

How a palliative approach can help older people being cared for at home

A booklet for older people and their families

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This booklet is available from:

<http://www.health.gov.au/palliativecare>

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

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Contents

1	Introduction.....	5
	About this booklet.....	5
	What is a palliative approach?	6
	Who provides a palliative approach?	6
2	How can older people plan for their care?	8
	Advance health care planning	8
	Advance health care directives	8
3	How can physical symptoms be managed?.....	10
	Managing common physical symptoms.....	10
	Complementary and alternative therapies.....	17
4	How can other symptoms be eased?.....	19
	Recognising symptoms	19
	Strategies that may help	19
5	What about spiritual issues?	21
6	What about when a hospital stay is needed?	22
	Going into hospital.....	22
	Returning home from hospital	22
7	What about when help is needed in a crisis?.....	24
8	How can family or friends be supported?.....	25
	Supporting family carers in their caring role	25
	Supporting family carers to look after their own health	27
	Financial assistance.....	28
9	What is the best way to manage grief and bereavement?	29

Answers to questions about grief.....29

10 What about end-of-life care?31

11 What resources are available for older people and their families?.....32

1 Introduction

About this booklet

This booklet is for older people living in the community and for their family and friends.

Family carers (sometimes called ‘carers’) are friends or relatives who provide care or support for the older person.

The booklet is a simplified summary of a much more detailed and technical document called *Guidelines for a Palliative Approach for Aged Care in the Community Setting* (referred to in this booklet as the ‘Community Care Guidelines’), which has been published by the Australian Government Department of Health and Ageing, Canberra. This plain-English summary provides older people and their family carers with helpful information about good care practices for older people living in the community.

Most of the information in this booklet is based on ‘good practice points’ agreed by the experts who developed the Community Care Guidelines described above. Where the information is based on evidence from scientific studies, this is indicated as follows:

What the research shows

Other types of information presented throughout this booklet are:

Practical tip Clear instructions for things that you (the older person) need to do.

Advice Additional advice for your for carers family carers.

Case study Shows how advice in the booklet might work in practice.

Contacts for further information are also given throughout the booklet.

Telephone numbers

Weblinks

The full version of the **Community Care Guidelines** and accompanying booklets are available at:

Weblink: www.caresearch.com.au

Weblink: www.palliativecare.gov.au

Telephone: 1800 500 853

What is a palliative approach?

A palliative approach to care is health care that aims to maintain or improve quality of life.

The emphasis is on improving living, although end-of-life care is addressed as well as care over longer periods. Bereavement care is also part of a palliative approach.

You may benefit from a palliative approach to care if you have an illness or condition that is likely to affect how long you will live or if you are becoming frail. People who have severe chronic heart failure, severe lung disease, moderate or severe dementia, motor neurone disease, advanced Parkinson's disease or cancer may benefit from a palliative approach to their care, as may many others. This approach values and supports quality of life and comfort — but it does not provide a cure.

A palliative approach to care is helpful whenever a need arises. Sometimes it may be provided over years and sometimes over a shorter period. It might suddenly be needed or be introduced gradually.

A palliative approach aims to:

- manage physical symptoms
- address emotional, social or spiritual issues
- support family carers.

Who provides a palliative approach?

A team of family carers, care workers, health care professionals and volunteers may provide a palliative approach to care for an older person. This team is called the 'health care team' throughout this booklet.

Family carers can help you manage at home as you need greater support. They may call to check on you, help with shopping or cooking, help you with your daily physical care, or do many other things. Often the things they do to help will change over time. Whether the friend or relative provides emotional support or physical support, and even if their contact is by phone rather than face to face, they are still viewed as a family carer.

Care workers are employed by a service provider to deliver help and care in the home. They work under the supervision of a health care professional (usually a nurse) but are not allowed to do some things that health care professionals look after. Supervision of care workers is often from a distance.

Health care professionals may include doctors (such as general practitioners, geriatricians or palliative medical specialists), nurses, physiotherapists, occupational therapists, speech pathologists, community pharmacists, pastoral care workers and others.

Volunteers, who provide unpaid care or support, may also form an important part of the health care team. They can offer many services, including companionship, counselling, transport and home help.

Throughout this booklet, you will be advised to ask your health care professional for more information. This usually means that you should speak to your nurse or doctor. Sometimes another professional may be mentioned. Care workers can help by arranging for their supervising health care professional to contact you.

2 How can older people plan for their care?

Advance health care planning

Advance health care planning allows you to express your wishes about your future health care.

Advance health care planning involves thinking about and discussing your future care and treatment options with health care professionals, family and other important people in your life, so that you can make choices. In this way, you can make sure that everyone involved in your care knows what you prefer. The process allows you to explain your wishes in advance, in case you are not able to do this later because you are too unwell. It is a good idea to allow time for lots of discussion as you may have many questions.

Whenever things change for you, you need to think about how this might affect your health care plans. If you want to alter these plans, it is important that the health care team and the important people in your life know what changes you make.

Talking to a doctor about the care and treatment choices you may have is a good way to start to organise an advance health care plan. Before your doctor's visit, it is helpful to write down what you would like to discuss. For example, you may wish to talk about your illness, how symptoms can be managed, and how certain decisions can be made for you by others (eg by arranging an enduring power of attorney). Your family or friends may also have questions.

Advance health care directives

An advance health care directive describes in writing how you would like to be treated and cared for. It is a way of communicating your advance health care plan.

You can write down your advance health care plan in an advance health care directive or have this done for you. Sometimes, an advance health care directive is called a 'statement of choices', a 'statement of wishes' or a 'living will'.

Health care professionals will use your advance health care directive to guide care or treatment if and when you are unable to make or tell people about your own decisions. A key part of an advance health care directive is also naming a family member or friend who can 'speak for you', if and when you are unable to speak for yourself. This is in case the advance health care directive does not cover a particular choice that needs to be made.

Further information about advance health care planning and directives, specific information for people from other cultures and backgrounds, and information for Aboriginal and Torres Strait Islander people is included in the Community Care Guidelines (see page 7).

Information on advance health care planning and advance health care directives is available through:

Respecting Patient Choices

Weblink: www.respectingpatientchoices.org.au

National Dementia Helpline

Weblink: www.alzheimers.org.au

Telephone: 1800 100 500

3 How can physical symptoms be managed?

It is important for your comfort that any physical symptoms are managed well.

The best way to help manage your symptoms is to make notes about them, as well as how any treatments are working. When you next see your doctor or nurse, you can give them your notes. This will help them to treat the symptoms as well as possible.

Practical tip

It will help health care professionals to manage symptoms if you make detailed notes on:

1. what the symptom was and how it felt (Example: Dull ache in the back)
2. when the symptom occurred (Example: Woken by this in the night)
3. what was done to ease (Example: My carer rubbed my knee and gave me a hot pack)
4. the effect of what was done (Example: The pain went away in about 10 minutes)
5. how long it took to work (Example: The pain went away in about 10 minutes)

Family and friends can help you to keep these records.

Advice for carers

Help the older person for whom you provide care to keep notes of any symptoms and how well any treatments worked. Make sure that the health care professional (the doctor or nurse) sees these records so they can work out the best ways to keep the older person comfortable. If necessary, keep notes yourself and discuss them with the doctor or nurse.

Managing common physical symptoms

The following section describes physical symptoms that are common when older people are being cared for at home. Each entry also describes actions you and your carer can take to help keep you comfortable. This information is drawn from the Community Care Guidelines and from material referred to in those guidelines. See the Community Care Guidelines for more information on symptoms (see page 7).

Fatigue

Fatigue feels like constant tiredness. It can include a lack of energy, difficulty concentrating and a lack of motivation. Fatigue can be caused by illness and treatments (eg some tablets and liquid medicines). It can also be related to poor eating or sleeping patterns.

Most people want to rest when they feel fatigued. However, fatigue can sometimes be improved by exercise or activity that suits your situation and ability (eg going for a short walk with your family when they visit). Other things likely to help are eating a healthy diet, drinking plenty of fluids and sleeping well.

Pain

Your health care professional (eg your doctor or nurse) can advise you how to keep pain levels as low as possible. Describing your pain in detail will help them manage your pain.

Pain can be:

- acute (coming on quickly and lasting for a short time)
- chronic (on and off, lasting for months or years)
- incident (only coming on during an activity).

Pain can also be felt in different ways, such as aching, burning or throbbing. The more you can tell the health care professional about your pain and what makes it better or worse, the more likely it is that they can help manage your pain well.

Ways to relieve pain may include changing your position, having someone give you a gentle massage, or using hot packs (but not if you have a problem with feeling heat or cannot easily move the pack if it causes discomfort). You can also try distracting yourself, such as by watching television or reading a book.

A doctor can prescribe medications or recommend suitable over-the-counter medicines (available without prescription) to manage pain. Medications might be in the form of tablets, liquids, injections, suppositories or skin patches. It is usually best to use these regularly if the pain is chronic, as explained by your doctor or pharmacist.

If the pain is still there even when you have used regular pain medication, tell

your doctor, who can organise extra medication for you. If you need strong pain relief, or if you find it difficult to swallow, your health care professional may suggest a syringe driver. This is a small machine that injects the medication at a controlled rate over time so that the correct amount is given.

Practical tip

Keep a pain diary — you or your carer can write down when pain occurs, describe the pain, list treatment that is used and how well this works. Showing this to your health care professional will help them to treat your pain.

Poor nutrition

Poor nutrition can develop if you don't feel hungry, have trouble shopping or cooking, don't feel well, or have mouth problems that make it hard to eat.

Lack of appetite is common. Try to keep eating a healthy diet. If you find this difficult, talk to a health care professional (eg a nurse). Sometimes a dietician might be available to help you plan a special diet or suggest helpful foods.

Advice for carers

Watch what and how much the older person is eating. Lack of appetite is common and can be normal in very advanced illness. It may not be appropriate to try to make an older person eat when he or she is extremely frail or unwell. In these cases, or if you are concerned about poor nutrition, seek advice from someone in the health care team — for example, a nurse.

When a person who has dementia does not settle well to eat at mealtimes, they may take enough food if you provide snacks often.

Advice on mouth problems is covered later in this section.

Meals on Wheels can help older people to live more independently at home by delivering meals.

Weblink: www.mealsonwheels.org.au

Telephone: See the White Pages

Dehydration

Older people can easily become dehydrated (lacking enough fluid). This can cause problems including constipation, weakness and dizziness. Make sure that you have enough to drink. Include plenty of drinks that are not tea, coffee or alcohol, as these drinks all tend to increase dehydration.

Don't wait until you feel thirsty. As you get older, you don't feel thirst as much and you can be dehydrated before you are thirsty.

Advice for carers

Encourage the older person to take favourite drinks that are not tea, coffee or alcohol (which can all worsen dehydration). If the older person is very unwell and refusing drinks, or is finding it difficult to drink, it is important to seek advice from the doctor or nurse. Dehydration can occur quickly so don't delay reporting this problem for long. When the older person is very unwell, you may be asked to try ice chips instead of drinks.

Mouth problems

Mouth problems can be caused by not brushing teeth properly, dentures that don't fit well, or a dry mouth (which can be a side effect of some medications).

It's important to look after your mouth and teeth because eating will be easier and you will feel better. If your dentures do not fit properly or you have problems with your teeth, seek help from a dentist. If you are having other mouth problems, such as a dry mouth, tell your doctor, who can check out the cause.

Advice for carers

Talk with the dentist about mouth care in general but also seek help from Alzheimer's Australia (via the National Dementia Helpline) when helping to provide mouth care for an older person who has dementia.

National Dementia Helpline

Telephone: 1800 100 500

Swallowing difficulties

Swallowing difficulties are common in many conditions. If your swallowing is gradually becoming worse, discuss this with a health care professional (eg your doctor or nurse). Your food may need to be mashed or vitamised, and drinks may need to be thickened.

The nurse or doctor may ask a speech pathologist for advice about your needs. Speech pathologists help plan ways in which meals and drinks can be enjoyed safely.

If you develop swallowing difficulties, it may help to:

- eat in a quiet room with no distractions
- take small mouthfuls and eat slowly
- avoid talking while eating
- make sure you have completely swallowed each mouthful before taking another
- sit upright with your head forward (ie not leaning back) during the meal or drink, and for at least 30 minutes afterwards.

With some conditions, such as motor neurone disease, swallowing can become dangerous. In these cases, it may be an option to be fed with a tube (eg one that goes directly into the stomach). There are benefits and risks with this type of feeding that need to be considered carefully in discussions with a health care professional.

Advice for carers

Thickening drinks and vitamising food is likely to help when an older person has swallowing difficulties. Talk to the health care professional about this because a plan for the individual will need to be developed (eg a particular degree of thickening will be recommended for drinks).

If swallowing problems develop suddenly, contact a health care professional right away.

Nausea and vomiting

Nausea is the unpleasant feeling of the need to vomit. Vomiting is 'throwing up'. Simple things that may ease nausea are:

- eating or drinking smaller amounts, but more frequently
- getting plenty of fresh air and avoiding unpleasant smells
- not lying down straight after eating
- taking prescribed medicines (ie those to reduce nausea)
- learning to relax more fully.

Vomiting can quickly lead to dehydration so contact your nurse or doctor if it lasts for more than 24 hours.

Breathing problems

Difficulty breathing or breathlessness can be frightening. Sudden onset of prolonged breathlessness for no obvious reason needs urgent professional advice. If you are concerned, call an ambulance.

If you become breathless as an expected part of your illness and have discussed what to do with your doctor, take any medication that has been prescribed and follow your doctor's other instructions. Additional things that you might try are:

- sitting upright
- setting a fan to blow gently onto your face
- making sure any pain is controlled (because pain can stop you taking deep breaths or coughing to clear secretions).

Advice for carers

Check to make sure that the older person always has good pain control. Being able to breathe deeply and cough to clear secretions without pain is very important to help avoid and manage breathlessness.

Skin problems

Skin problems in older people include abnormal sweating, itching, swelling,

wounds and ulcers. Pressure ulcers result from damage to skin and tissue caused by pressure or rubbing. Poor nutrition, limited feeling in the affected parts of the body, and incontinence may increase the likelihood of developing pressure ulcers.

If a skin problem is starting to develop, tell a health care professional (eg a nurse who visits) so that treatments can be started quickly.

Avoid skin problems by:

- keeping your skin clean and dry
- eating well
- drinking enough fluids.

Advice for carers

You can reduce the likelihood of pressure ulcers by relieving pressure. Make sure that the older person changes position regularly. Use pressure-relieving devices (special mattresses, pillows, etc) to avoid pressure on bony areas. Reduce skin damage by using lifting aids when necessary. Health care professionals can advise about the kind of lifting aid that will be useful.

Independent living centres can provide information and advice on devices and equipment.

Weblink: www.ilcaustralia.org

Telephone: See the White Pages under 'Independent living centres'

Incontinence

Continence is the ability to control bladder or bowel function. Incontinence is the loss of this ability. It is sometimes treatable (eg with prescribed medication or exercises). Ask your doctor or nurse. Continence specialists may also be available through the health care team.

If you have problems with incontinence, you can use aids, such as special bed linen and protective pads, to minimise distress, embarrassment and inconvenience.

Advice for carers

There is assistance available to help with the cost of continence aids.

See the phone number below.

Special strategies can help people who have dementia if they have trouble finding the toilet; for example, you could try putting stickers of footsteps on the floor to make a pathway leading to the toilet. Much more information is available from the National Dementia Helpline.

National Continence Helpline

Telephone: 1800 330 066

Continence Aids Payment Scheme

This scheme can help with the cost of continence aids.

Telephone: Call the National Continence Helpline (see above)

Weblink: www.bladderbowel.gov.au/furtherinfo/caps

National Dementia Helpline

Telephone: 1800 100 500

Constipation

Constipation involves infrequent, incomplete and difficult (hard) bowel movements. It is common when older people become unwell and can cause uncomfortable symptoms, such as abdominal pain and bloating. When you are constipated, small fluid bowel movements may also occur. This is when fluid escapes around the hard contents of the bowel. If you become constipated, contact your health care professional so that treatment can be started quickly.

- You can help prevent constipation by:
- drinking enough fluid

- eating enough fibre
- getting some physical activity if possible (eg walking)
- taking medications or supplements as prescribed or recommended by health care professionals.

Delirium

Delirium is sometimes called ‘acute confusion’; it begins suddenly and is often caused by an illness, such as a bladder infection. It is important to tell the health care team if you feel unwell; for example, if you feel feverish, have a cough, or have pain when you urinate (pass water). Early treatment may avoid delirium.

A person who is delirious may:

- have problems with listening and understanding
- be disorientated (eg not know where they are)
- speak unclearly or ‘ramble’
- be unable to carry out their usual activities
- be more withdrawn or more active than usual.

If you become delirious, your health care team will treat the cause of the delirium, try to ease any distress and keep you safe.

Advice for carers

Delirium can often be caused by treatable conditions. If the older person has dementia, a sudden increase in confusion can indicate delirium. Delirium is also common in very advanced illness. If you think that the older person has delirium, have someone stay with them to avoid falls and to comfort them. Arrange for them to see a doctor.

Falls

Falling over can cause serious injury when you are older. Falls can have lasting effects on how you get around and care for yourself. Falls can also lead to a loss of confidence.

Preventing falls is better than treating them. You can avoid falls by:

- doing special exercises that improve strength or balance (ask your doctor who may refer you to a special program or a physiotherapist)
- making sure your environment is safe (eg with good lighting and a nonslip floor)
- having your doctor or pharmacist review your medications if you
- sometimes feel unsteady, sleepy during the day, or dizzy
- using walking frames or other aids.

If you are worried about falling and not being able to get help, talk to your health care team about getting a personal response system (an alert pendant). This pendant can be worn around your neck and has a button to press if you need help.

Contact the **Council on the Ageing** for information about the ‘**Living Longer Living Stronger**’ program — an exercise program for older people.

Weblink: www.cota.org.au

Telephone: See the White Pages

Managing medications

Medications are used to prevent and treat symptoms but they can also cause harm, especially if they are used incorrectly.

It is very important to take your medications exactly as you have been instructed by the doctor. Also, it is important that you tell your doctor and pharmacist about any over-the-counter medication (bought without a prescription) and any herbal remedies or supplements that you take. This is so they can check that everything works together safely and effectively.

Your doctor may arrange a home medicines review to help you manage your medication. This is when a pharmacist visits you at home to provide advice about your medication use.

It is important to talk to your doctor or pharmacist urgently if you are confused about your medications or if you think you may be having bad effects from them. If you have sudden, severe, bad effects that you think might be from your medication, you may need to seek urgent medical help (as you would with any sudden, severe illness). It is helpful to take your medication with you if this occurs.

Medicines Line

Telephone: 1300 633 424

This service gives people independent, accurate, up-to-date information about prescription, over-the-counter and complementary medicines.

Adverse Medicine Events Line

Telephone: 1300 134 237

For people to report possible drug reactions and errors when taking medication. This service allows consumers to speak to a pharmacist during business hours. Reports of adverse events are used to make the use of medicines safer.

Pharmaceutical Benefits Scheme

Telephone: 1800 020 613 |

For information on medicines subsidised through the Pharmaceutical Benefits Scheme (PBS) and about the PBS Safety Net.

Complementary and alternative therapies

Complementary therapies are used at the same time as other treatments; for example, aromatherapy. Alternative therapies are used in place of usual treatments, such as when someone chooses to take herbal remedies instead of prescribed medicines.

To make sure that all treatments are working together effectively, it is very important to tell your doctor, pharmacist and nurse about all therapies that you use.

4 How can other symptoms be eased?

Nonphysical symptoms (emotional symptoms) can also be helped

Recognising symptoms

Your emotional symptoms might include:

- **Anxiety** — which includes feelings of fear that might be intense. Anxiety can also lead to physical symptoms such as nausea, dizziness, shortness of breath and diarrhoea.
- **Depression** — which might result in loss of pleasure or interest in activities, becoming isolated from others, and feelings of hopelessness or helplessness.
- **Anger** — which might be part of a reaction to having an illness and losing independence. Anger can affect the way you speak to others and the way you act.

If you have emotional symptoms, tell your health care professional because, just like physical symptoms, they can be helped.

Strategies that may help

Sometimes emotional support from others can help. This kind of support can be over the phone, face to face, or even in the form of letters. Sometimes just sitting quietly with another person can provide emotional support. At other times you may wish to express your feelings. Comfort can come from being with, and talking with, other people.

Sometimes treatments, such as counselling or medication, are needed. Discussing strong emotions and feelings with the doctor or health care professional is therefore important.

Advice for carers

It is important to observe and report any emotional symptoms to the nurse or doctor so they can arrange or suggest suitable treatment. Symptoms can be difficult to recognise and often an older person won't report the symptom themselves.

The following strategies may also be helpful. Consider the ones that you might prefer and discuss these with your health care team. Professional input is often needed to make sure that these strategies have the best results.

- **Reminiscence (reflecting on memories)**. This can remind you how you coped with problems in the past and help you to cope now; knowing how to cope may reduce anxiety. Reminiscence can also help you to consider what is important to you. For example, you may want get in touch with a friend after a long-standing disagreement.
- **Music therapy (using music in 'treatment')**. Music can be used in combination with relaxation to ease pain, in reminiscence, and for a calming effect.

- **Using computers.** Computers can help you keep in touch with friends or access support and information via the internet. For example, the website of Parkinson's Australia is a great resource for those who have Parkinson's disease. Using a computer can also be enjoyable and distract you from problems. Family carers or volunteers can help if you have difficulties with typing or using a mouse.
- **Health-promotion programs (such as exercise programs).** These programs may help you to manage symptoms; for example, suitable exercise programs may ease depression.
- **Relaxation therapy.** This therapy can help to manage anxiety.
- **Mind–body therapies (such as tai chi).** These therapies may help to manage stress.
- **Animal-assisted therapy (such as visits from specially trained dogs).** Animal visits may help if you are feeling depressed.
- **Changing your environment (such as positioning chairs to face natural, outside views).** This strategy may have many benefits, including distraction, which can ease anxiety or anger. Repositioning furniture is best discussed with your health care team because this can affect how care is provided (eg how you can be helped into your chair).

5 What about spiritual issues?

Towards the end of life, reflection on the meaning of your life is often important.

Spiritual needs may become more important towards the end of your life. You may find that you wish to finalise things you have set out to do and ‘make peace’ with others. These things can provide spiritual comfort.

Sometimes, you might like a visit from someone who can help with your spiritual needs, for example, a minister from a local church or a friend likely to understand your needs. You can draw comfort from these visits in many ways. You may wish to talk over the things you have done during your life and discuss plans for what else you will do. You might, instead, prefer to spend time in prayer. The care team may include a pastoral care worker who can visit.

You may prefer to spend ‘quiet time’, for example, when listening to music. If you let the care team know, they can try to avoid disturbing you.

Practical tip

Many religious organisations provide home visiting services and can also help people with transport to churches or other religious centres.

Advice for carers

Because you know the older person well, you are likely to be able to discuss spiritual issues with them. Allow them to talk about what is important at this time in their life. Even if you have not discussed spiritual issues before, this opportunity may be welcomed. As a carer, you do not need to share the same beliefs to recognise and support the older person’s spiritual needs.

Advice for carers of older people with dementia

Using music and laughter, rather than words, may be a meaningful way of connecting with the older person who has dementia and can no longer understand words. This provides another way of giving ‘spiritual care’.

6 What about when a hospital stay is needed?

Going into hospital

If you need to go into hospital, there is important information that you should take with you.

When you go into hospital, the staff there will require information about your needs and preferences. You or your health care team need to send:

- your advance health care plan and/or directive
- a summary of your health (including a record of symptoms and how they are managed)
- a list of medications and any allergies.

Having a pack of this information ready to go at all times is helpful. A health care professional can help you to organise this. You and your family should know where it is in case you need to be transferred to hospital.

Returning home from hospital

When you come home after a stay in hospital, you and your family carers — along with everyone else involved in your health care — need to understand the care and support that you will need at home.

When you leave the hospital, doctors and community nurses will help to develop a health care plan that will be specific to your needs.

Case study

Mr & Mrs Clark

Mr Clark suffers from advanced chronic heart failure and has to go to hospital often. He lives with his wife, who is his carer, in their family home. When he is discharged from the hospital, special support is arranged for him.

First, a nurse explains Mr Clark's condition to him and his wife. This nurse also explains the care he will need at home and provides a written plan to follow when he has symptoms.

Second, once Mr Clark is home, nurses and care workers visit daily (more often than before) to monitor his condition and help him with certain tasks, such as showering. These staff members have also received information from the hospital about the plan of care agreed with Mr and Mrs Clark and know whom to contact at the hospital if they have any concerns. When they visit, they check that the plan is understood.

As soon as Mr Clark experiences symptoms, he and his wife, supported by the community health care team, follow the plan they were given. This plan works well and he avoids having to go back into the hospital.

What the research shows

If you have advanced chronic heart failure, you are likely to benefit from extra support when you return home from hospital. This support should include education about managing your health and may make hospital readmission less likely.

If you are frail or generally unwell,* extra support when you come home from hospital can help you to stay in your own home for longer.

What the experts agree on

Whenever an older person in need of a palliative approach to care is discharged from hospital, health professionals need to check to see if there is support available to help that older person and/or their family carer as they readjust to managing at home.

What this means for older people

If you need to go into hospital, you or your family carer need to ask if there is extra support available for you when you come home. You may find this support very helpful as you adjust to managing at home again.

See the Community Care Guidelines for more details (see page 7).

*with advanced life-limiting illness that is nonspecific or due to many illnesses

Advice for carers

Care changes are often made when an older person is in hospital and these changes may need to be communicated to a number of carers and care workers in the home. Use a message board or notebook that all those providing care can use. This will help make sure that the correct care is given.

7 What about when help is needed in a crisis?

Having a plan makes things less stressful when a crisis occurs.

It is helpful to think about the kinds of crises that might occur because of your health and make a list of the help that is available, especially at night or on the weekend. Your nurse can help you to make a plan.

Generally, crisis care involves 'out of hours' telephone support or home visits from members of the health care team (eg nurses). You could also consider getting a personal response system, such as an alert pendant, with a button to call for help in a crisis.

Case study

Mrs Adams

Mrs Adams is an elderly lady who lives alone in her home. She is very frail and often unsteady on her feet. She wears a personal response system alert pendant around her neck, 24 hours a day. It is waterproof, so she can even wear it in the shower. If Mrs Adams falls or needs help and is unable to reach the phone, she can press the button on the pendant. This will alert a call centre, even if she is in her garden, and Mrs Adams' family will be contacted. Having the alert pendant reassures Mrs Adams and her family that she will get help in a crisis.

What the research shows

If you are an older person with an illness that affects how long you will live, if you are frail, or if you are extremely elderly, having access to crisis care can have health benefits for you and your family carer.

What the experts agree upon

Having a plan for what to do in a crisis can avoid anxiety, even if a crisis never happens.

Those providing a palliative approach for older people living at home need to work with the older person and their family carer to develop a plan for crises that may occur.

What this means for older people

Ask your health professional what services are available to you after hours. Ask for help to make a plan for what to do in case of a health crisis.

See the Community Care Guidelines for more details (see page 7).

8 How can family or friends be supported?

Family carers (sometimes called ‘carers’) are friends or relatives who provide physical and/or emotional care and support for the older person.

Family carers can sometimes help you stay at home when you are frail or unwell by providing support. Carers may help with phone calls, shopping, preparing meals, house cleaning, laundry, transport, household tasks, medicines and handling finances. Carers may also help with bathing, dressing, eating, grooming, using the toilet and many other things. Being a carer is rewarding; however, it can also be exhausting.

There are two main ways in which family carers can be supported. The first way is to help them understand and feel confident about being a carer. The second way is to help them look after their own health.

Supporting family carers in their caring role

Family carers may need resources to help them provide care.

Advice for carers

Things you might like to know:

- diagnosis and prognosis (outlook)
- what a carer can do
- the cause of the disease
- likely symptoms and how to manage them
- treatment options and side effects
- what to do at the end of life.

There may also be pressing practical questions, such as ways to access equipment, transport or home help.

If you would like this kind of information, talk with a health professional involved in the care of the older person for whom you provide care. Writing a list of questions first may be a good strategy.

Case study

Jack & Vera

Jack has been the carer for his wife, Vera, for several years. Vera has advanced dementia. Due to the progression of her dementia, about six months ago, Vera started to become agitated and to wander. Initially, Jack was unsure of what to do about these behaviours and worried that he might not be able to continue caring for Vera at home.

Jack called Alzheimer's Australia and was told how he could occupy and distract Vera so that she would be more settled. The nurses and care workers then worked with Jack to put these strategies in place. In this way, Vera's agitation and wandering were reduced and Jack was able to continue providing care at home. Although he still gets tired from the care that he provides, Jack is less stressed now and better able to enjoy spending time caring for Vera.

What the research shows

If you are very frail or disabled because of a stroke, your family carer's health can be helped if they receive stroke-specific information, education and skills training.

If you have advanced cancer, your family carer's health can be helped if they receive cancer-specific information, education and skills training.

When an older person has moderate or severe dementia, their family carer's health can be helped if they receive dementia-specific information, education and skills training.

What the experts agree upon

Helping a family carer to provide effective care can help make the caring experience more meaningful for them.

What this means for older people

Ask a health care professional (eg a nurse) about suitable family carer information, education and training.

See the Community Care Guidelines for more details (see page 7).

The Australian Government **National Carer Counselling Program** is operated by **Carers Australia**.

Weblink: www.carersaustralia.com.au

Telephone: 1800 242 636

The Australian Government **National Dementia Helpline**, which is operated by **Alzheimer's Australia**, or the state-based branches of this organisation, is an excellent resource for family carers of people who have dementia.

Weblink: www.alzheimers.org.au

Telephone: 1800 100 500

Aged Care Information

For information on:

- aged care services in your region
- carer support, counselling, respite and advocacy.

Weblink: www.agedcareaustralia.gov.au

Telephone: 1800 200 422

Advice for carers

It is very important to look after your own health and ask for help when you need it. However much you want to provide care, you can only do this if you look after your own needs too.

Supporting family carers to look after their own health

Caring can be physically and emotionally exhausting and one way to support carers is to make sure they can have breaks from their caring responsibilities.

Although caring can be very satisfying, it can also affect carers socially, emotionally and physically. Carers may have:

- sleeping problems
- fatigue
- headaches
- feelings of uncertainty, hopelessness and helplessness.

To allow your family carer to take a break, alternative arrangements will be needed for your care. These alternative arrangements are called respite care. Respite care provides breaks for carers to take a holiday, attend to their own health, or do anything else that they choose. Having regular breaks, and even just knowing that respite is available if needed, may help carers continue to provide care at home.

Respite care can be provided for a few hours or for several weeks. There are four main types of respite services:

- home-based respite — when a care worker comes to your home to provide care usually provided by your family carer
- centre-based day respite — in a day centre
- short stay respite — in residential aged care or a hospital
- special holiday arrangements — such as when you stay with another family.

Family and friends can also provide respite care.

Case study

John & Sheila

John and Sheila have been married for 55 years. John is very frail now and Sheila is his carer. Once a week, John is picked up in a community bus and goes to a day centre where he meets his friends. John is involved in activities that he enjoys and is taken for scenic drives.

Once a month, John stays overnight at a respite centre; for two weeks of the year, he goes into a residential facility. John enjoys getting out and about and the respite gives Sheila time to look after herself and to have a break. This respite supports Sheila to care for John at home and helps to keep her feeling well.

Financial assistance

Caring for family members can also be financially hard, such as when carers need to reduce their working hours, give up their job, or use their savings. Government assistance is available in some cases.

Centrelink can provide financial assistance for carers.

Telephone: 13 27 17

What the research shows

If you are frail or generally unwell,* respite care for you while your carer takes a break can mean that your carer is at less risk of depression.

If an older person has moderate or severe dementia, respite care can help support their carer's health.

What the experts agree upon

Flexible arrangements for respite care are likely to be the most helpful. In particular, respite care needs to be readily available in the case of an emergency; for example, if a carer becomes sick.

Respite care needs to be made available at frequent intervals because its benefits are likely to be short lived.

What this means for older people

Ask your health care professional about what respite options are available. Planning ahead for respite care is a good option but you also need to know what is available in case of an emergency.

See the Community Care Guidelines for more details (see page 7).

*with advanced life-limiting illness that is nonspecific or due to many illnesses

9 What is the best way to manage grief and bereavement?

Grief is experienced when a loss occurs and includes feelings of unhappiness, pain, guilt, anger and sadness. Bereavement is the reaction to a loss and includes the process of healing or 'recovery' from that loss.

You may experience many losses during the course of your illness (eg loss of good health and physical ability). Grieving will almost certainly occur for these losses and may also occur because death is drawing near.

Although taking great comfort from being with you, family carers are also likely to experience loss and grief during your illness. For example, they may miss the things you used to be able to do together and anticipate the separation brought about by death. After your death they will grieve because they can no longer spend time with you.

Each person will grieve and recover in his or her own way. Common reactions to grief include:

- feelings of disbelief, confusion, anxiety, fear, sadness, anger, guilt and relief
- sleep disturbances
- loss of appetite
- restlessness.

Answers to questions about grief

Anyone dealing with grief might ask themselves the questions in the following sections.

Will grief ease with time?

Grief is an individual experience. Grief can be experienced by you and your family in response to your illness. Initially, grief is overwhelming and people can feel out of control. With time, people find they have more ability to control their memories and emotions.

Is there a right way and a wrong way of coping with grief?

Everyone experiences grief differently depending on personality and life experiences. There is no right or wrong way to deal with grief. However, support can help recovery.

When is help needed?

Reassurance from others who have also experienced grief can be helpful. An understanding of what other people have commonly undergone when grieving can also help.

It is important to seek professional help if you suffer long-lasting intense emotion or obsessive thoughts or behaviours. Seek help urgently if you have any strong fears or anxieties about wellbeing or thoughts of self-harm.

The **National Carer Counselling Program** (operated by Carers Australia) offers a national carer counselling service.

Weblink: www.carersaustralia.com.au

Telephone: 1800 242 636

Lifeline offers a confidential 24-hour counselling service that may be helpful for people who are distressed.

Telephone: 13 11 14

10 What about end-of-life care?

A plan for your end-of-life care will help to ensure you receive the care that you would like at this time.

It is a good idea to discuss details about your end-of-life care with your health care team, especially any worries that you may have. For example, you may be concerned about particular symptoms and how they can be managed. Your health care professional (eg your nurse or doctor) can help develop a plan for managing care at the very end of life. It can outline your wishes. The plan can also document any special symptom needs and provide important contact details. If you also involve your family carers in these discussions, this will help ensure that their needs are considered.

Your plan needs to:

- be kept up to date
- be known about and understood by your family and all those providing care
- identify your care preferences
- identify any spiritual or religious preferences
- be very clear about how your family can make arrangements that will meet your wishes after you have died (what to do and whom to contact).

Advice for carers

You may have many questions about end-of-life care and the best way to provide this. It is best to make a list of questions for the health care professional to answer. You will probably need to know:

- contact details of staff or other support available after hours
- details of any equipment that might be needed, such as special mattresses or oxygen, and information about how to obtain it, especially after hours
- things that you need to do or of which you would like to be aware.

It is also very important for you to consider your own needs, speak to the health care team about support that is available for you, and keep in touch with family or friends who can help you.

Knowing that you have a plan and that support is available can make a great deal of difference at this time.

11 What resources are available for older people and their families?

The GP or community nurse will be a good resource. They will be able to answer your questions and direct you to appropriate organisations or practitioners. You may wish to discuss the contents of this booklet with them or seek other help or advice.

Useful information and resources are also available through the following organisations:

Aged Care Information

For information on:

- aged care services in your region
- carer support, counselling, respite and advocacy

Telephone: 1800 200 422

Weblink: www.agedcareaustralia.gov.au

Aged Care Complaints Investigation Scheme

Telephone: 1800 550 552

CareSearch (a good source of palliative care resources)

Telephone: (08) 7221 8233 (general enquiries)

Weblink: www.caresearch.com.au

Council on the Ageing

Telephone: 1800 182 324

Weblink: www.cota.org.au

Dementia Behaviour Management Advisory Service

Telephone: 1800 699 799

National Aged Care Advocacy Line

Telephone: 1800 700 600

National Carer Counselling Program

Telephone: 1800 242 636

Weblink: www.carersaustralia.com.au

National Continence Helpline

Telephone: 1800 330 066

National Dementia Helpline

Telephone: 1800 100 500

Palliative Care Australia
Telephone: 1800 660 055

See the **Age Page** in the local White Pages