial grimacing occurs this may be a sign of discomfort. Consider helping to change position slightly, provide a foot, hand or shoulder massage, and put on some relaxing music or aromatherapy oils. If pain has been an issue, then the palliative care team will ensure that there is a pain relieving medicine on hand for you to give. If pain is still a concern phone the palliative care team. You can try and prevent discomfort by having a pressure-relieving device on the bed. It also helps if the person's position is changed slightly every 4 to 6 hours. Regular position changes overnight are not usually required. However, if no pressure-relieving mattress is available, frequent position changes are needed, as the patient can develop pressure sores very quickly if left in one position too long.

Hygiene care. In some situations the person does not need a full body wash everyday. Regular face and hand washes are advised. The nurse can provide you with practical hands on tips for this and other hygiene care needs. It may be easier and more comfortable if the person is dressed in very loose fitting bedclothes.

Loss of bladder and bowel control. Control over bladder and bowels is sometimes lost when death is near. There are lots of aids that the nurses can show you that help keep a person clean and comfortable. Often, the person's need to pass urine and faeces is much less as they have consumed only very small amounts of fluid. However, constipation can become a serious problem causing pain and discomfort; all steps should be taken to prevent it.

Care as death approaches & bereavement

Breathing. Breathing patterns may change. There may be long periods of time where breathing appears to have stopped. Breath sounds may also appear slightly noisy and 'rattly'. This is because of air passing over small amounts of fluid at the back of the throat. There are medicines which can be used to help lessen the noise. This noisy breathing is unlikely to be distressing to your relative even though you may find it difficult to listen to. If breathing seems to be difficult, open a window, put on a fan and help your relative to change position. Raising the head of the bed can also help. In most cases oxygen via a mask is not required; the nurse and/or GP can assess if it is needed.

Consciousness. The person may lapse in and out of consciousness. Some people go into a deep sleep and do not awake. Others appear to have periods where they seem quite alert. There are usually only a few, if any, words spoken and sometimes the comments made may not appear to make sense. Try and lessen confusion by introducing yourself, speaking clearly and directly and comment on the time of day. If possible, keep the room bright during the day by keeping blinds open.

Restlessness. Some people appear restless. They may call out, groan, muscles may twitch and they may be agitated. If these signs occur speak with the palliative care team who will help manage this issue. You could also try and help by providing a gentle massage or changing your relative's position. Make sure your relative is not too hot by reducing the number of bedclothes.

Being there. When your relative is nearing death you may find some benefit in sitting alongside them from time to time. It is perfectly normal to hug, kiss, talk, read to, reminisce, hold hands and play music. Whether you do all, some or none of the above is up to you and what makes you feel comfortable. The person you are caring for may lapse in and out of consciousness. Even though they may appear to be in a deep sleep it is fine to talk to them as hearing is often still present. This carer's feedback supports the importance of continuing communication:

'I told her it was ok to go, she didn't have to stay just for me. You know I really believe she heard me. She seemed to be more peaceful, not as restless and she died a couple of hours later.'

Care as death approaches & bereavement

Have I covered everything?

None of us can cover everything and there may always be some lingering regrets. 'I wish I'd thought of ...' or 'I'll always regret that I didn't'. One way of trying to ensure you have done your best is to ask your relative, and to repeat the question at different times throughout the course of the illness: 'Is there anything else you want while there's still time?' Or, 'Is there anything on your mind that we haven't talked about yet?' It may also be the opportunity for a more light-hearted discussion, e.g., 'Right! I've got my pen and paper. What are your instructions?'

The timing of death and saying goodbye

The timing of death is naturally beyond our control. No matter what time of day or night it is, the palliative care service is there to help. Some carers have said that they were sad to find out that their relative died while they had left the room to take a few minutes break, have a shower or to go down the street. You can't be with your relative every minute of the day or night. You may like to say some things to your relative when you know death is near, that way if death happens to occur whilst you are out of the room you won't feel as though certain things have been left unsaid. It is perfectly ok to say goodbye as many times as you like. Once it seems that death is near it is best to contact very close relatives and friends. You may like to ask someone else to do this for you.

Care as death approaches & bereavement

What do I do when death occurs?

Recognising death

When a person dies there is no breathing: the chest does not move. There is also no heartbeat: the pulse normally felt in the wrist or side of the neck stops. The person's eyes and mouth may be open. If you think, (you don't have to be sure), the person you are caring for has died, phone the palliative care service and if you desire, a nurse may be able to visit to assist you during this time.

When a person dies they can often look different. They may appear pale, hands and feet may feel cool (this is because blood is not circulating). The jaw might drop slightly (as muscles have relaxed). There may be some passing of urine or faeces.

Sometimes if the person's position is changed there is an escape of air from the lungs, which sounds like breathing out or sighing.

People's reflections on the image of their deceased relative vary, some good and some not so good. It is common however for carers to say that their relative appeared serene, content and at peace when they died.

In many palliative care situations, and especially those associated with chronic illness affecting older people, the dying process is more or less predictable, with changes occurring gradually over many months. However, it is important to understand that death can occur suddenly, often leaving carers unprepared. This situation may result in unanswered questions, particularly if you, the carer, were not present at the last moment.

What was the cause of death?

Did he/she suffer?

Could the death have been prevented?

Care as death approaches & bereavement

You may have regrets about being unprepared, having no chance to say goodbye, and leaving other issues unresolved. One way of responding to this unexpected event is to seek factual information about the cause of death. While death under any circumstances often results in 'shock' for relatives and carers, you may need to speak with a trusted friend/counsellor about the physical and emotional responses you experience. It is also important to note the chapter on 'advance care planning' so that you have made all the advance preparations well ahead of time. When death occurs unexpectedly, or much sooner than anticipated, relatives can feel greatly relieved if these issues have been covered. However, these practical tasks do not prevent you from feeling the normal emotions associated with loss and grief.

What to do when death has occurred

You may feel overwhelmed at the time of death. It is also important to realise that you may have a flood of different emotions. Some of these emotions may surprise you. For example you may feel a sense of relief or joy; you may also feel anger or guilt. You may feel quite strange. You may feel quite numb. Naturally you may be extremely distraught, although some carers have said that they felt a sense of peace at this time. You may feel some of these emotions at different times within a short period. The amount and type of emotions you feel depends entirely on you as a person. There is no right or wrong way to feel.

The first thing to remember is that there is no rush. You can do things at a pace that suits you. It is okay to embrace, kiss, hold hands and talk to your relative. You may want to ask someone else to do the 'phoning around' to inform close relatives/friends if this is easier for you. Depending on your circumstances and beliefs, you may also like to call your minister, priest or other religious representative.

Care as death approaches & bereavement

If death has occurred at home it is a good idea to phone the palliative care service. If you desire, a nurse can visit, usually within a few hours or so (dependent upon location and resources), to assist you (even if it is the middle of the night!). The doctor will also need to be contacted to arrange a death certificate. Whether or not the doctor visits depends on the time, your relationship and your wishes. The funeral company should also be notified. It is very important that you say when you would like the funeral company to arrive: this is your choice! It is perfectly okay to ask them to come as soon as possible or later that day or the following day if death occurs overnight.

Some people choose to have their deceased relative bathed and dressed in favourite clothing. The palliative care nurse may be able to assist with this if desired. Please let the nurse know if you wish to be helped.

If the death occurs in a hospital, nursing home or palliative care unit you can still have a role in care once death has occurred by helping dress or bathe your relative. You can also request that you and other friends have some time alone and ask for additional time if you have close family or friends who wish to visit. If you are unsure about anything please ask a health professional to help you.

If the death occurs at home, you need to take time, preferably in discussion with others, as to what needs to be removed immediately (such as equipment, etc) and what can wait. Some people think that removing everything that belonged to the person helps grieving relatives to 'move on'; others cannot bear to touch any of the person's belongings, preferring things to remain 'just as they are'. There is no right or wrong approach, but the answer probably lies somewhere in between those two extremes. The important thing is not to rush the decisions, taking time to consider and re-consider, and talk it over with trusted friends and/or family. There may be some objects which have no emotional significance and can be discarded fairly quickly; while other things may hold deep memories to be treasured always. 'I'll think about that later' can be an effective way of giving yourself time.

Care as death approaches & bereavement

If the death occurs in a hospital, hospice or aged care home, ask the person in charge what is their policy about removal of belongings. You may prefer to pack and remove personal items such as clothing without assistance from staff. This can be a final act of attention to things which hold special memories. Or you may prefer staff to attend to the belongings. Whatever the process, it's important that you are involved in the decision.

How will I feel after the death?

There may be relief and guilt, anger and resentment. There are also some common physical symptoms that may be experienced. Because the mind and body are linked by complicated nerve and hormone pathways you may experience physical symptoms immediately or soon after the death. These may include shivering, shaking, trembling, feeling hot or cold, or both. You may drop things; you may feel 'out of control'. You may experience palpitations (when your heart seems to be racing) or hear noises or have vivid dreams. You may also of course, remain very calm and experience none of these symptoms. However, it is wise to be alert for changes you may experience and to recognise they are a normal part of grieving and especially after such an episode of caring.

The time between the death and the funeral may be very busy. At the funeral you may feel all kinds of emotions: disbelief, relief, joy, sadness, you may also feel overwhelmed. You may also feel some physical affects such as headaches, tiredness or even a little nauseous. The time after the funeral may be a bit weird or strange; some people feel they are 'in another world'. Some people feel empty and unsure about what to do with themselves. This is a normal response and is part of the grief process. There is no standard way that you should feel and no normal time frames. Your responses and emotions very much depend on you as a person and your relationship to your relative. The following carer's comments highlight this.

'When I was caring for Jack, I used to say to him: 'you've got the easy part'. Now that he has died I know he had the easy part.'

Care as death approaches & bereavement

Another carer said that although it was hard for him, he knew his partner was resisting death with all her might. *"I know it was so hard for her to face leaving me and the children."*

You may also be getting used to a new environment. Those intense aspects of caring will have ceased. You may have to reconnect with old friends or relatives or make new friends. Once again, you do not have to go through this adjustment on your own.

Bereavement care

Bereavement or grief refers to a person's response to a major loss and includes physical, spiritual, social and emotional reactions. Grief can start well before death, e.g. when your relative was diagnosed, or when they were referred for palliative care. Some people draw on support during this time from friends and family or spiritual associates while others seek professional assistance via bereavement counsellors. The palliative care service or local health care centre should be able to advise you of bereavement services in your area. The important thing to remember is that there is no set period of time for bereavement. So please ignore comments like *'He should not be so sad now it's been 3 months'*.

Sometimes family and friends, with the very best of intent, can try to tell you what you are feeling. *'You must be so relieved now it's all over!'* You may indeed be relieved; on the other hand you may still wish your relative were alive even for a few more hours or days. Other well meaning advice can include *'You must take a holiday (or get a dog, or move to a smaller house)'*. All these reactions and decisions are very personal and no other person can tell you how you should feel, even if they say *'I know exactly how you feel!'* Remember, your feelings are yours, and there are no right or wrong feelings. Also, your feelings can change frequently, even in the same hour!

The bereavement experience will vary in intensity from person to person. However, if you believe that your feelings are worrying you greatly on a day-to-day basis then seeking advice from a bereavement counsellor or other suitably qualified professional is recommended.

Main tips from Chapter Seven

- Talking about and trying to understand death can be very hard. Consider seeking help from the palliative care team or a spiritual or religious person.
- The timing of death varies greatly, but there are a few signs which indicate that death may be only a few days or weeks away.
- A decision about the preferred place of death should be considered when death appears to be close (or before if possible).
- As death approaches there are many ways that you can help comfort your relative.
- If your relative dies at home, in most situations a nurse can visit and assist you or at least be available to give advice by phone.
- The time after death can be very difficult; you may feel all types of emotions.
- The bereavement experience varies in intensity from person to person.
- Some people benefit from seeing a bereavement counsellor, particularly if they are very worried about their ongoing 'persistent' feelings.

Care as death approaches & bereavement

Some final thoughts

At times your role as carer may be very hard. It seems there are so many questions and sometimes not many answers. You may look back and wish some things had been done differently. This is normal and it is impossible to care with absolute perfection! It is possible, however, to do your best and be content with that. Remember, caring can also have great rewards, as this carer noted.

'To care for my wife was the most challenging and rewarding experience of my life. I felt privileged to assist and support her until she died. My life will never be the same, but I have learnt so much about myself, my wife and life in general.'

However smooth or bumpy your experience proves to be, there is one thing for sure, you will learn a lot about yourself and this will influence the way you meet life's challenges in the future. Please remember it is the palliative care team's role to support and guide you.

Chapter Eight

What resources are available?

Palliative care resources

- Palliative Care Australia
A national organisation focused on improving palliative care
Tel: 02 6232 4433 Website: www.palliativecare.org.au
- State based palliative care services:
Freecall: 1800 660 055 to contact organisation within your State/Territory.
 - Palliative Care Council of South Australia Inc
Tel: 08 8291 4137 Website: www.pallcare.asn.au
 - Palliative Care New South Wales
Tel: 02 9206 2094 Website: www.palliativecare.nsw.org.au
 - Palliative Care Northern Territory
Tel: 08 8951 6762 Website: www.nt.palliativecare.org.au
 - Palliative Care Queensland
Tel: 07 3256 2486 Website: www.palliativecareqld.org.au
 - Palliative Care Society ACT Inc
Tel: 02 6273 9606 Website: www.pallcareact.org.au
 - Palliative Care Victoria
Tel: 03 9662 9644 Website: www.pallcarevic.asn.au
 - Palliative Care WA Incorporated
Tel: 1300 551 704 Website: www.palliativecarewa.asn.au
 - Tasmanian Association for Hospice and Palliative Care
Tel: 03 6285 2514 Website: www.tas.palliativecare.org.au

What resources are available?

National Resources

- Aged Care Information Tel: 1800 200 422
Website: www.agedcareaustralia.gov.au
- Alzheimer's Australia Tel: 1800 100 500 (National Dementia Helpline)
Website: www.fightdementia.org.au
- Australian Centre for Grief & Bereavement
Tel: 1800 642 066 or 1300 664 786
Website: www.grief.org.au
- beyondblue Tel: 1300 22 4636
Website: www.beyondblue.org.au
- Cancer Council Australia Tel: 13 11 20
Website: www.cancer.org.au
- Carers Australia (inc National Carer Counselling Service)
Tel: 1800 242 636
Website: www.carersaustralia.com.au
- Centrelink Tel: 132 300 (Bereavement assistance)
Tel: 132 717 (Carer payment and Carer allowance)
Tel: 132 468 (recorded info about payments & services)
Website: www.humanservices.gov.au/
- Commonwealth Respite and Carelink Centres
Tel: 1800 052 222
Website: www.commcarelink.health.gov.au
- Motor Neurone Disease Association of Australia
Tel: 1800 777 175
Website: www.mndaust.asn.au
- Translating & Interpreter Services (TIS)
Tel: 131 450
Website:
www.immi.gov.au/living-in-australia/help-with-english/

We strongly recommend that you use official websites, such as those mentioned above. Other 'unofficial' websites may not provide the accurate information you need.

Publications

An unrecognised grief a Carer's guide is available for download from www.carersvic.org.au

Guidelines for a palliative approach in residential aged care is available by emailing palliativecare@health.gov.au or can be downloaded from www.health.gov.au/palliativecare

Affirming Life: what is a palliative approach? A guide for family and friends with loved ones in aged care is available for download from www.pcvlibrary.asn.au

“This is a really great resource, and one I wish had come my way when I was caring and stumbling along, reinventing the wheel. It’s a handbook for the whole journey, and I can see someone referring to it many times over for reassurance and guidance. Full of liberty and generous permissions, and strengthened by the anecdotes from family carers which bring out the human elements.”

(Sue Binzer – family carer)

About the authors

Peter Hudson is Director of the Centre for Palliative Care (c/- St Vincent’s Hospital and Collaborative Centre of The University of Melbourne), Professor (Hon) at The University of Melbourne and Professor of Palliative Care at Queen’s University, Belfast (UK). Peter is a registered nurse with more than twenty years’ experience in palliative care practice, education and research. He is a Board member of the International Association of Hospice and Palliative Care and co-founder of the International Palliative Care Family Carer Research Collaboration, which operates under the auspices of the European Association of Palliative Care (EAPC).

Rosalie Hudson is a nurse educator in palliative care, aged care, dementia care, ethics and pastoral care. She has many years clinical and administrative experience in community palliative care and hospice care; and for 12 years was director of nursing of an aged care home. She now teaches at several universities and other health care institutions. Rosalie has written or contributed to several books and many journal articles on end-of-life issues and is an experienced conference speaker within Australia and overseas. Her PhD thesis described the transforming power of relationships in the context of death and dying.



Level 2 182 Victoria Parade, East Melbourne, Vic 3002, Australia
Tel +61 (0) 3 9662 9644 Fax +61 (0) 3 9662 9722
Email info@pallcarevic.asn.au
Web www.pallcarevic.asn.au and www.pcvlibrary.asn.au