How a palliative approach can help older people receiving care at home

A booklet for care workers

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This booklet is available from:

http://www.health.gov.au/palliativecare
http://www.caresearch.com.au

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1 Introduction

About this booklet

This booklet is for care workers providing a palliative approach to care for older people living in the community and support for their family carers.

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 care workers with helpful information about good care practices for older people living in the community. It is in two parts:

- Part A — includes general information care workers need to consider when caring for older people who are receiving a palliative approach to care at home.
- Part B — includes information care workers need to consider when caring for specific groups of people who are receiving a palliative approach to care at home.

Most of the information in this booklet is based on 'good practice points' agreed by the experts who developed the Community Care Guidelines. 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 care workers 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

A companion booklet is also available for older people receiving care in the community and their family carers.

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.

An older person may benefit from a palliative approach to care if they have an illness or condition that is likely to affect how long they will live or if they 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 sometimes help an older person to manage at home as they need greater support. They may call to check on the older person, help with shopping or cooking, help with daily physical care, or do many other things. Often their role 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 considered to be 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 (eg general practitioners, geriatricians, 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.

Volunteering Australia provides guidance for current volunteers and for people interested in volunteering.
Weblink: **www.volunteeringaustralia.org**

Throughout this booklet, care workers are often advised to ask a health care professional for more information or to provide information to a health care professional. Care workers may also:

- be asked questions by an older person or their family carer that need
- to be answered by a health care professional
- be asked to pass on information to a health care professional by an older person or their family carer
- have concerns about the health or wellbeing of the older person or their family carer
- have concerns about their work environment and how to undertake care safely.

It is absolutely essential for a care worker to keep their supervising health care professional fully informed at all times.

PART A

Information relevant to all older people who are receiving a palliative approach to care at home

2 How can older people plan for their care?

Advance health care planning

Advance health care planning allows people to express wishes about their future health care.

Advance health care planning involves the older person considering and discussing their future care and treatment options with health care professionals, family and other important people in their life, so that they can make choices. In this way, the older person can make sure that everyone involved in their care knows what they prefer.

The advance health care planning process allows the older person to explain their wishes in advance, in case they are not able to do this later because they are too unwell. It is a good idea for the older person to allow time for lots of discussion about advance health care plans. Therefore, if possible, it is best for them to make their plans early in their illness.

Whenever things change for the older person, they need to consider how this might affect their health care plans. If they want to alter these plans, they need to make sure that the health care team and the important people in their life know what changes are involved.

A good way for an older person to start to organise an advance health care plan is to talk to a doctor about the care and treatment choices they may have. Before they visit the doctor, it is helpful for them to list things that they want to discuss. For example, they may wish to talk about their illness, how symptoms can be managed, and how some decisions can be made for them by others (eg by arranging an enduring power of attorney). Their family or friends may also have questions.

Older people and their family carers may ask care workers how to obtain information that will help them to make plans for future care and treatment. Such requests need to be passed on to the supervising health care professional.

Advance health care directives

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

The older person can write down their advance health care plan in an advance health care directive or have this done for them. Sometimes, this directive is called a ‘statement of choices’, ‘a statement of wishes’ or a ‘living will’.

Health care professionals will use the advance health care directive to guide care or treatment if and when the older person is no longer able to make or communicate their own decisions.

A family member or friend may also be named in the advance health care directive to ‘speak for’ the person who has written the directive, if and when that person becomes unable to communicate their wishes. This is in case the directive does not cover a particular choice that needs to be made.

When care workers are providing care for an older person who cannot communicate their preferences, they need to be aware that care plans may be based upon advance health care directives. These care plans are therefore likely to reflect the older person's wishes.

Special resources are available for advance health care planning for people from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander people. See the Community Care Guidelines for further information (see page 7).

Information on advance health care planning and advance health care 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?

To keep the older person comfortable, physical symptoms need to be well managed.

Care workers should always make sure that the health care professional who supervises their work is kept informed about the older person's symptoms.

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.

Managing common physical symptoms

The following sections describe physical symptoms that are common when older people are being cared for at home. Each entry also describes actions that care workers can take to help manage these symptoms. This information is drawn directly from the Community Care Guidelines and from a synthesis of literature incorporated into the relevant section of the guidelines.

See the **Community Care Guidelines** for more information on symptoms (see page 7).

Fatigue

Fatigue is a feeling of 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 medications), or by poor eating or sleeping patterns.

Although an older person with fatigue is likely to want to rest, this symptom can sometimes be improved by exercise that suits their situation and ability. Other things likely to help are eating a healthy diet, drinking plenty of fluids and managing sleep patterns.

Care workers can observe and report fatigue, encourage a good diet and fluid intake, and help to support suitable exercise and sleep patterns, as agreed with the older person, family carer and supervising health care professional.

Pain

The health care team can help keep the older person's pain levels as low as possible. Pain can be acute (coming on quickly and lasting for a short time), chronic (lasting, on and off, for months or years) or incident (only coming on during an activity). Pain can also be felt in

different ways, such as aching, burning or throbbing. Clear and detailed descriptions of pain can help to identify how pain can be managed. If care workers keep good records, it is more likely that the best treatment can be chosen.

Practical tip

When the older person can report pain — such as when they have dementia — it is important to report the things that they do, the way they react, and how they appear, if these things may show that they are in pain. Ask the health care professional who supervises you about the ways in which you may do this — such as by using a special pain assessment tool.

Ways to relieve pain may include a change of position, a gentle massage or using hot packs (but not if the older person has a problem with feeling heat, cannot easily move the pack if it causes discomfort, or if your supervising health professional advises against this for other reasons). Care workers can also distract the older person from their pain (eg by using music that the older person likes or by talking with them).

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

If the pain is still there even when the older person has taken their regular pain medication, make sure that the health care professional is told so that extra medication can be organised.

If the older person needs strong pain relief, and especially if they find swallowing difficult, a syringe driver may be used. This is a small machine that injects the medication at a controlled rate over time so that the correct amount is given. Nurses set up and make changes to syringe drivers and they need to be contacted about any concerns.

The Australian Government Department of Health and Ageing has produced a pain management kit for use in residential aged care. This kit is also useful for care workers in a community setting.

PMG Kit for Aged Care
Weblink: www.health.gov.au
or email acc@health.gov.au to request a copy

Poor nutrition

Poor nutrition can develop when an older person is feeling unwell, has a low appetite, has limited ability to shop or cook, or has mouth problems that make it hard to eat. Anorexia (lack of appetite) is normal towards the end of life.

Family carers, volunteers and care workers need to be alert to poor nutrition so they can provide help (or seek help, where needed). The health care team may include a dietician, who can provide advice. Care workers may find offering frequent snacks to be a good option in some cases — such as when the older person has dementia and does not eat enough at mealtimes.

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, which means they are lacking enough fluid. This may make them constipated, weak or dizzy. Dehydration should not be confused with thirst. Reduced feelings of thirst are a part of the normal ageing process so feelings of thirst are not a good sign of how much to drink. Care workers can help the older person avoid dehydration by encouraging drinking and providing favourite drinks. Tea, coffee and alcoholic drinks may dehydrate people even more so other fluids, such as water, are better.

It is sometimes not appropriate to try to get an older person to drink when they are extremely frail or unwell — such as when death is approaching. At these times, the care worker needs to consult with the supervising health care professional about giving drinks.

Practical tip

When an older person becomes so frail or unwell that they have difficulty drinking, ice chips may make them feel more comfortable. Ask your supervising health care professional if this would be appropriate.

Mouth problems

Mouth problems can be caused by badly fitting dentures, not brushing teeth properly or a dry mouth (sometimes a side effect of medication). The care worker needs to encourage the older person to look after their mouth and teeth because this can help to increase their appetite, make eating easier and generally help them to feel better.

If the person's dentures do not fit properly, the care worker or their supervisor can organise a visit to (or from) the dentist to have them fixed. If the mouth problem is due to a side-effect from medication, the older person's GP can give advice on what to do. If an older person who has dementia refuses mouth or dental care, the care worker needs to consult with their supervising health care professional. Sometimes advice from experts in dementia is needed (eg from Alzheimer's Australia).

Swallowing difficulties

Swallowing difficulties (also called 'dysphagia') are common in many diseases experienced by older people. People with some types of motor neurone disease are at particular risk but many others are also affected, including some who have dementia.

If a care worker sees that the older person is having swallowing difficulties, it is important for them to tell their supervising health care professional. This professional is likely to contact a speech pathologist for a swallowing assessment. The speech pathologist can then work with the older person, their family carer and others in the health care team to make a plan that will help the person safely enjoy their meals and drinks.

The following strategies are generally useful when a care worker is helping an older person with swallowing difficulties:

- providing meals in a quiet place with no distractions
- making sure that the older person takes small mouthfuls and eats slowly
- making sure that the older person avoids talking while eating
- making sure that each mouthful has been swallowed before another is taken
- positioning the older person sitting upright with the head forward (ie not leaning back) when meals or drinks are taken and for at least 30 minutes afterwards.

A soft or vitamised diet is usually needed when the older person has swallowing difficulties. Thickening fluids can also help, but ask the supervising health care professional or speech pathologist because a particular consistency (degree of thickening) might be needed.

On rare occasions, if swallowing becomes dangerous, the older person might need to be fed using a tube that goes into their stomach or intestines (enteral feeding). This is not usually advised for people who have dementia but may be helpful in other conditions, such as motor neurone disease. Enteral feeding is only used after the older person, family carer and health care team have weighed up the benefits and risks carefully.

Nausea and vomiting

Nausea is the unpleasant feeling of the need to vomit. Vomiting is ‘throwing up’. When the care worker is supporting an older person who is feeling nauseous, it will probably help to encourage or help with (as appropriate):

- smaller, but more frequent, drinks and/or meals
- plenty of fresh air and avoiding unpleasant smells
- sitting upright after meals
- specially prescribed medication
- relaxing more fully.

Vomiting can quickly lead to dehydration so care workers always need to keep their supervising health professional informed about this symptom.

Breathing problems

Difficulty breathing (called ‘dyspnoea’) can be frightening. Sudden onset of prolonged breathlessness for no obvious reason needs urgent professional advice so calling an ambulance may be appropriate. However, breathlessness is often an ongoing symptom for which plans will be in place for the care worker to follow.

The following strategies are likely to help the care worker support an older person who is breathless:

- making sure the older person is sitting upright
- setting a fan to blow gently on their face

- making sure that pain is well controlled (because pain often stops people taking deep breaths or coughing to clear secretions)
- making sure that the older person remembers to take any specially prescribed medication.

Skin problems

Skin problems in older people include abnormal sweating, itching, swelling and wounds or ulcers. Pressure ulcers result from damage to skin and tissue caused by pressure or rubbing. Things that increase the risk of pressure ulcers include poor nutrition, limited sensation, incontinence, and other common problems that occur when people are unwell. It is important to tell the supervising health care professional immediately if the older person develops any skin problems so that treatment can be started quickly.

Measures that help care workers to prevent pressure ulcers include:

- keeping the skin clean and dry
- making sure that the older person is eating well
- making sure that the older person is drinking enough fluids
- relieving pressure by helping to change the older person's position regularly
- avoiding pressure on bony areas
- using pressure-relieving devices (special mattresses, pillows, etc)
- using lifting or repositioning aids to reduce skin damage.

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 and is sometimes treatable with the help of professionals (eg with medication and/or exercises). Care workers need to keep the supervising health care professional aware of continence issues so treatments can be arranged if appropriate.

When incontinence persists, the appropriate use of aids (eg special bed linen and protective pads) can minimise distress, embarrassment and inconvenience. Financial assistance may be available to help with costs.

Practical tip

Special strategies can be used when people with dementia have difficulty finding the toilet; for example, you can label the toilet door or put stickers of footsteps on the floor to make a pathway leading to the toilet. Much more information is available from the Alzheimer's Australia Dementia Helpline (1800 100 500)

National Continence Helpline
Telephone: 1800 330 006

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

Constipation

Constipation involves infrequent, incomplete or difficult (hard) bowel movements. It is common when older people become unwell and it needs to be monitored. Constipation can also cause other symptoms such as abdominal pain and bloating. When a person has constipation, it is possible that small fluid bowel actions may also occur. This is when fluid escapes around the hard contents of the bowel and can result in 'overflow incontinence'.

If the older person becomes constipated, care workers need to tell their supervising health care professional so that treatment can be started quickly. To prevent constipation, care workers can help ensure that the older person is:

- drinking enough fluid
- eating adequate fibre
- being physically active when possible (eg walking)
- taking medications or supplements as prescribed or recommended by health care professionals.

Delirium

Delirium is sometimes called 'acute confusion' and is an altered awareness that may last for hours to weeks. Older people who are delirious can be overactive (eg calling out or wandering) or underactive (unusually quiet and withdrawn). Delirium usually begins suddenly and can be caused by treatable illness.

Signs of delirium may include:

- problems with attention and understanding
- disorientation (eg not knowing what time of day it is)
- rambling or unclear speech
- reduced ability to carry out usual activities.

A sudden increase in confusion in an older person who has dementia may be due to delirium.

If an older person is suspected of having delirium, the care worker needs to inform their supervising health care professional. It is highly likely that a GP visit will be needed. In the interim, keep the person safe because they are more likely to have a fall or injure themselves in other ways when they are in this state. Reassuring the person, who may be very anxious or frightened, is also likely to help.

Managing delirium is aimed at treating the underlying cause (as appropriate), easing distress and avoiding injury.

Delirium is also common when people are dying and may be managed with medications when other causes have been ruled out.

Falls

When an older person falls, this can cause serious injury. Falls can have lasting effects on the older person's independence. If a person's ability to move or get up is affected by a fall, they may have added problems such as pressure-related injuries.

Falls can also lead to a loss of confidence.

Preventing falls is better than treating them. Care workers can help by:

- supervising exercises designed for the older person (eg by the physiotherapist) that may improve their muscle strength or balance
- making sure the person's environment is safe (eg with good lighting and no trip hazards)
- asking the supervising health care professional if a medication review might be needed (eg if the older person becomes dizzy or they are sleepy during the day)
- supervising the use of aids that have been recommended for the older person (eg a walking frame recommended by the physiotherapist).

Personal response systems (alert pendants) can ease people's fear of falling and not being found, particularly older people who live alone. It is important for the care worker to check that the older person always wears their pendant and knows how to use the aid (usually by pressing the button on the pendant).

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 for older people to take their medications exactly as they have been instructed by their doctor. Also, it is important that the doctor and pharmacist are aware of any over-the-counter medicines (bought without a prescription) and any herbal remedies or supplements that the older person takes. This is so that these health professionals can check that everything works together safely and effectively. Care workers can help by reporting any problems with medications to their supervising health care professional; for example, if the older person is confused about when to take their medication or how much to take, or if the medication seems to have bad effects. If the older person has sudden, severe bad effects that are likely to be from their medications, they may need urgent medical help (as they may for any sudden, severe illness). Whenever the older person is taken to hospital in an emergency,

it is best for their medications to be taken with them. The GP may arrange a home medicines review to help the older person to manage their medicines. This is when a pharmacist visits the home to advise the older person about their medication use and suggest aids that may be suitable.

Medicines Line
This service gives people independent, accurate, up-to-date information about prescription, over-the-counter and complementary medicines.
Telephone: 1300 633 424

Adverse Medicine Events Line
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.
Telephone: 1300 134 237

Pharmaceutical Benefits Scheme
For information on medicines subsidised through the Pharmaceutical Benefits Scheme (PBS) and about the PBS Safety Net.
Telephone: 1800 020 613

Complementary and alternative therapies

Complementary therapies are sometimes 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 medication. To make sure that all treatments are working together effectively, the health care team needs to know about all therapies used. It is important for care workers to explain this need to the older person and/or their family carer and to let their supervising health care professional know about any concerns.

Information about the use of complementary and alternative therapies is available from the **CareSearch** website.
Weblink: www.caresearch.com.au

4 How can other symptoms be eased?

People who are unwell sometimes experience other, nonphysical, symptoms. These symptoms are called 'emotional symptoms' in this section of the booklet.

Recognising symptoms

The following emotional symptoms may be experienced by older people:

- **Anxiety** — which includes feelings of apprehension, fear and dread. This can also lead to physical symptoms such as nausea, dizziness, shortness of breath and diarrhoea.
- **Depression** — which may result in loss of pleasure or interest in activities. Depressed people may also become isolated from others and experience feelings of hopelessness or helplessness.
- **Anger** — which may be part of a reaction to having an illness and losing independence. Anger can affect the way people talk, act and accept treatment.

If the older person has any emotional symptoms, tell your supervising health care professional because, just like physical symptoms, they can be helped.

Strategies that may help

Sometimes emotional support from others can help a great deal. This kind of support can be over the phone, face to face, or even in the form of letters. Sometimes, just sitting quietly with the older person can provide emotional support. At other times, the older person may wish to express their feelings or may be helped by talking about other things. Comfort is drawn in many different ways from being with, or talking with, other people.

Medication or professional counselling is sometimes needed to help emotional symptoms, but care workers may also help with the use of other strategies agreed with their supervising health care professional (who may be guided by other health care professionals, such as psychologists or music therapists):

- **Reminiscence** (reflecting on memories). This can help to remind the older person how they coped with problems in the past, which may help them cope with new problems. Reminiscence can also help the older person identify issues that it would be helpful to resolve (eg not having contacted a friend for many years because of an argument).
- **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 the older person keep in touch with friends or access support and information via the internet. For example, the website for Parkinson's Australia is a great resource for those who have Parkinson's disease. Using a computer can also be enjoyable and distract an older person from their problems. Care workers, family carers or volunteers may be able to help if the older person has difficulties with typing or using a mouse.

- **Health-promotion programs.** These programs may help older people manage symptoms; for example, suitable exercise programs may ease depression.
- **Relaxation therapy.** Relaxation may be used to manage anxiety.
- **Mind–body therapies** (such as yoga and tai chi). These therapies may help manage stress.
- **Animal-assisted therapy** (such as visits from specially trained dogs). These visits may help with depression.
- **Changing the environment** (such as positioning chairs to face natural, outside views). This strategy may have many benefits, including distraction, which can reduce anxiety or anger.

If the older person helps to choose the strategy that they prefer, they are more likely to stick with it and it is therefore more likely to work. Care workers need to keep their supervising health care professional informed of progress and changes when helping with these strategies.

5 What about spiritual issues?

As a person grows older, they often reflect on the meaning or purpose of their life.

Spiritual needs may become more important towards the end of life. The older person may wish to prepare themselves; for example, by finalising things that they have set out to do and 'making peace' with others. These things can provide spiritual comfort.

Older people may have questions about things they can achieve before they die and fears they may have (eg about symptoms). When care workers recognise this need, it is important for them to inform a health care professional who can then arrange to visit and answer these questions.

Sometimes, however, the older person may prefer to spend time quietly — with a companion or alone — while they reflect. It is also important to respect this need for quiet time.

For many older people, spirituality involves religion. When providing care for these people, an understanding of their religious beliefs and practices will help to make sure that care is in line with, and respectful of, their religion.

Family and friends, with their greater understanding of the older person's particular spiritual beliefs, can help. For example, they might suggest home visits from a pastoral care worker.

It is important to remember the spiritual needs of a person who has moderate or severe dementia and so might have difficulty expressing these needs. Providing spiritual care for people who have dementia can often involve making connections with the person using approaches such as music and laughter.

Practical tip

As a care worker, you do not need to share the same beliefs as your client to recognise and support their spiritual or religious needs.

Many religious organisations provide home visiting services and can also help people with outings to church services or other religious meetings. It is important to consider the needs of an older person to prepare for such an outing. The older person might be anxious to arrive with time to settle and reflect before the service or meeting begins.

6 What about when a hospital stay is needed?

Going into hospital

If an older person goes into hospital, there is important information that should go with them.

When an older person requires a hospital stay, it is important that information about their needs and preferences goes with them. The health care team need to ensure that the following information is provided:

- the older person's advance health care plan and/or directive
- a summary of their health (including a record of symptoms and their management)
- a list of current medications and any known allergies.

Having a pack of this information ready to go at all times is helpful. The care worker may be asked to help the health care professional to organise this and needs to know where the pack is kept in case of an urgent transfer.

Returning home from hospital

When the older person comes home after a stay in hospital, they and everyone involved in their health care need to understand the care and support required at home.

When the older person leaves the hospital, the community health care team will develop a care plan that reflects the older person's and family carers' needs. This plan will sometimes reflect needs due to particular illnesses.

What the research shows

- If an older person has advanced chronic heart failure, they are likely to benefit from extra support when returning home from hospital. This support should include health education and may mean that readmission to hospital is less likely.
- If the older person is frail or generally unwell,* extra support when they return home from hospital can help them to stay in their 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, those providing care need to check 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 care workers

Care workers need to inform the supervising health care professional promptly when a hospital admission is arranged for an older person. The health care professional can then arrange appropriate support when they are discharged. When the older person comes home from hospital they may have special needs that they did not have before. For example, they or their family carer may need to know how to manage new symptoms. The health care professional may ask the care worker to play a role in providing education or support.

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

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

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.

7 What about when help is needed in a crisis?

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

It is helpful for the care worker to work with the older person, their family carers and the supervising health care professional to think about the kinds of health-related crises that might occur for the older person, and to make a list of the help that is available, especially at night or on the weekend. A plan can then be developed to manage these crises.

Generally, crisis care involves 'out of hours' help, such as telephone support or home visits from members of the health care team (eg nurses). A personal response system, such as an alert pendant with a button to call for help, can also help the older person to get 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 the older person has an illness that affects how long they will live, is frail or extremely elderly, having access to crisis care can have health benefits for them and their 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 care workers

Care workers may be asked by health professionals to contribute to a plan to support the older person and their family carer in case a crisis should occur. They may also need to help put this plan in place.

Care workers who know an older person and their family carer well may be particularly helpful in advising health care professionals on the kinds of crises that might need to be considered when developing a plan.

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 support the older person to stay at home when frail or unwell. 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 tasks.

Providing the carer with support can sometimes allow an older person to die in their own home, if this is the choice of the older person and of their carer. However, a wish to die at home can change over the course of an illness. Also, it is not always possible to fulfil this wish, given care needs and available services.

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 learn and feel confident in their caring role. The second way is to support them to look after their own health.

Supporting family carers in their caring role

Family carers might like information and education about:

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

Family carers may also need resources to help them provide care; these resources sometimes relate to specific illnesses experienced by the older person.

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 the older person is very frail or disabled because of a stroke, their family carer may stay healthier if supported with stroke-specific information, education and skills training.
- If the older person has advanced cancer, their family carer may stay healthier if supported with cancer-specific information, education and skills training.
- If the older person has moderate or severe dementia, their family carer may stay healthier if supported with 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 care workers

Care workers can help by reporting the needs of family carers for more information, education, or improved care-giving skills to the supervising health care professional.

Care workers may be asked by the health care professional to help in skills training for the family carer.

Care workers may be able to help family carers access relevant information, including information about equipment, transport or home help (under the guidance of the health care professional).

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

The Australian Government's **National Carer Counselling Program** is operated by **Carers Australia**.
Weblink: www.carersaustralia.com.au
Telephone: 1800 242 636

The Australian Government's **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

Supporting family carers to look after their own health

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.

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.

To allow the family carer to take a break, alternative arrangements will be needed for the older person's 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 someone provides the care that the family carer would usually provide, within the home setting
- centre-based day respite — in a day centre
- short stay respite — in residential aged care or a hospital
- special holiday arrangements — such as when the older person stays with another family.

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.

What the research shows

If the older person is frail or generally unwell,* the family carer may be less likely to be depressed when respite care is provided.

If the older person has moderate or severe dementia, the carer's health may also be helped when respite care is provided.

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 care workers

Care workers need to observe family carers for signs that they might need a break and report these signs, and any requests for respite, to the supervising health care professional. This is so that any available respite can be organised.

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

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

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

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.

Older people and their family carers experience different kinds of losses during the course of the older person's illness. The older person loses good health and independence. Family carers may have to give up work or seeing their friends. Relationships can change when the older person has dementia because it becomes more difficult to communicate; this can also cause feelings of loss. Later, the older person and their family carer will know that they will soon be separated by the older person's death. Grieving will almost certainly occur for these losses.

Care workers and others providing care (eg volunteers) may also be affected as the health of the older person for whom they provide care fails and when the death occurs.

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.

What care workers need to know about grief

Will grief ease with time?

Grief is an individual experience. Grief can be experienced in response to illness, or in response to the illness of a family member or friend. 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 may 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. Those suffering long-lasting intense emotion or obsessive thoughts or behaviours need professional help.

Care workers may be able to help others by suggesting where support may be accessed (as agreed with the supervising health care professional). The resources mentioned in this section may be useful. Care workers may also need support themselves and should be able to access this through their supervising health care professional or from their own GP.

Care workers who have strong fears about the wellbeing of a person who is grieving, or who are concerned that this person might harm themselves, need to ask their supervising health care professional for guidance immediately.

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 end-of-life care will help the health care team to provide good care at this time.

A health care professional will develop the end-of-life care plan with input from the older person and their family. Input from the care worker is also likely to be requested. It is especially important that the plan supports the needs and wishes of the family carer, who may be concerned about their ability to manage at this time.

Care needs may be intense and emotionally taxing for all those involved in providing care, including volunteers, so the plan must also address these issues. Additionally, the plan should address safety (eg by recommending equipment to help with repositioning) and debriefing.

This plan needs to be:

- up to date
- known and understood by all who are involved in care.

The plan should include:

- contact details of staff or other support available after hours
- details of any equipment that might be needed (eg oxygen cylinders) and information about where to obtain it, especially after hours
- details of any religious requirements or preferences
- clinical information to help the carer or care worker recognise the signs that death is near, such as
  - a decrease in consciousness
  - an inability to swallow
  - changes in breathing
  - cooling of the legs and arms
- enough detail to ensure that the family and care worker know what to do and whom to contact in the event of a change or crisis, and when the death occurs.

Signs of death

The following are signs of death:[1]

- no pulse
- no breathing
- the pupils are fixed and dilated

[1] *Guidelines for a Palliative Approach in Residential Aged Care — Enhanced Version, 2006*. Prepared by Edith Cowan University, Western Australia for the Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra, page 169.
Available from www.caresearch.com.au

- the body becomes pale and its temperature drops
- muscles and sphincters relax
- urine and faeces may be released
- the eyes may remain open
- the jaw may fall open
- body fluids can be heard moving.

Although care workers may like to be able to recognise these signs, they are not responsible for deciding when the person has died.

After the death

The plan for end-of-life care needs to incorporate how to support the family after the death. Special support may be needed if it is likely that the person who has died will remain in the home for a long time (eg in a remote area that is difficult for a GP to reach), or if there are special cultural or religious requirements (eg for washing or dressing the person who has died). The plan also needs to indicate the name and contact details of the funeral director preferred by the older person.

Death must be confirmed by a health care professional. Generally, a GP will do this but, in some instances, this can be done by a registered nurse. In some states, confirmation of death must be done where the person dies rather than in a funeral home. A death certificate must be completed.

If there is uncertainty about the cause of death (eg if there has been a fall that may have contributed to the person's death), the coroner may need to be informed, even if death was expected. The GP will organise this.

How can care workers help at this time?

As well as being involved with the physical and emotional care of the older person, care workers can help to provide emotional support for the family as the older person is dying and after the death. It is particularly important for the family to have unhurried, private time to say 'goodbye'.

It is also very important for care workers to consult and follow the end-of-life care plan carefully as there may be particular cultural or religious requirements to be observed. Care workers may help to wash the older person after death and may also be asked to help dress them in preferred clothes.

The family generally contacts the funeral director. However, a care worker can contact a priest or minister of religion, or a friend to comfort the family, if the family authorise the care worker to do so.

PART B

Information relevant to particular groups of older people who are receiving a palliative approach to care at home

11 Older Aboriginal and Torres Strait Islander people

It is important to respect and value the culture of older Aboriginal and Torres Strait Islander people.

Many Australian Aboriginal and Torres Strait Islander people live in communities; each has its own unique language, customs, beliefs, healing practices, diets and cultural practices.

Indigenous people generally have a strong connection with the land or sea (or both) and their community, and a strong sense of obligation to their family. Indigenous staff or cultural advisors can guide care and help to:

- consider family and kinship relationships
- determine who is appropriate to be approached about the older person and who is allowed to provide care within the home
- obtain culturally appropriate and informed consent
- recognise the importance of choosing the place of death
- respect ceremonies and practices
- consider after-death requirements and support.

Language interpreters may be needed in some cases.

Death and dying

Traditional beliefs and practices around death and dying are particularly sensitive areas for Aboriginal and Torres Strait Islander people. Often end-oflife issues cannot be spoken about directly, but only in a roundabout way. A variety of ceremonies and practices occur. Care workers need to know what is appropriate and preferred by the older person regarding:

- place of death
- who should be there
- what care is needed for the person when they have died.

Grief and bereavement

In many communities, deaths occur often and there is little opportunity to recover from the grief experienced. Funerals can help with healing. Other practices may include periods of wailing, going away from the community, and ‘sorry camps’. Care workers can help by supporting communities in these practices, as agreed with their supervising health care professional. Support might include transporting people and making sure that they have food and water while they grieve.

12 Older people from diverse cultural and language groups

Care workers need to be sensitive to what is important for older people from cultural backgrounds that differ from their own.

It is important to respect the values of older people from different cultural backgrounds and to be able to provide information about relevant services. Considering how your own cultural background affects the way that you think, behave and relate to others is an important first step to understanding the needs of those from other backgrounds. Overcoming language barriers and seeking additional help to understand cultural values (what is important to people from a particular culture) are also helpful strategies.

Things that may help when providing care are:

- obtaining information fact sheets about services or treatments that are in the person's preferred language
- accessing cultural translators (trusted members of the cultural group who can understand and interpret the values of that group)
- using language translation and interpreter services.

Care workers can work with their supervising health care professional to obtain resources that will help them provide appropriate care. The resources listed here are likely to be helpful.

Services that may be helpful

Telephone Interpreter Service
(24 hours, 7 days)
Telephone: 13 14 50

On-site Interpreter
(9 am to 5 pm)
Telephone: 1300 655 082

On-site Interpreter Bookings
Telephone: 1300 655 082
Weblink: For online booking form:
www.immi.gov.au/living-inaustralia/help-with-english/help_with_translating
Email: tis@immi.gov.au

Other resources

Centre for Cultural Diversity in Ageing
Weblink: www.culturaldiversity.com.au

Centrelink Multilingual Information
Telephone: 13 12 02

13 Older people who live alone

Some older people who live alone have carers nearby. However, some have long-distance family carers (such as family living interstate) and others have no family carers at all.

Older people who live alone may have special care requirements, including the need for:

- extra help with activities of daily living (eg showering)
- extra help with housekeeping
- more companionship
- more support with medications
- specialised plans for falls and other emergencies.

The care worker's role may include more emotional care than usual when an older person lives alone. Also, because care workers may see the older person more often than others, they need to be especially careful to observe health concerns and report them to the supervising health care professional.

A special fear of the older person may be to die alone and not be found for some time or to be unwell and unable to summon help. Care workers need to consider these fears when providing care. Having an emergency call system, such as an alert pendant, is especially helpful. Other crisis plans also become particularly important when the older person lives alone.

Care workers need to know the care wishes of an older person who lives alone. The health care professional will work with the older person, any family carers, and the care worker to make sure that the care plan is suitable and up to date. The health care professional will also advise the care worker about any existing advance health care directive.

Finally, care workers may be asked by the supervising health care professional to help keep carers (including long distance carers) informed of care needs and circumstances.

14 Older people who live with mental illness

Physical and mental illnesses can affect one another, making symptoms worse. Mental illness can also lead to serious disability.

Some mental illnesses affecting older adults include:

- anxiety
- depression
- schizophrenia
- bipolar disorder
- personality disorders.

Sometimes we describe people as anxious or depressed when these are normal responses to illness (symptoms). However, anxiety and depression can also be mental illnesses.

Older people who have a mental illness can be very severely disabled, physically as well as mentally. For example, older people who have schizophrenia may need help with washing and dressing because their thinking and planning abilities have been affected by the illness.

Symptoms of physical illness can also be made worse because of mental illness. For example, depression can mean that pain is experienced as being more severe.

Some mental illnesses can cause people to behave in unpredictable ways. Also, some people with mental illness can become upset when routines are changed. Therefore, it can be particularly important for care workers to know the older person's preferred routines.

Special support may also be needed by family carers of older people who have a mental illness. This is particularly the case when family carers are affected by the older person's unpredictable behaviour. Health care plans for people who have a mental illness are usually developed in conjunction with mental health professionals and need to be followed carefully. In particular, crisis management plans are needed, along with urgent access to respite care. Care workers need to be aware of crisis-management plans and who to contact when respite is needed (eg if the family carer is sick). They also need to understand the disability and symptoms of the older person with a mental illness so that they can provide care that meets their needs.

Lifeline
offers a confidential 24-hour counselling service that may be helpful for people who are distressed.
Telephone: 13 11 14

15 Older people living with acute stress disorder or *post-traumatic stress disorder*

Traumatic events involve life-threatening situations or serious injury and may lead to feelings of intense fear, helplessness or horror.

Acute stress disorder (ASD) and post-traumatic stress disorder (PTSD) are names for reactions that can develop in people who have experienced or seen a traumatic event.

Most people exposed to a traumatic event experience strong feelings — such as fear, sadness, guilt, anger — in the days and weeks following the event. Most recover with the support of family and friends.

If someone continues to feel distressed after the first couple of weeks and is unable to cope with their usual daily life, they may be experiencing ASD or PTSD. Symptoms can increase and re-emerge in later life. Care workers are most likely to see ASD or PTSD in older veterans or refugees.

ASD and PTSD have three main types of symptoms:

- reliving the traumatic event (flashbacks, nightmares)
- avoiding reminders of the event
- being overly alert (eg having difficulty sleeping).

To avoid causing distress, care workers need to be aware of triggers for flashbacks or other reactions and take steps accordingly. These triggers may be different for each person. For example, an older person with ASD or PTSD who believes that they are being restrained (stopped from moving around) might find that this triggers a flashback. Pain may also trigger flashbacks in some older people.

A plan of care needs to be developed by the supervising health care professional in conjunction with advice about ASD and PTSD. The input into the care plan of the older person is of key importance, as is the advice of others who know them well, such as the family carer and the care worker.

The **Australian Government Department of Veterans' Affairs**
can advise care providers and provide services for veterans, such as counselling and support.
Weblink: www.dva.gov.au
Telephone: See the White Pages under 'Veterans' Affairs'

16 Older gay, lesbian, bisexual, transsexual or intersex people

Older people who identify as being gay, lesbian, bisexual, transsexual or intersex (GLBTI) may need special consideration when they are receiving care.

Some older people and their carers may be hesitant to disclose their GLBTI status to community care workers because they fear discrimination. The older person and their carer will be more likely to confide about their health and care concerns in a care team that is seen to be trustworthy. Trustworthiness may be shown by being:

- respectful of personal preferences and lifestyles
- nonjudgmental
- respectful of confidentiality.

These attitudes are therefore essential in care workers if they are to understand care needs and how they can best be met. Some older people who identify as GLBTI may also identify their ‘family’ in terms of their being ‘chosen kin’ and they may have few links with their biological family. Therefore, some issues related to care planning become especially important, for example, knowing:

- who has an enduring power of attorney (authority to make certain decisions on behalf of the older person)
- about any existing advance health care directive.

Care workers need to ask their supervising health care professional about these important issues.

Also, some people identifying as being GLBTI may have become isolated because of their fears of discrimination. There is then a particular need for the care worker to become a trusted support person as the end of life approaches.

17 Older people living with an intellectual disability

Staying in a familiar environment is particularly important for some people who have an intellectual disability.

Older people who have an intellectual disability, and their families, may especially value care workers who know their preferences and routines. Learning how to communicate with the older person with an intellectual disability may require skills that are learned over time. These skills can then be used when helping to manage symptoms such as pain.

Special assessment tools may also help manage symptoms of older people who have an intellectual disability. The care worker can ask the advice of the supervising health care professional about tools that are available.

Family carers of an older person with an intellectual disability are sometimes their parents. These parents are likely to be extremely old and frail, yet may still wish to provide home care. A great deal of care worker input may be needed in these cases.

An older person who has an intellectual disability will experience loss and grief in the same ways as other people. However, expressing this grief is influenced by their communication and intellectual abilities. Care workers need to be sensitive to this issue and ask for extra support if behaviours are extreme, such as when there is aggression, mutism (not talking) or self-harm. Grief can be particularly extreme when a person with an intellectual disability experiences the death of their aged parent.

When experiencing the death of someone dear to them, an older person who has an intellectual disability is likely to benefit from supported participation in the funeral. Cherished mementos need to be respected and any major changes should be minimised in the months following the death.

Disability Advocacy and Information Service Inc
Weblink: www.dais.org.au

18 Older people who have motor neurone disease

Motor neurone disease (MND) is a progressive disease that leads to muscle wasting. There are several types of MND that affect people differently.

Some people with MND have trouble with speech or swallowing; in others, only their legs or arms are involved. Some people have a combination of both. MND does not usually lead to incontinence.

The main symptoms that care workers need to know about are listed below:

- **Emotional difficulties** — people with MND can be sad as they lose their independence. The disease can also affect emotions, so people with MND might cry when they are not really sad or laugh uncontrollably at times. It is important to show understanding and caring support.
- **Communication problems** — some people with MND cannot speak; therefore, they use aids, such as communication boards or machines to type messages. This can be time consuming. However, it will save time in the long run because care can then be planned exactly as it is needed. The person with MND understands what you are saying but may not be able to respond verbally.
- **Swallowing difficulties or choking** — some people with MND will have a 'feeding tube'. People still able to eat normally may need a soft diet and thickened fluids because of swallowing problems. A speech pathologist needs to advise on the correct diet and on the thickness of the fluid. It is important for those who help with feeding (which should be under the direction of a health care professional) to feed the older person slowly, making sure that they have swallowed each mouthful before providing the next.
- **Breathing problems** — if the breathing muscles are affected by MND, the person will find it difficult to lie flat in bed. This is often the first sign of breathing problems. Extra pillows, set up so that the older person sleeps in a more upright position, may help.
- **Mobility problems** — some older people with MND will have trouble walking and this will become more evident as the disease progresses. Eventually, most people will require a wheelchair or need to stay in bed.
- **Pain and discomfort** — these symptoms occur mainly because of an inability to move. This inability causes weakness and stiffness of the limbs. As muscles waste, the joints are no longer supported and this can also cause discomfort. Some people have cramps or spasms that can be painful. The health care professional will show care workers how to help.
- **Constipation** — this symptom is generally caused by immobility and inadequate food or fluid intake. The care worker should be guided by their supervising health care professional to avoid or manage constipation.

Care workers always need to be guided by health care professionals regarding the most appropriate way to manage problems as they arise for a person with MND. In most cases, specialist palliative care services are also involved and will provide advice.

If care workers notice changes or have any concerns about a person with MND, they need to tell a health care professional.

MND Australia can provide information and support
Weblink: www.mndaust.asn.au
Telephone: See the White Pages under support. ‘Motor Neurone Disease Australia’

19 Older people who have advanced Parkinson's disease

Parkinson's disease (PD) is a disease of the nervous system. It affects people in many different ways.

Symptoms of PD include:

- tremor (shaking)
- slowness of movement
- increased muscle tone (stiffness)
- balance changes, which can lead to falls.

In later stages, the following symptoms develop:

- swallowing problems
- excessive (extra) saliva
- weight loss
- constipation
- increased mobility problems, to the extent that the person is eventually confined to bed.

People with PD can also experience pain and fatigue, and speech is often affected severely. PD limits facial expressions so knowing when a person has pain may depend on responses to questions. Care workers need to be aware of ways in which they can determine the needs of people who have PD; for example, using aids, such as microphones, to amplify the person's speech.

Meal times need to be frequent and supplemented as eating will be slow because of swallowing difficulties and fatigue can limit intake. Be guided by a speech pathologist or supervising health care professional.

Drooling is common and can cause embarrassment; it needs to be dealt with sensitively. People with PD have a high risk of falls and may 'freeze' (be unable to move for a period of time). The supervising health care professional will work with the older person, their family carers and care workers to develop a plan for safe mobility. Care workers need to follow this plan carefully and report any concerns.

It is especially important for care workers to allow enough time to provide care for people who have PD. Extra time is often needed to understand what the older person needs and then provide the required assistance.

Parkinson's Australia has many helpful fact sheets.
Weblink: www.parkinsons.org.au
Telephone: 1800 644 189

20 Older people who have moderate or severe dementia

Dementia is caused by changes in the brain and affects memory and ability. Changes usually occur slowly and symptoms develop over many years.

Care workers usually have an increasing role to play in supporting the person who has dementia as symptoms progress. In this section, some of the key aspects of the care of people who have moderate or severe dementia are addressed.

Communication

The ability to communicate in words and to understand words is generally affected by dementia as time goes by.

Speaking in short, clear sentences can be helpful when caring for an older person with moderate dementia. However, other ways of communicating gradually become more important. For example, care workers need to consider the tone of voice that they use, their body language, and their facial expressions.

Observing how the person with dementia reacts (to see what brings them pleasure or distress) is also important.

Assessing pain and other symptoms

Although pain is not usually caused by dementia, older people with dementia often have symptoms such as pain because of other conditions. Symptoms are more difficult to assess when communication is affected. Care workers need to observe the older person carefully. For example, is the person limping or rubbing their leg, or are they becoming tense and agitated?

Ask the supervising health care professional how to assess for pain. Also, think of any other reasons for distress and agitation, such as frustration with communication, a need to use the toilet, feeling too hot, and so on.

The **Dementia Behaviour Management Advisory Service** can provide information and advice for health professionals and care workers providing care for older people with dementia, and for family carers. When a person who has dementia is behaving in a way that affects their care, this resource can help.
Telephone: 1800 699 799

The **National Dementia Helpline** can advise on education about the much more extensive knowledge needed to provide good care for people who have dementia.
Weblink: www.alzheimers.org.au
Telephone: 1800 100 500

Delirium is quite common when a person who has dementia becomes unwell. Care workers need to watch for a sudden increase in confusion and contact their supervising health care professional if this occurs. See page 24 of this booklet for further details.

As dementia progresses, the older person will become unable to walk or stand and will need much more help. Eventually, other symptoms may include:

- poor nutrition
- dehydration
- mouth problems
- swallowing difficulties
- skin problems
- incontinence
- constipation.

Further details of these symptoms are provided on pages 15–25 of this booklet. Death generally occurs after many years of gradual deterioration. Carers of older people who have dementia may need extra support because they provide care over such long periods. Also, care can be particularly exhausting because of communication issues. Care workers have special opportunities to build long-term, supportive relationships with people who have dementia, and with their family carers.

Resources available for care workers

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

Australian Government Department of Veterans' Affairs
Telephone: 13 32 54
Weblink: www.dva.gov.au

Cancer Australia
(Cancer Council Helpline)
Telephone**:** 13 11 20
Weblink: www.cancer.org.au

CareSearch
(A good source of palliative care resources)
Telephone: (08) 7221 8233 (general enquiries)
Weblink: www.caresearch.com.au

Centre for Cultural Diversity in Ageing
Weblink: www.culturaldiversity.com.au

Centrelink
(financial assistance for carers)
Telephone: 13 27 17
Telephone for multilingual information**:** 13 12 02

Continence Aids Payment Scheme
Telephone: 1800 330 066 (National Continence Helpline)
Weblink: www.bladderbowel.gov.au/furtherinfo/caps

Dementia Behaviour Management Advisory Service
Telephone: 1800 699 799

Disability Advocacy and Information Service
Weblink**:** www.dias.org.au

Lifeline
Telephone: 13 11 14

Medicines Line
Telephone: 1300 633 424

MND Australia (Motor Neuron Disease Australia)
Telephone: 1800 777 175
Weblink: www.mndaust.asn.au

National Carers Counselling Service
Telephone: 1800 242 636
Weblink: www.carersaustralia.com.au

National Continence Helpline
Telephone**:** 1800 330 066

National Dementia Helpline
(Alzheimer's Australia)
Telephone: 1800 100 500
Weblink: www.alzheimers.org.au

National Stroke Foundation
(Stroke Information Line)
Telephone: 1800 787 653
Weblink: www.strokefoundation.com.au

Palliative Care Australia
Telephone: 1800 660 055
Weblink: www.pallcare.org.au

Parkinson's Australia
Telephone: 1800 644 189
Weblink: www.parkinsons.org.au

Pharmaceutical Benefits Scheme Information Line
Telephone: 1800 020 613

Translating and Interpreting Service
Telephone: 13 14 50

Veterans and Veterans Families Counselling Service
Telephone: 1800 011 046

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