



15 Bedbrook Place
Shenton Park WA 6008
ABN 13 107 780 017
Phone/Fax: 1300 551 704
Email: pcwainc@palliativecarewa.asn.au
Web: www.palliativecarewa.asn.au

Palliative Caring at Home

Information for those caring for a person with advanced and terminal illness.
Western Australia Edition – January 2012

This booklet is available for download as a PDF file from the Palliative Care WA Inc website, www.palliativecarewa.asn.au/resources.php. Users may make copies of the booklet. Hardcopies are available from the Palliative Care WA Inc office (postage may be charged for bulk orders).

This booklet aims to help carers and others who are involved in the practicalities of caring for someone with advanced and terminal illness. It provides practical ideas and concludes with a resource listing of useful contacts.

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- Purslowe Funerals – www.purslowefunerals.com.au
- Rotary Club of Fremantle Inc – www.fremantlerotary.org
- Silver Chain Nursing Association – www.silverchain.org.au
- WA Centre for Cancer & Palliative Care, Curtin University – www.supportiveandpalliativecare.org.au

Corrections and Improvements

Palliative Care WA Inc invites all users of this book to provide their feedback, corrections and suggestions so that future editions can be improved. Simply contact our office (phone/fax 1300 551 704, or email pcwainc@palliativecarewa.asn.au).

Disclaimer

The information contained in this booklet is for general guidance only. Every effort has been made to ensure that the recommendations in this booklet are consistent with accepted standards of practice at the time of publication, but neither the authors nor publisher accepts responsibilities for errors or omissions. It is the responsibility of the reader to seek professional advice before using any medication, technique or procedure.

1. Introduction

What do we do now?

Facing the reality of a life limiting illness is a traumatic time for you and the person who has the illness. What will happen next? How long do we have? These are questions most people ask.

Your doctor will be able to give you some ideas about what problems are likely to arise but it is sometimes difficult to be specific, particularly about how long someone has to live. Some illnesses advance more quickly than others and the person may rapidly lose the ability to look after themselves, whereas others may be able to maintain a high degree of independence for some time. Asking questions can help.

What is palliative care?

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹

Palliative care professionals work in teams including, for example, nurses, doctors, social workers, pastoral care workers, and volunteers. They work alongside GPs, specialists and other community organisations that manage day-to-day care and support, to make sure that the person and family get the best care possible.

Palliative care can be provided at home, in an aged care facility, in an acute hospital or in a hospice or a palliative care unit.

Caring at home is a big commitment on the part of the carer/s. If you are considering becoming the carer at home, discuss the options with your doctor or your community or palliative care nurse. There is a lot of help available if you do decide to care for the person at home, but you should not feel guilty if you feel that you can't manage it.

If I really can't manage at home, can the person spend the rest of their days in a hospice, palliative care unit or hospital?

Hospices and palliative care units function as centres where people who are having difficulties with the symptoms of their illness can go for treatment, for respite care, or for care in the last days of their illness. They offer intensive nursing, medical and allied health support. Not everyone needs this. People seldom stay in hospices or palliative care units for long periods of time. If the person you are caring for is assessed as not requiring this level of care then you will be helped to find an alternative care facility, possibly a nursing home or hostel.

Aren't nursing homes and hostels for old people?

There have been many changes to the care provided by nursing homes and hostels in recent years. They are now also called residential aged care facilities. In the main they care for frail elderly people, but they are also forging ahead in providing palliative care for people of all ages.

¹ accessed Aug 08 at <http://www.who.int/cancer/palliative/definition/en/>

2. Caring at home – some considerations

Talking things through

You need to discuss as openly as possible the person's wishes and thoughts about being cared for at home. It can be a very rewarding time for all concerned but it is also a big commitment for you and your supporters, so it is important that everyone is realistic and clear about what help they can offer.

What do I need to consider?

Caring at home is a 24 hour a day, 7 day a week job. It is important that you are aware of your own limitations and exactly what help you can expect from others. Try to think of all the relevant factors, for example:

- What time do you have available? In the early days, the person may be quite independent and able to be left alone for long periods; but this could change rapidly.
- Are your employers supportive? If you are employed, you may have to discuss with your employers the leave available to you. How much time you will need is hard to predict.
- Can someone else help? It may be practical to share the care with someone else, such as another member of the family or a friend, or you may be able to afford to pay for professional help.
- Do you have any conditions or disabilities, which would make your caring role more difficult, or do you have other commitments that cannot be put 'on hold' such as children?

If you cannot give your full time to care, it doesn't mean that you can't care for the person at home, but you will need to consider your resources carefully and plan ahead. If, realistically, you think you can't do the job, no matter how much you would like to, then it is better to say so in the beginning, rather than risk disappointment when you have to alter your plans in the future.

What are the advantages?

The advantages of caring for someone at home are:

For the carer:

- being close to the person
- not having to spend time making visits to hospital
- accepting the help of neighbours and friends, or just continuing to enjoy their company.

For the person:

- being close to the carer
- being in familiar surroundings
- having familiar people around
- accepting the help of neighbours and friends, or just continuing to enjoy their company.

What may prevent me from caring at home?

Sometimes it's just not possible to care for someone at home because:

- the person has medical needs which cannot be met at home
- you live too far away from medical, nursing or support services
- you have your own health concerns or problems
- the cost of providing care at home may be too much.

How do I know what help I will need?

You can start by thinking about what aspects of care are difficult for you at the moment and what sort of help would be useful. Your palliative care nurse will discuss with you what help is available and how to access it. For instance, an occupational therapist (OT) can come into your home and make a detailed assessment of physical needs, recommending modifications in the home such as handrails, ramps etc, and assess what equipment may be necessary. You don't have to think of everything at once. Extra help can be added in as you go along.

Apart from the professionals, is there anyone else who can offer support?

Yes, there are other people who can support you:

- Think of family and friends. Often people want to help but are not sure how. They may be pleased to offer practical support such as doing the shopping, cooking a meal, providing transport etc. Don't refuse any genuine offer of help if it supports you in your role.
- The palliative care service may have volunteers who can give you time, for instance by sitting with the person while you go out for a while.
- The palliative care service may also offer home help to assist you to manage your home. Ask your palliative care nurse about this service.
- Local councils offer various programs to help people in your situation. Each one is different. Telephone your council and ask what help they can provide.
- Local churches or community groups may have programs to help people who are sick. Ask what help they can provide.

3. Outside help

What services are available when you want to care for someone at home?

General Practitioner

The person's General Practitioner is a key person in providing information about palliative care. Some GPs have a special interest in palliative care or may have had extra training in this field. Any GP who does not have special expertise in this area can receive advice and support from the palliative care team.

Community-based palliative care services

Palliative care services provide specialist consultative and clinical care for those with a life limiting illness wherever it is needed: at home, in hospitals, nursing homes etc. Palliative care services also provide practical physical support and counselling.

The palliative care team can include doctors, nurses, social workers, pastoral care workers, volunteers, administrative assistants and ancillary staff and they operate on a regional basis. The team can call on the expertise of other health professionals such as physiotherapists, dieticians, occupational therapists, etc.

A palliative care nurse helps to coordinate the care of the person and keeps in touch with all the other professionals involved. They can guide you and the person through this confusing period, advising what services you can access.

In Perth the Silver Chain Hospice Care Service provides 24 hour specialised palliative care for people and their families in their own home. The care and support is provided by an interdisciplinary team of registered nurses, care aids, doctors, chaplains, counsellors and trained volunteers. Referral to the service is made by your GP or specialist. A hospice nurse and doctor will come to your home to assess your situation and consult with you, your family and your GP about the support that you require and advise you on the care that they can provide. You can learn more at the Silver Chain website (www.silverchain.org.au) or by calling Silver Chain on 08 9242 0242.

Community-based palliative care services are also offered in country areas of Western Australia – please check the listing of palliative care services in Section 20 on page 24 of this booklet, or visit the National Palliative Care Service Directory at www.palliativecare.org.au for more information.

Other medical specialists

People may still benefit from treatment even though the illness cannot be cured. Specialists will communicate with the GP, who will need to know all the opinions and treatments that are being given.

Private nursing agencies

Private nursing agencies can provide nursing or personal care services to assist you in the home. Some health insurance funds will pay for this help in their ancillary cover, but they vary so check with your fund. Nursing agencies are listed in the Yellow Pages.

What services can help if home care is no longer possible?

Hospices/palliative care units

There are palliative care services at most major public and private hospitals in Perth and in some country centres. All the palliative care services provide specialist medical and nursing care as well as psychological and social support for people and their carers. Some hospitals have palliative care units, where the person can be admitted for symptom management, respite care, or at the end stage of the illness. People seldom stay in hospices or palliative care units for long periods of time. There is also day respite available at the Murdoch Community Hospice.

Some inpatient services (hospice and palliative care units) receive state government funding to provide a service at no cost to the person or their family. Most facilities are also able to admit people as private patients, which means their health insurance fund pays for the care. The amount of cover provided can vary between health insurance funds. Being admitted as a private patient to a facility which receives government funding for palliative care may help ensure there are more places for people without health insurance.

Details of these services can be found in the palliative care services listing at the back of this book.

Hospitals

The person with advanced illness may need the specialist services of a hospital for treatment. These treatments may include radiotherapy, chemotherapy or blood transfusions. If an admission is needed urgently and there is no bed available in the hospice or palliative care unit, the person may be admitted to a hospital until a place in a hospice becomes available.

Hostels, nursing homes and community support services

Sometimes the person's illness is progressing slowly or it may not be causing major discomfort, but it is no longer possible to provide care at home. Residential aged care facilities (the formal name for nursing homes) and hostels can provide some short-term respite or longer-term care for the person.

Aged care services can also be provided at home using what is called a 'community package' – the two most common packages are called the Community Aged Care Package (CACP) and the Extended Aged Care at Home Package (EACH). The person needs to be specially assessed by an Aged Care Assessment Team (ACAT) to access these services.

In general, aged care services are paid for by the Commonwealth Government. You can access more information from the Aged Care Information Line on 1800 500 853, or visit www.agedcareaustralia.gov.au.

Ask your doctor or palliative care nurse for information about any of these services.

4. Finances

What costs may be involved in providing care at home?

There may be charges for some of the services provided at home, although most are provided free of charge. Don't be afraid to ask about the costs of services: it's better to know in advance than receive a bill you weren't expecting! In some cases you may be able to negotiate a reduction if your circumstances warrant it. If you are having financial difficulties, a social worker can give you advice.

Visits at home

General Practitioners

Some GPs will visit people at home who are unable to attend their surgery. Many will bulk bill for the visit, but some may charge a fee in excess of this amount. You need to check with the doctor what the usual practice is.

Silver Chain Hospice Care Service

There is no fee for the Silver Chain Hospice Care Service which provides home care in the Perth metropolitan area (Peel Community Palliative Care covers from Singleton Beach Rd to Lake Clifton).

Other palliative care services

Depending on where you live, a palliative care service may be able to provide home visits. To find contact details for your local service, follow the link to the National Palliative Care Service Directory at

the Palliative Care Australia website (www.palliativecare.org.au), or call Palliative Care WA Inc on 1300 551 704.

Medications

Many medications commonly used by people at the end of life are listed on the Pharmaceutical Benefits Schedule (www.pbs.gov.au), which means that the Commonwealth Government helps to meet the cost – talk to your doctor to ensure you get ‘PBS scripts’ where-ever possible.

Some medications you need may not be available from your local pharmacy; they may need to be ordered in especially, which can take a day or two, so plan ahead if possible. In extreme circumstances a hospital may supply what is needed with the help of a palliative care doctor or specialist. In the case of hardship, talk to your pharmacist, your doctor, or your palliative care nurse.

What financial support is available?

Centrelink (a federal government agency) administers several support payments:

Carer Allowance

The Carer Allowance may be paid to people who care for either an adult or a child. A health professional must provide a report to help establish eligibility. Where a child is being cared for the child and carer must live together. You can get the Carer Allowance for up to two adults if you are caring for both of them, equally two carers of the same person may share the payment.

The Carer Allowance is not means-tested and does not affect other entitlements, pensions or benefits. It is not regarded as taxable income. The condition of payment is that the person would be otherwise requiring nursing home care. Your GP has to fill out the form, available from Centrelink. The allowance is paid from the date of receipt of the application form.

Carer's Payment

The person receiving the care must need care permanently or for an extended period but the carer does not have to live with or next to the person being cared for as long as constant care is being provided. Recipients can temporarily suspend their caring role for up to 63 days in a year without losing their payment. Carers can spend up to 25 hours (including travel) a week working, doing unpaid voluntary work, studying or training without losing their payment. This payment is counted as income and is means-tested. Contact a social worker or approach your local Centrelink office directly.

Carer Supplement

Introduced in June 2009, eligible recipients of the Carer Payment, Carer Allowance, Wife pension (Age or DSP), DVA Carer Service Pension and DVA Partner Service pension are entitled to receive the Carer Supplement which is an ongoing, non-indexed annual sum payment of \$600 made around July.

Other Allowances

People may be eligible for a range of other financial supports and should always contact Centrelink to ensure they are aware of any potential entitlements. Supports include a Bereavement Payment which provides temporary financial help when a pensioner suffers the death of their pensioner partner. Eligibility for any Bereavement Payment is automatically assessed when you advise Centrelink of the death of your partner. This payment is subject to pension income and asset tests.

For further information contact Centrelink on 13 27 17 or visit www.centrelink.gov.au.

Other financial help

The Cancer Council WA can offer limited financial support. Your palliative care nurse, social worker or GP can help organise this, if needed.

Eligible veterans and war widows can seek assistance from the Department of Veterans' Affairs for services, equipment and, in some cases, medications. For more information visit www.dva.gov.au or call 13 32 54.

Many superannuation funds automatically offer life and other insurance benefits for their members which may be able to be paid upon the diagnosis of a terminal illness, so that funds are available to pay for care. It may be false economy for people with serious illnesses to close or consolidate old superannuation accounts if they relinquish valuable insurance policies. Maurice Blackburn Lawyers offer confidential obligation-free advice on how to access these benefits on 1800 196 050.

5. Home nursing practicalities

Preparing the home

When caring for someone at home it may be necessary to consider some practical alterations to make the job easier. Changing the home can be disruptive. Try and have an open discussion so that everyone can feel comfortable and have their needs met, and to prepare for a smooth transition. You may need to revisit this topic a few times as the situation changes.

First, consider where the person will sleep or spend most of their time and, if they have limited mobility, the best place for their bed? The bedroom may not be the most efficient or suitable place to nurse someone. The person could feel isolated or depressed if nursed away from the comings and goings of everyday life. Bringing the bed into the larger living area may prove a good move. It is important to work out between you how things will be arranged and whether the person wants to be 'in among things' or would prefer peace and quiet. You, and anyone else in the home, will also need space away from the demands of the bedside to relax and have private time.

If the person is mobile encourage them to get up for meals and to use the bathroom. If they are bed-bound, they need easy access to basic items (drink, telephone, television, radio controls etc) so they do not have to keep calling for help. You need to be prepared for changing needs as the person loses the ability to do things.

The Independent Living Centre can offer guidance on preparing the home – call them on 1300 885 886 or visit www.ilc.com.au.

Bedroom

- Ensure that the place where the person spends most of their time has good access to a toilet or bathroom.
- Move any unnecessary furniture and floor rugs away from the bed. People need room to move around the bed, and you may need bedside equipment in the future.
- Have the things that the person needs like a clock, drinks, radio, torch, etc around the bed.
- Have a telephone at hand if possible.
- A means to summon help is reassuring for the person. It can be as simple as a bell or you may want to invest in a remote system such as a baby alarm so that you can be contacted in any part of the house and garden.
- The person may appreciate a radio, music centre, a computer or television. These help to maintain contact with the outside world and provide entertainment.
- A small chair near the bed is useful for visitors and for the person to sit on while you make the bed.
- Room for a bedside commode might be necessary if the person cannot get to the bathroom.
- A small table that can be positioned over the bed is useful for meals or other activities. In some areas these can be borrowed from a local palliative care service or hired from other equipment agencies (more ideas listed in the equipment section on page 19 of this booklet). These agencies also have specialised equipment that helps the person move around in bed or to manoeuvre in and out of bed.
- A small table or drawer will keep equipment or dressings left by the nurse clean and dry.
- A convenient but safe place for any medications is necessary. If children are likely to be around be sure to keep all medications and medical equipment out of their reach.

Living area

- If the person is able to move to the living area it would be useful to set up a special spot with a comfortable chair or a day bed with necessary things close at hand. Consider a place with an outlook of the garden or other interesting views.
- Ramps used to overcome steps and handrails placed in strategic places can help the person move around.

Bathroom

- A bathroom can feel very small once you try to fit in the person, perhaps on a shower chair, yourself and possibly a palliative care nurse as well! Modifications may have to be made; your palliative care service or an occupational therapist can offer advice in this area.
- If there is a drain hole in the floor of the bathroom, it may be easier to shower the person on a chair outside the shower cubicle. A shower hose can be fitted onto the taps. Be careful of slipping though, a non-slip mat may be a good idea.
- A raised toilet seat and handrails can be fitted.
- The bathroom door can be adjusted to swing outward rather than inward to make access easier.

Outside

Ramps can be installed if there are steps to negotiate outside the house. This will make it much easier if a wheelchair has to be used.

Equipment

Consider some equipment that might make the job of caring easier:

- walking frames, walking sticks
- wheelchairs
- ramps, handrails
- shower chairs, commodes
- toilet raisers, toilet surrounds - these assist in getting on and off the toilet
- pressure relieving products including air, holofill and egg crate mattresses
- 'goose necks', bed poles - these help the person to move around, and get in and out of bed
- bed rails - these prevent the person rolling out of bed
- bed tables
- macs and washable incontinence sheets to protect the bed
- bedpans and urinary bottles
- hospital beds, lifting machines - if there are particular difficulties nursing the person.

As you can see, there is a lot that can be done to make the job of caring much easier, and help is available for some of the modifications. There could be a waiting list for such assistance, but if agencies know the person you are caring for has a life limiting illness they will try to give you priority. Discuss any problems with your community or palliative care nurse.

6. Personal care practicalities

Like most people, the person will feel fresher and more comfortable if their personal care, ie washing, showering etc, is attended to every day. However, individual preferences must be taken into account and it would be a mistake to force your own ideas. Discuss their preferences with the person and respect them.

If the palliative care nurse or care assistant is attending to personal care, become their apprentice and learn how to do things yourself. The nurses do not usually visit every day to do this.

Showering or washing

The person may have a shower when the palliative care nurse or care assistant attends and just a small wash will do on the other days. If you are attending to the person's personal care yourself, work out what can be managed without too much of a struggle. A shower is refreshing, but if it involves heavy lifting or too much energy expended by the person, an acceptable wash can be done in the bed or on a chair. Another method of washing in bed with warm moist towels is called a 'hot towel bath'. It is best to discuss this with your palliative care nurse.

The palliative care nurse will be able to show you these methods.

Wherever you are carrying out the wash or shower, make sure that the person has adequate privacy and that their dignity is preserved, even if you think they are not fully aware of what is happening. Ensure that the area is warm and draught-free. Using fresh, dry, warm linen makes the experience of a wash much more pleasurable. Using lightly scented soaps or cologne may also help, but be aware that strongly perfumed soaps can dry out or irritate the skin.

Skin care and massage

If the person spends a lot of time in bed or in a chair, check the skin every day for red areas or sore spots, especially on the back, ears, heels and elbows. The feet can get especially dry.

When you are helping the person with personal care it might be a good time to try some gentle massage. You don't have to be especially skilled. Try gentle squeezing and stroking movements; whatever feels comfortable for the person. You can use oils, lotions and creams to massage dry skin and sore spots. Massage is often comforting for the person and helps to maintain soft supple skin. Do not massage skin areas that are infected or inflamed, and do not massage the legs if the person has a deep vein thrombosis (clot). If you are unsure, check with the palliative care nurse.

Bed linen

If the person is in bed, change the sheets as often as you can without putting too much stress on yourself. Bed linen can be changed while a person is in bed, ask the nurse to show you how. You can put the top sheet to the bottom and put a clean one on top again every day or two.

A draw sheet and plastic mackintosh ('mac'), available from pharmacies, over the bottom sheet will limit any soiling due to incontinence, so you can avoid remaking the whole bed. If the person has an ongoing problem with incontinence, aids can contain it and minimise mess and odour. Please talk to the palliative care nurse.

Manual handling

If a person is bed-bound and requires a hospital bed, your palliative care nurse can arrange to provide the bed and a special pressure-relieving mattress. This means that the person doesn't need to be moved frequently to relieve pressure. On occasions this will depend on what equipment is available, so discuss your needs with the palliative care nurse.

Depending on the strength and capabilities of the person, you may find yourself having to help them to move. Bending and twisting while lifting can cause you injury. Your palliative care nurse will teach you how to lift and move the person in a way that minimises this risk. Learn the correct way to do things for your own safety. Training is available from some agencies, including the Independent Living Centre.

Mouth care

Sick people are much more prone to mouth infections such as thrush. Thrush appears like small white patches on the tongue, gums and lips and can make the mouth very sore and eating difficult. Thrush is readily treated with drops, anti fungal lozenges, or oral tablets. If the person cannot swallow properly and debris is left in the mouth it encourages infections of the salivary glands which appear as hard, hot, painful swellings around the jaws and cheeks. Antibiotics may be necessary; in either case, please refer to the doctor or palliative care nurse.

It is vitally important to check the person's mouth daily, and to help keep the mouth clean. If a normal toothbrush is too painful you can try a very soft toothbrush, use special mouth swabs or use some moistened gauze wrapped around your finger. You can use commercial mouthwashes or normal saline.

Dryness of the mouth can also be a problem. If the person can swallow, they could try sucking small pieces of ice or icy poles to keep the mouth moist. Sucking sweets like mints or jellies can stimulate the production of saliva. If the person is not eating or drinking, wipe the lips and tongue every hour or two during the day with a wet swab and whenever you attend the person at night. Iced water is usually the most comfortable and refreshing. Lip balm, vaseline or lanolin is helpful for dry lips.

Hair care

It is quite possible to wash a bed-bound person's hair in bed and it usually makes them feel better. If you have a plastic sheet, towels, jug and a bucket or bowl you are in business! Ask the palliative care nurse to show you how to do it, giving them a day or two's notice so it can be included in their schedule. It is also possible to have hair cut or permed at home. Look in the Yellow Pages for hairdressers who have mobile services.

Nail care, shaving etc

It is also important to help the person feel good about personal appearance. Keep the nails clean and trimmed. You may do this yourself or call a podiatrist to trim the toenails if they are hard and thickened. A man may enjoy a daily shave; you may just have to prepare things, or you may have to do the shave yourself. A woman might like her legs and underarms shaved.

Clothing

It is important that the person is clothed comfortably and that clothes can be put on and removed with the minimum of fuss. It is not a good idea to wear night attire all day (unless the person is very sick and bed-bound) because it emphasises the 'sick role'. On the other hand, day clothes such as skirts, tights, shirts and tailored trousers might feel restrictive and are difficult to put on and take off. Garments like tracksuits or t-shirts made from soft, stretchy jersey material are much easier to deal with and can be just as stylish. Openings can be made to ease dressing and undressing.

If you are handy at sewing, or know someone who is, you can organise alterations or new garments yourself. Suitable clothing is available in shops or on the internet (try searching for 'adaptive clothing'). An occupational therapist may be able to recommend or source clothing designed for people with a limited range of movement or other impairments. Ask the nurse or physiotherapist to check the person's shoes or slippers to make sure they are suitable.

7. Symptoms that may occur in advanced illness

The Western Australia Palliative Care Network, part of the Department of Health, publishes an excellent booklet called *Palliative Care Medicine and Symptom Guide*, which is available by calling 08 9222 4222 or by download from www.healthnetworks.health.wa.gov.au/cancer/palliative/resources.cfm.

Silver Chain Hospice Care Service provides a brochure titled *Helpful Comfort Measures*, download it from www.silverchain.org.au/assets/files/Palliative-Helpful-comfort-measures-brochure.pdf or call Silver Chain on 08 9242 0242.

Pain

Pain is the most feared symptom of advanced illness. Pain is not inevitable and many people with advanced illness do not have significant pain. If pain is a problem, it can usually be managed effectively.

Pain can be aggravated by social or emotional problems. Companionship and discussion of their fears and problems may be helpful for the person.

Pain is commonly managed with regular medications (called analgesics) to prevent pain, rather than waiting for pain to occur before taking something. Aim for a base-line of medications that give constant relief. Additional doses of medication can then be given at times when the regular dose is not enough; these are called 'rescue', 'PRN' or 'breakthrough' doses.

Analgesic medications come in various forms - tablets, syrups, suppositories, injections or skin patches. The doctor may prescribe morphine or similar strong analgesics. These drugs are not used as a last resort or when a person is near to death, in fact they are the most common pain medications used in advanced illness. There is no risk of the person becoming addicted to these drugs when they are used to control pain. Palliative Care Australia publishes a useful pamphlet, *Facts about morphine and other opioid medicines in palliative care*, which is available at www.palliativecare.org.au, or from Palliative Care WA Inc on 1300 551 704.

Other medications such as anti-depressants, steroids or milder pain medications may be used in conjunction with strong analgesics to achieve pain relief. For instance, you may be confused to find that the person is asked to take paracetamol and morphine together. You might wonder "Why take paracetamol if you are already taking morphine?" but these drugs have different ways of relieving pain and they complement each other.

Strong analgesics, like many drugs, can have side effects as well as benefits. These may include constipation, nausea and vomiting, drowsiness and confusion. In most cases the side effects can be managed so that they do not present severe problems. Talk to the doctor or palliative nurse so that you understand the actions of each medication being used, and what can be done to lessen troublesome side effects.

Constipation

Constipation is a very common problem in people with advanced illness, due to lack of mobility, poor diet and reduced of fluid intake. Strong analgesics like morphine reduce bowel activity, and people using these medications will often need to take laxatives. Constipation makes other symptoms, especially pain, worse, and should be prevented. Even when someone is eating very little, a bowel action is expected at least every 3 days. If a person has not had a bowel movement for 3 days or more, ask a health professional for advice.

Encourage the person to take prescribed laxatives regularly, to drink adequate fluids and to remain mobile while they can. Extra fibre in the diet such as vegetable soups and fruit (both of which could be pureed), wholemeal bread and porridge will help those who are eating relatively normally.

Nausea and vomiting

Nausea and vomiting can be troubling and may be due to medications, illness in the stomach or other medical problems. The doctor will investigate the cause and may give medication to alleviate the problem. It is helpful to reduce any odours that cause distress, eg when preparing food. Nausea may be reduced by simple measures such as fresh air, adjusting the body position or by sipping cold fizzy drinks such as soda, ginger ale or lemonade. If the symptoms of nausea persist discuss this with the palliative care nurse.

Loss of appetite and weight

Loss of appetite in advanced illness is common and it can be distressing for those who are providing care. Sometimes the doctor can prescribe small doses of steroid medication which often increase the appetite. Ask the doctor if this would help the person for whom you are caring.

Weight loss is common in advanced illness and some people become distressingly thin. There is not a lot that you can do. Usually there is no point in trying to 'feed someone up', especially if they have no appetite, as this can cause tension and it may make them feel even worse.

Don't draw undue attention to the loss of weight. The person may want to avoid looking in the mirror because the change in body image is upsetting. Buying new clothes or adapting existing items so they fit will help the person to feel as attractive as possible. They may need extra padding in bed or on the chair so that prominent bones are more comfortable. The person may also feel the cold more than normal, and need extra layers of clothes and heating in the house.

Weakness

Weakness is a frustrating symptom of advanced illness and very difficult to improve. Treatment with tonics or vitamins will not help significantly although the person could discuss this with their doctor. If there is anaemia (shortage of red blood cells) then blood transfusions can bring temporary relief. As the illness progresses, the person will spend increasing periods of time in bed or in a chair. Rest periods between outings and after visitors become more important.

Dehydration

In the final stages of advanced illness there is often a lack of interest in fluids as well as food. It is a natural preparation by the body for death. You may feel quite anxious because the person is not drinking but it is not usually a source of discomfort for them. In fact it prevents build up of saliva which can become difficult to swallow. Reducing fluid intake can reduce noisy breathing in the back of the throat, leading to less coughing and vomiting. It also reduces the amount of urine the person has to pass.

A dry mouth may be uncomfortable however, and if the person can still swallow, sucking on ice chips or swabs soaked in iced water will help. Sometimes, if thirst causes discomfort, a gentle infusion of fluids under the skin through a drip may bring relief, and can be easily administered in the home by the palliative care nurse.

Confusion

Confusion or delirium is not uncommon in advanced illness. It is not a sign that the person is 'going mad'. Confusion could be caused by medications or by one of several medical conditions.

A dying person may not recognise familiar people or may misinterpret events around them or what people are saying. There may be nightmares, vivid daydreams or hallucinations. A person may become restless, plucking at the bedclothes, and try actions that are no longer possible, such as getting out of bed. They may need to pass urine or open their bowels, or may be in pain, but unable to communicate.

Keep the person safe from a fall or harm. Do not try to tie a restless person into a bed or chair. This could frighten them and make them more restless. Sit with the person and talk with them about the experience and try to reassure them. Before things become unmanageable, contact your community or palliative care nurse.

8. Food and nutrition

People with advanced illness often lose their appetite, and the reasons are various:

- tiredness
- pain
- diarrhoea, nausea and vomiting
- altered taste sensations
- depression
- constipation
- sore, dry mouth or throat.

Some of these causes can be reversed, however the nutritional needs of a person are likely to be different from what they were in the past. Offer a selection of small portions of savoury and sweet foods, and don't forget adult tastes such as spices and alcohol (check with the doctor if the latter is acceptable). Because taste is dulled, spicy foods may be better tolerated than usual. If you are cooking for others the food you have prepared can be easily adapted for the person.

Don't be too disheartened if the food which was requested, and which you have taken much trouble to prepare, is rejected. This is a common response, and a feature of the illness rather than the person just being difficult.

Don't neglect your own needs - try to maintain regular meal times and a good intake.

Odours

Sometimes the smell of food preparation, such as frying, can be off-putting. Keep odours to a minimum, turn on the extractor fan or open the windows.

Frequency and amount of food

It is better to offer small frequent meals rather than large infrequent ones, even if that was the person's eating pattern in the past. Large amounts of food are probably no longer needed. Offer food when it is wanted and try to present it attractively. Cook a quantity of food and then freeze portions to be warmed quickly in the oven or microwave.

Texture

Texture is an important characteristic of food. If the person has a dry or sore mouth soft food may be preferred. To prevent food being too bland, moisten it with sauces or add a little extra milk or cream to mashed potatoes, soup and porridge for instance. If solid food is a problem it should be blended or strained through a sieve. Keep the individual nature of the ingredients of the meal if possible, rather than blending everything together into a grey mash. Tasty and tender stews are readily prepared in a slow cooker.

Ready-packaged or canned food might be an option - soups, yoghurts, custards or even baby foods. Soups and milky drinks are tasty and nutritious if fluids are all that can be managed. Fortified drinks such as Ensure or Sustagen can replace a whole meal, and may be bought locally. Sometimes they are better tolerated chilled. The person may like fruit juice frozen onto a stick, especially in hot weather.

Extra nourishment can be supplied by fortifying food with dried milk, cream, ice cream, eggs, honey and dried food supplements.

If I am finding it hard to prepare meals, what can I do?

If you really want to prepare the person's food yourself, let your family and friends prepare meals for you instead. They could prepare food for you to put in the freezer or work out a roster to bring food on various days to relieve the burden for you. Try not to be too proud of your own independence.

If you are having great difficulty and have no one to help you, then you can ask the doctor or palliative care nurse to refer you to Meals on Wheels. There are also private companies that can supply gourmet meals – look in the Yellow Pages.

9. Complementary or alternative therapies

It is common for individuals and families facing advanced illness to be willing to try remedies other than those offered by conventional medicine. You may feel that conventional Western medicine does not support all of the needs of a person, and we must admit that this is sometimes true.

On the whole, professionals experienced in palliative care will be sympathetic to the person's need to seek holistic care, relief and support. They may warn against therapies that are known to be harmful, but they will not take away the individual's right to choose, or refuse to continue supporting you.

Non-medical treatments and therapies fall into two broad categories:

- Alternative: sometimes called 'unproven' or 'unconventional', these replace conventional therapies
- Complementary: these supplement and add to conventional treatment and care.

Cancer Council WA publishes a very helpful guide to complementary and alternative therapies which is available by calling the Cancer Helpline on 13 11 20, or by internet download from www.cancerwa.asn.au.

Many palliative care nurses and volunteers incorporate complementary practices into their care, including:

- Massage
- Music therapy
- Relaxation, visualisation and meditation
- Some aspects of aromatherapy
- Therapeutic touch and reiki.

It is important that the person does not feel pressured into treatments and therapies merely to satisfy the enthusiasm of friends. Some questions a person should ask:

- Is the therapy working for me?
- Do I expend a lot of time and energy attending appointments?
- What is the financial cost? Is it affordable?
- Do I fully understand the benefits and side effects of the therapy or treatment?
- Is the practitioner qualified or experienced?
- Is the practitioner an accredited member of a traditional medicine society or similar group?
- If I am concerned or dissatisfied will I be able to voice this?
- What does my doctor know about the therapy, and does he/she support its use?

10. Caring for yourself

Accepting help

Caring for another person can be very demanding. You may have other family or work commitments, which have to be fitted into your day. Do not feel guilty about accepting help from family and friends with shopping, cooking, housework or staying with the person so you can do tasks outside the home or just have some time to yourself. Organisations which can offer you support are listed at the end of this booklet.

Feelings

In these circumstances it is quite normal to experience a whole range of feelings at the same time. You may feel angry, resentful or bitter because of the extra demands caring puts on you. These feelings can be mixed with grief, anxiety and sadness about what is happening to the person. The person for whom you are caring may display emotions that are difficult for you to accept, or may unload negative feelings on to those who are closest.

Fears

You may feel unable to leave the person even for a short time in case they experience some suffering, or you may fear that the person could die when you are absent. It is important to share your fears and feelings with someone who can understand them. A palliative care worker is such a person.

Physical wellbeing

It is important to look after yourself physically. Try and make sure you are having:

- adequate sleep
- regular nutritious meals
- exercise.

It is also important not to hurt yourself physically. Remember that back injuries can happen easily.

Visitors

Visitors can be very welcome but some may stay too long. This can exhaust the sick person who feels a need to put on a good front and to entertain the visitor. Suggest to visitors that they stay for a short time only. You may have to indicate for how long eg ten minutes. Don't be afraid to enforce this and remind them to leave if necessary. It may help to suggest the best time to visit to your visitors. For example, late morning may suit you and the person, which will allow for you both to have an early afternoon rest.

Install a telephone answering machine to take calls when you cannot get to the phone. You could put a nicely worded sign near the doorbell stating what times are convenient to visit, or that your person is not receiving calls today.

Time out and respite care

You need time to do things that you enjoy. If you feel that you cannot leave the person, ask a friend or relative to stay while you are absent. The palliative care service or local council may be able to supply a volunteer to sit for several hours a week if you don't have anyone you can call upon.

Do you need a break? Respite care is available and, if you have a complete rest from the daily demands of care, you may feel a whole lot better. Your doctor or palliative care nurse will help you find respite care when it is needed, or your local Carer Respite Centre may be able to help, call 1800 052 222 or visit www.commcarelink.health.gov.au to learn more about these services.

Changing your plans

Do not demand too much of yourself. You do not have to be perfect. Work out the major priorities, and let other things go for a while, or ask somebody else to help. Goals that you have set for yourself may have to be put 'on hold' for a while.

It may be that the care demands are beyond your capacity and the person needs additional professional care. Discuss this with your doctor and/or palliative nurse. It may be better that the person receives all the physical aspects of care from skilled professionals, leaving you with more time to offer them your love and personal and emotional support.

It is not a failure to feel that you have not met the expectations you gave yourself. You may feel that you just want it all over and done with. Most people in this situation have times when they feel like this reflecting a strain which is inevitable and understandable. It is important to talk so don't feel guilty about these thoughts.

11. Caring for the family

You may have family commitments but also need to alter or adapt your normal routine. You may find yourself supporting others as they deal with their own reactions to the situation.

The following points may be useful in your role:

- Be as honest as you can about what is happening.
- Try to involve those close to you in making decisions and solving problems, and then they will have a better understanding of your role and the whole situation.
- Try to involve family members in the tasks of caring. They will feel they have a role and there will be a less burden on you.
- Have honest discussions about your commitments with other family members. While you carry this extra responsibility, others could 'fill in' for you or take over some of your former roles completely.
- Try to share feelings with each other about the difficulties, joys and feelings of grief that are bound to arise.

Involving the children

Children can manage stressful situations if they are gently told the truth at their level of understanding. They are often aware that 'something is going on' and, in the absence of truth, may create fantastic explanations. They can become quite distressed if they see adults are upset but are not given a truthful reason or their questions are dismissed because it's 'too hard' to explain. They may also feel resentful that your attention has been taken away from them.

Every situation is different. Some general points to bear in mind include:

- Young children especially may feel that everything is their fault – you may have to explain that it isn't.
- Don't be afraid to give children caring tasks, perhaps a small task in supporting you, so they feel part of the caring team.
- Don't overburden children with adult responsibilities.
- Maintain family routines as much as possible.
- Include children as much as possible without creating extra strain on yourself or the person. They can then understand your commitment.
- Encourage children to share their feelings about illness and death. This will prepare them better for the loss.

12. Putting affairs in order

Making a Will

A will is a legal document setting out how a person wants their assets and belongings to be distributed after death. Everyone, ill or not, needs to make a will if they have money and property, otherwise the estate is shared out according to a formula set by state laws which may not be what the person wanted. If a will has not been made it may prove difficult to raise the issue, especially if a person has not come to terms with the progress of the illness. The person may feel more comfortable talking to a social worker in this situation. The social worker may help contact the Public Trustee (phone 1800 642 777 or visit www.publictrustee.wa.gov.au) or a solicitor for advice. Palliative care teams include social workers.

It can cost approximately \$200-\$300, or much more, for a solicitor to prepare a simple will. The Public Trustee also prepares wills at no cost but will charge a fee to administer the estate. This charge ranges from zero if the assets are jointly owned (eg husband to wife or vice versa) to 1.1% of the value of the family home and 4.4% of the first \$200,000 of the other assets. This reduces down for the next \$200,000 to 3.3% and then 2.2%. Commercial trustee companies also provide a service with charges for the administration of the estate based on its value.

Power of Attorney

A person may wish to appoint someone to make financial decisions on their behalf, including the signing of documents, now or in the future. A Power of Attorney or Enduring Power of Attorney only relates to decisions about relating to money and property and not a person's medical care or lifestyle.

The Office of the Public Advocate of WA can provide more information about Enduring Powers of Attorney, including the necessary forms. Call 1300 858 455, or visit www.publicadvocate.wa.gov.au. You can also get help from a solicitor or a social worker.

13. Advance care planning, living will and consent to medical treatment

What is advance care planning?

Advance care planning is the process of making plans for a person's healthcare in advance. The plans take effect when the person is no longer able to legally make their own healthcare decisions. Advance care planning is not compulsory.

There is a better chance advance care plans will be respected if the person:

- outlines their values and end of life care preferences clearly
- appoints and empowers someone to make decisions on their behalf
- discusses and reviews plans regularly with their healthcare providers and family and friends to make sure they are up-to-date and well understood
- provides copies of any planning documents to doctors, hospitals, family and carer/s.

Consent to medical treatment

All Australians with the capacity to make legal decisions have a right to refuse medical treatment (including resuscitation, artificial feeding and hydration, antibiotics etc). In anticipation of a time when they are no longer able to make decisions for themselves, people often use 'living wills' or 'advance directives' to record treatment decisions (normally refusing medical treatments), or appoint family-members or friends to make decisions on their behalf. The law recognises and upholds these advance directives providing they are clear, realistic and not made under coercion.

What is an Enduring Power of Guardianship?

If a person has legal decision making capacity and is over 18 years of age, they can use the Enduring Power of Guardianship to appoint a person (or people) who are empowered to make healthcare decisions on their behalf when they are no longer able to make your own decisions. The operation of the Enduring Power of Guardianship is governed by the *WA Guardianship and Administration Act 1990*.

Palliative Care WA Inc recommends people appoint an Enduring Guardian if possible because a real live person can then make treatment decisions when required, taking into account the person's expressed wishes, their clinical situation, and the risks, burdens and advantages of proposed treatments. People should choose their Enduring Guardian carefully, and brief them thoroughly and regularly so they know what is wanted in the person's particular situation.

Get Enduring Power of Guardianship forms and other information from the Office of the Public Advocate on 1300 858 455 or visit www.publicadvocate.wa.gov.au.

What is a 'living will' or Advance Health Directive?

'Living will' is a general term. In many respects the term 'advance directive' describes the purpose of this sort of document better than the term 'living will'. An advance directive is a document (or video or audio recording) in which a person outlines in advance the outcomes they want from medical treatment or care when they are no longer able to make reasonable decisions for themselves. A person may revoke their advance directive (verbally or in writing) at any time.

Palliative Care WA Inc acknowledges evidence that many advance directives are difficult interpret, may not apply to a person's situation or may not provide a treating health professional with enough information. For these reasons we recommend people appoint an Enduring Guardian.

In Western Australia there are two main types of advance directives in use. Both types

- record treatment decisions (refusing or consenting to medical treatment)
- only take effect when a person is unable to make their own decisions
- can be made by any person with legal decision-making capacity who is at least 18 years old.

The two types of advance directives operating in WA are:

1. Advance Health Directives:
 - are governed by state laws called the *Guardianship and Administration Act 1990*
 - use a standard format outlined in the legislation.
2. 'Common law advance directives'
 - are acknowledged and preserved by law in Western Australia
 - do not conform to any standard format
 - go by a wide variety of names including Statement of Choices, Advance Directive, Living Will, etc.

Palliative Care WA Inc notes health professionals are likely to be familiar with the format of the Advance Health Directive provided by the Department of Health. Get Advance Health Directive forms and other information from the Department of Health on 08 9222 2300 or visit www.health.wa.gov.au/advancehealthdirective/home/.

Can a person use both the Advance Health Directive and the Enduring Power of Guardianship?

A person can complete both an Advance Health Directive and an Enduring Power of Guardianship under Western Australian law. If an Advance Health Directive applies to the treatment decision that must be made in a particular case, the Advance Health Directive must be followed when the time comes, and cannot be overturned by an Enduring Guardian (if appointed). If an Advance Health Directive is not relevant or does not cover the situation, then the person appointed as the Enduring Power of Guardianship would make the decision/s.

What if a person doesn't complete an Advance Health Directive or Enduring Power of Guardianship before losing decision-making capacity?

The *Guardianship and Administration Act 1990* lays out a list of people ('persons responsible') who would be asked to make a treatment decision on a person's behalf if they are unable to do so for themselves and if they have not completed an Advance Health Directive or Enduring Power of Guardianship, or if the Advance Health Directive does not apply to the particular situation. The list includes:

- spouse or defacto partner if that person is living with you
- your nearest relative (child, parent or sibling) who maintains a close personal relationship with you
- any other person who maintains a close personal relationship with you.

What is 'legal decision-making capacity'?

In general legal terms, a person has 'decision making capacity' if he or she is:²

- over 18 years in age
- able to understand the facts involved in a decision
- able to appreciate the significance of a decision
- capable of weighing risks and benefits and choosing between options.

Capacity is assessed in terms of each new decision. Note that this is a complex area and that it is sometimes difficult to determine whether a person has decision making capacity, a medical assessment may be needed. Capacity may vary according to the nature of the decision that is to be made, the health status of the person, or even the time of day or the person's immediate living environment. The law maps out processes to determine capacity where it is not clear that a person is capable of making 'reasonable judgements in respect of matters relating to his or her person.'

Will advance care planning documents from elsewhere in Australia count in Western Australia?

If the person has completed advance care planning documents in another state or territory of Australia these will normally be respected in Western Australia – the final decision could be made by the Western Australian State Administrative Tribunal (www.sat.justice.wa.gov.au). Equally, Western Australia documents should be effective in other Australian states and territories, although the process to confirm this may be time-consuming.

² <http://plato.stanford.edu/entries/decision-capacity/#Ter>

Can Advance Health Directive or Enduring Power of Guardianship be registered?

There is no register of Advance Health Directives or Enduring Power of Guardianships in Western Australia. It is possible to record information with the Medic Alert Foundation (www.medicalert.com.au or 1800 882 222). Please note that a fee may be charged.

Palliative Care WA Inc recommends providing certified copies of Enduring Power of Guardianship, Advance Health Directive, Enduring Power of Attorney etc to health care providers and close family or friends. A copy of the person's medications list, Advance Health Directive and Enduring Power of Guardianship can also be put on the front of the fridge – ambulance officers normally look there if they attend your house in an emergency.

The Multiple Sclerosis Society of WA runs the Neurodegenerative Conditions Coordinated Care Program (NCCCP). Services include assistance with advance care planning for eligible people with rapidly degenerating neurological conditions. Contact the MS Society on 08 9365 4888 or visit <http://mswa.org.au/nccp.html> for more information.

14. When to call an ambulance

Many carers call an ambulance when the condition of person for whom they are caring unexpectedly or rapidly changes. You may feel scared or unable to cope, so calling for help is understandable.

Before you dial 000

Where it is available, we recommend that you contact your palliative care or community nurse before you call 000 because it may be difficult for you to know whether the person's problems are an expected part of their illness (and able to be appropriately supported at home), or result from some other temporary cause (in which case an ambulance will be able to help).

Ask the doctor in advance what is likely occur in the course of the illness so that you have some idea of what to expect. The doctor or palliative care nurse can help you make a plan so you know what to do if the person's condition changes quickly. *Asking Questions Can Help*, available online from www.palliativecare.org.au, or by calling Palliative Care WA Inc on 1300 551 704, gives question prompts which may be helpful in a discussion with the doctor.

It may be helpful to have on hand either a letter from the person's doctor or a formal advance directive (see chapter 13) explaining to ambulance officers that the person has a terminal illness and clarifying their wishes regarding (for example) resuscitation and preferred place of care. Ambulance staff are sometimes reluctant to cease treatment if there are no written directions and will transport the person to the emergency department.

Some palliative care services provide their clients with a one-page information sheet which should be given to ambulance staff if they attend the home. The information sheet asks ambulance staff to call the palliative care service to get more information about the person before major decisions about their treatment or place of care are made.

Call an ambulance if...

Examples of when to call an ambulance include if the person you are caring for needs urgent care as a result of an accident (a fall, burn, cut etc), or if you think the person has taken the wrong dose of medications or some other type of dangerous substance.

Silver Chain Hospice Care in Perth will attend to clients who have fallen (08 9242 0242). The Silver Chain Priority Assessment team (08 9242 0242 or www.homehospital.org.au) can also visit if a client has a laceration requiring stitching (in order to prevent a visit to an emergency department).

Beware

Changes in breathing and consciousness are common as a person approaches death (see chapter 15). If you call for an ambulance and say anything like 'the patient is unconscious,' or 'the patient is having trouble/has stopped breathing,' the ambulance service is likely to respond with full lights and sirens and want to take the person direct to the emergency department at the nearest hospital. This may not be appropriate if the person is actually dying and a home death is the agreed aim. Contact the community or palliative care service before you dial 000.

Pre-arranged patient transfers

Your palliative care nurse or the person's GP may call an ambulance to arrange a non-urgent transfer from home to a palliative care unit, or from hospital to home. The transfer can be arranged up to 24 hours in advance. A doctor will need to authorise the transfer. The person arranging the transfer should call the St John Ambulance Patient Transfer Service on 08 9334 1234 and should avoid using terms like 'the patient is unconscious' or 'the patient has breathing difficulties' because the ambulance service is likely to respond as if the situation is an emergency.

Most hospices and inpatient palliative care services in Western Australia are not funded for ambulance transfers. If there is a reasonable likelihood of an ambulance transfer at some point in the future, consider ambulance insurance cover and have it in place before it is required. If there is any doubt, ask.

General information

Please note that ambulance transportation is not necessarily free. The costs may amount to several hundred dollars, depending on your situation.

Aged pensioners are not normally charged for ambulance services, while people aged over 65 may be entitled to a 50% discount. Please contact St John Ambulance on 08 9334 1212 to clarify your or the person's situation.

St John Ambulance provides ambulance cover (insurance) in country areas, contact your local Sub Centre for more information. St John Ambulance no longer provides ambulance cover in metropolitan Perth. The health insurance company HBF now owns and operates HBF St John Ambulance Cover, and most other health funds offer policies in this area. Contact your health insurer to see what level of ambulance cover you hold.

For more information about ambulance services in Western Australia visit the St John Ambulance website at www.stjohnambulance.com.au/ or call 08 9334 1222.

15. The approach of death

The approach of death in someone with an advanced illness is usually a gradual, peaceful process. In the majority of cases good palliative care ensures the absence of physical pain or discomfort. Most changes that occur at this time are normal and do not require any special treatment, hospitalisation or professional assistance. If you are unsure please discuss this with your doctor, community nurse or palliative care nurse, who can help you plan what to do as death approaches.

Please note that if you call an ambulance they are required to attempt to resuscitate anyone who appears to be dying. An Advance Health Directive or living will (see section 13, above) can help clarify the person's wishes regarding resuscitation for ambulance attenders. If you wish, the doctor can prepare a letter for you to give to the ambulance personnel instructing them not to engage in resuscitation measures if the person dies during transportation to a hospital.

This section outlines the changes that normally occur as death approaches, and what you can do. Not everybody will experience these changes, and they do not occur in any particular sequence.

Drowsiness

In the last days the person may become drowsier and spend a lot of time sleeping. You can move their position in bed from time to time, if you think that they are uncomfortable, but you do not need to adhere to any strict schedule. If the person becomes a bit restless or increases consciousness, then it may be time to change position. In the last few hours there is often no need to move the person at all.

Appetite and thirst

Interest in food and drinks decreases to the point that nothing is taken at all. The person will lose the ability to swallow. Do not try to give fluids at this stage, as it will only pool in the back of the throat. If the mouth is dry, use large mouth swabs dipped in iced water and moisten the lips with Vaseline, lanolin or lip balm.

Confusion, restlessness

The person may become vague, confused or restless. It is not unusual for someone who is dying to become quite restless in the 24-48 hours before death. Try to reassure the person by talking calmly and identifying yourself. Avoid sudden noises or approaches which can startle. Constant touching or stroking may be disturbing, but gently holding a hand is not. Leaving a soft light on and playing the person's favourite music may be helpful. Have someone stay beside the person as much as possible. If the restlessness becomes a real problem talk to your doctor, community nurse or palliative care nurse.

Vision and hearing

Vision may cloud; the person develops a 'far away' look in the eyes and doesn't seem to focus on anything or anyone. A soft light, left on all the time, may help. Hearing may not be so acute although it is said that this is the last sense to be lost. Provide an opportunity for family or friends to talk to the person and encourage quiet conversation in the room to maintain awareness that people are there, making sure that there are no distressing conversations within the person's hearing.

Incontinence

Incontinence (loss of control) of bladder and bowel may occur when the person is very near death. Ensure there is an incontinence pad and a drawsheet and 'mac' protecting the bed to maintain comfort and hygiene. Due to reduced food and fluid intakes, quantities of urine and faeces may be small.

Breathing

As death approaches you will notice that the breathing pattern changes. There may be gaps in the breathing ranging from several seconds to several minutes. This is normal and requires no intervention, it is simply a sign of imminent death when the gaps between breaths lengthen progressively.

As the person's ability to swallow diminishes, saliva and secretions may collect at the back of the throat and make a noise as the person breathes. It is not distressing for the person who is dying but may be distressing for you to hear. Sometimes elevating the head of the bed with pillows or gently re-positioning the person may be useful.

The doctor may prescribe an injection to reduce the secretions, but it is not always effective.

Colour and temperature

As the blood circulation slows, the arms and legs become cool to the touch and may look mottled and dark. The person's face may look pale and 'pinched' and the nose feels cold. You may notice that the skin is clammy and marks easily, bearing the imprint of clothing, bedding or fingers as you provide personal care. There is no need to put on a lot of extra bedding or an electric blanket to warm the person. This could just make them restless. A sheet and a couple of warm blankets or a doona should be sufficient.

How will you know death has occurred?

The following signs typically (but not necessarily) indicate death has occurred:

- breathing ceases
- no heartbeat
- no response to loud talking
- eyes are fixed, pupils dilated, eyelids may be open
- jaw relaxes and mouth remains open
- the person may be incontinent.

What to do when death occurs

It is helpful to have a plan in place for when death occurs, and your palliative care nurse or General Practitioner can help you prepare such a plan. You may want a friend, minister or family member to be with you at this time. Ask someone to be ready at short notice if you wish.

You do not have to do anything immediately when the person dies. There is no need to call the police or an ambulance. You may wish to call your doctor or community or palliative care nurse to confirm that death has occurred.

The person's body can remain at home for several hours for relatives and friends to visit and say goodbye. If this is the case the body will need to be positioned on the back with head and chest very slightly elevated on pillows and hands on the chest. A towel can be rolled up and tucked underneath the chin to close the mouth. This can usually be taken away after a couple of hours. The community or palliative care nurse will help you with these preparations if you call them.

There will be another opportunity for people to say goodbye at the funeral.

A doctor or registered nurse with the required qualification will need to attend prior to the funeral director in order to complete a Certificate of Life Extinct. After this the funeral director can attend to the body. They can usually come within a short period of time. It is possible to have the body removed at night but there may be an extra charge for this. You may wish for someone else like a friend or relative to contact the funeral director on your behalf. The funeral director will make an appointment later that day or early the next to discuss arrangements and costs with you.

16. Funeral arrangements

If you are uncertain what the person would like for their funeral, ask them. Matters to consider include:

- the type and style of funeral
- burial, cremation or entombment
- preferred cemetery or crematorium
- the type and style of the coffin or casket
- details of any death notices, mourning vehicles and flowers
- special features in the funeral service like poetry or music
- the preferences of families and friends
- the cost.

If there is a pre-paid funeral, bond or funeral benefit with a private health fund, it is important that you know where the relevant papers are kept. A pre-paid or pre-arranged funeral can provide peace of mind and remove the need to arrange a funeral at the last moment, or pay for one at a time when finances can be tight. A funeral director can guide you through the planning process and explain your options, they are normally happy to visit at home.

You can find a list of reputable firms listed under the Australian Funeral Directors Association listing in the Yellow Pages.

How much does a funeral cost?

A simple funeral typically costs approximately \$6,000 to 8,000, depending on what's chosen.

What if funeral arrangements have not been made?

You need to be clear who will be charged for the funeral. If there is not enough money in the person's estate the family could be responsible. If you arrange the funeral then you could be responsible for the fees.

The Western Australia Department of Child Protection administers the Bereavement Assistance Program and will pay for a funeral (the person need not be a child) in certain circumstances. Please talk to a social worker or palliative care nurse if you think the person may be eligible for this benefit, or visit the Department's website (www.dcp.wa.gov.au) or call them on 1800 854 925.

Centrelink publishes an excellent booklet called *Needing help after someone has died?* which is available at their website (www.centrelink.gov.au) or by calling 13 2300. The booklet outlines the Commonwealth Government assistance available, what to do after someone has died and lists some services and organisations which can help.

17. Bereavement care

It can be a time of great loss and sadness for you when the person for whom you have been caring dies. Grief is a natural response to the loss of someone special or something we value, it is not a sign of weakness or poor coping skills.

You may have reactions which can be unpredictable, and which may seem quite alien to you. These can include anger, anxiety, depression, relief and guilt. They can be frightening, especially if you think you shouldn't feel some of these things. Not everybody will experience these feelings and reactions, and there is no set order or sequence of events for those that do. The length of time the grieving process takes will vary from person to person.

You need to be able to express in some way what you are experiencing, and you will need support while you grieve. A trusted friend or minister may fill that role, or you may need the help of a professional bereavement counsellor. You may need to go over the events leading up to and around the death with those that were there. You can contact your doctor, community nurse or palliative care nurse, chaplain or counsellor and talk with them, if you think it would be helpful

Look after yourself physically, make sure that you eat adequately and get enough exercise and rest. You may only be able to cope with the basics at first. Try not to do too much at all in the first few months. Delay any big decisions.

Your local palliative care service offers bereavement care in a variety of ways, such as individual counselling, (face to face and by telephone), and group support. Ask your community or palliative care nurse for information about bereavement services and local community support groups. Some of the larger funeral directors offer bereavement groups and limited counselling services. Books and articles on the grief process can also help you through the pain of your loss.

If there were difficulties surrounding the relationship with the person who died, or after a year or two you are finding it difficult to move on in life, you may want to visit a psychologist, social worker or counsellor. Your General Practitioner can make a referral.

Palliative Care Australia publishes a useful pamphlet, *Now what? Understanding grief*, which is available at www.palliativecare.org.au, or from Palliative Care WA Inc on 1300 551 704.

The following services, organisations and information resources might be helpful:

Grieflink

Free online information resource at www.grieflink.org.au

The Australian Funeral Directors Association

www.afda.org.au

The leaflet *It's all right to cry* may be useful and may be available from your funeral director. The Association's website includes a brief section on grief.

Department of Child Protection

Bereavement Assistance Program

Phone: 1800 854 925

www.dcp.wa.gov.au

The Department of Veterans' Affairs

Counselling Service

Phone: 1800 011 046

www.dva.gov.au

Centrelink

Phone:

13 23 00 - if you are an age pensioner

13 72 17 - if you are receiving a disability allowance

13 28 50 - if you are receiving unemployment payment

13 61 50 - if you are receiving a family payment.

www.centrelink.gov.au

There is a lot of information at the Centrelink website, www.centrelink.gov.au. Centrelink employs social workers who can help you and can also give you financial and other advice, if you are in receipt of a Centrelink payment. This is a free service. Centrelink also provide a Bereavement Allowance payment for eligible recipients.

18. Equipment options

Information Resource

Independent Living Centre of WA

Niche Building, Suite A
11 Aberdare Road
Nedlands WA 6009
Phone: 1300 885 886
Email: general@ilc.com.au
www.ilc.com.au

The Independent Living Centre of Western Australia (ILC) is a not for profit organisation staffed by teams of qualified and experienced health professionals who provide customers with disabilities, mobility and accessibility problems with personalised assistance to find the best solution for their needs that will maximise their quality of life.

Solutions include information, advice, support and training about suitable assistive technology and equipment, funding options, assessment and referral pathways, linking to community services and respite options. Our services are accessed by people with disability, older people, their carers, service providers, health professionals, educators and suppliers, and Home and Community Care services providers via the Commonwealth Respite and Carelink Centre.

Sales and Hire

Red Cross Equipment Hire

17-19 Belgravia Street
Belmont WA 6104
Phone: (08) 9334 6222
Email: wamehs@redcross.org.au
www.redcross.org.au

Look under 'Home Health Care Aids and Equipment' in your local Yellow Pages to see a list of organisations which hire and sell equipment.

Most large pharmacies hire and sell medical equipment as well. Contact your local pharmacy.

Some palliative care services have equipment that can be provided on a loan basis.

19. Information resources and supportive services

Palliative Care WA Inc

15 Bedbrook Place
Shenton Park WA 6008
Phone/Fax: 1300 551 704
Email: pcwainc@palliativecarewa.asn.au
www.palliativecarewa.asn.au

Palliative Care WA Inc can provide general advice about the palliative care service system. Brochures and booklets available to download from the Palliative Care Australia website (www.palliativecare.org.au), or contact Palliative Care WA Inc, include:

- *What is palliative care?* – This booklet answers your questions about palliative and end of life care.
- *What can I say? What can I do? When someone I know is living with a terminal condition* - suggests some strategies for helping someone you know who is living with a terminal condition.
- *Now what? Understanding grief* – explains grief and the grieving process.
- *Asking Questions Can Help: An aid for people seeing the palliative care team* – a booklet designed for people seeing the palliative care team to help you get the information you need about your condition.

Palliative Care WA Inc also sells *A Caregiver's Guide – A Handbook About End-Of-Life Care*³, which includes detailed advice and information for carers in the community. Please call for details.

³ *A Caregiver's Guide – A Handbook About End-of-Life Care*, Palliative Care Council of South Australia, August 2007 – 174 pages

Cancer Council WA

46 Ventnor Avenue
West Perth WA 6005
Phone: (08) 9212 4333
Fax: (08) 9212 4334
Email: enquiries@cancerwa.asn.au
www.cancerwa.asn.au

Phone the Cancer Council Helpline on 13 11 20 for all enquiries.

The Cancer Council, the peak cancer organisation in Western Australia, provides a comprehensive range of services across the community including:

- The Cancer Council Helpline - cancer information and support for persons, carers, family and health professionals. Open weekdays 8am to 8pm.
- Cancer Counselling Services – face to face and telephone counselling services for individuals, couples, or families affected by cancer. Free services are available in both metropolitan and regional areas.
- Accommodation for country cancer patients and their carers in Perth.
- The Cancer Council Professional Development Centre - provides palliative care education to meet the needs of workforce development for health professionals, carers and volunteers in metropolitan and regional areas of Western Australia.
- Group programs – The Cancer Council WA offers free relaxation/meditation, yoga and exercise programs for people living with cancer, their carers and family in many locations around Perth and some regional areas. Contact the Cancer Council Helpline for further information about groups running in your area on 13 11 20.
- Support Groups:
 - Consumer forums
 - Wig Service - provides new wigs, turbans and scarves at no cost, and for as long as required.
 - Cancer Support Service - statewide network of Cancer Support Coordinators that organise practical and emotional support for people with cancer and their families.
- An extensive range of booklets, pamphlets and CDs offering information for patients, family and friends are available to download from the Cancer Council WA website on www.cancerwa.asn.au. You can also order from the Cancer Council Helpline on 13 11 20.

Carers WA

182 Lord Street
Perth WA 6000
Phone: 1300 CARERS (1300 227 377)
Email: info@carerswa.asn.au
www.carerswa.asn.au

Carers WA is the recognised peak body for carers and can offer support in a variety of ways including counselling services, information on services available from other agencies including government, social support services, education and information sessions and activities for young carers. Membership of Carers WA is free as are all the services provided.

The Carers WA Carers Counselling Line provides you with "a safe place" to express your emotions, needs and wants. Carers WA's free professional and confidential counselling service can help you to discover effective ways of coping with everyday challenges of caring. The service is used by carers throughout the state, secure in the knowledge that there is someone they can contact for support who understands their needs and is able to guide them to appropriate services. The Carers Counselling Line number is 1800 007 332.

Commonwealth Respite and Carelink Centres

Commonwealth Respite and Carelink Centres are located around Australia to help people find care and support to continue living independently in their own homes. Centres can provide information about community, aged care, disability and other support services. The Centres can also help to arrange respite care when carers need a break, including in-home, emergency and other flexible respite options.

To contact your local Commonwealth Respite and Carelink Centre, phone 1800 052 222 during business hours or, for emergency respite support outside standard business hours, phone 1800 059 059. There is a list of Centres on the internet at www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-cresploc.htm.

Aboriginal Health Council of WA

Phone: (08) 9227 1631

www.ahcwa.org.au

The mission of the Aboriginal Health Council of WA is to support the Indigenous peoples of Western Australia to reach the same levels of life-expectancy and access to health services as the rest of the Australian population through Aboriginal Community Controlled Health Services, AHCWA's members. The Council's website includes a directory 18 Aboriginal health services.

Aboriginal Hospital Liaison Service

Phone: (08) 9347 6541

Fax: (08) 9347 6558

Hours: Monday – Friday 8.30am – 4.30pm (closed on public holidays)

A/H: Answering machine

www.wacountry.health.wa.gov.au

The Aboriginal Hospital Liaison Service provides support and coordination services to mainly Aboriginal people from rural and remote areas who require specialist medical treatment in Perth.

Aged Care Australia

Phone: 1800 500 853

Email: agedcare.website@health.gov.au

www.agedcareaustralia.gov.au

The Aged Care Australia group can offer information about the aged care system, including accessing help to stay at home, how to be assessed for place in a residential aged care facility, costs and finances and health care.

Australian Indigenous HealthInfoNet

Kurongkurl Katitjin

Phone: (08) 9370 6109

Fax: (08) 9370 6022

Email: healthinfonet@ecu.edu.au

www.healthinfonet.ecu.edu.au

Contributes to improving the health of Australia's Indigenous people by making relevant, high quality information easily accessible.

Alzheimer's Australia WA Ltd

Phone: (08) 9388 2800

www.alzheimers.asn.au

Alzheimer's Australia WA was formed by a group of carers more than 20 years ago, as the nation's first support group for people with dementia and their carers. They provide support, counselling, information, education and respite services to people throughout Western Australia who struggle with the daily challenges of dementia. In light of the growing dementia epidemic, they create widespread awareness and acceptance of dementia throughout rural and metropolitan Western Australia. This includes spreading the message to the community across various cultures and languages.

The National Dementia Helpline number is 1800 100 500.

Australian Huntington's Disease Association WA Inc

Centre for Neurological Support
B/11 Aberdare Road
Nedlands WA 6009
Phone: (08) 9346 7599
www.ahda.asn.au

Australian Huntington's Disease Association WA Inc aims to enable the best possible quality of life for people with Huntington's disease, their families and carers, through advocacy, support and education. Founded in 1974, AHDWA is a non profit organisation formed to provide support to the Huntington's community. The Association believes people with HD have meaningful and productive lives. Services focus on the quality of life and dignity of the individuals and their families.

Caresearch Knowledge Network

Palliative care knowledge network
www.caresearch.com.au

CareSearch Palliative Care Knowledge Network is an online resource consolidating evidence-based and quality information for various groups within the palliative care community. The website has been funded by the Australian Government as part of the National Palliative Care Program.

Crisis Care Helpline

Phone: (08) 9223 1111
Outside Perth Metro phone: 1800 199 008
TTY (08) 9325 1232
Can also be accessed through the Telephone Interpreter Service.

Offers 24 hour, 7 days a week telephone crisis care for counselling, information or other support.

Department for Communities

Phone: (08) 6217 8700
www.communities.wa.gov.au

Information WA State Office

Level 12 AMP Building
140 St Georges Terrace
Perth WA 6000
Phone: 13 32 54

Lifeline WA

Phone: 13 11 14
www.lifelinewa.org.au

Lifeline WA operates a 24-hour statewide telephone counselling and support service.

Meals on Wheels

Commonwealth Respite & Carelink Centre can advise you of your local provider, phone 1800 052 222. Clients using the service must be assessed as being eligible to receive a subsidised meal, that is, they must be frail aged or a young person with a disability. There are meals on wheels services in nearly every part of Western Australia. Most services are able to provide meals for most clients who have special needs, such as diabetics, and some offer a more specialised service such as Kosher or multicultural meals.

Multiple Sclerosis Society of WA

Phone: (08) 9365 4888
Fax: (08) 9451 4453
www.mswa.org.au

The MS Society of WA is an independent, state-based organisation supporting people with multiple sclerosis (MS), their families and carers through the supply of professional health care services and in-home supports. In addition, the Society plays a vital role in educating the community about the disease, liaising with government and other bodies on MS-related issues and advocating for the rights of all people with MS. Some programs also support people with similar neurological conditions.

Motor Neurone Disease Association of WA

Centre for Neurological Support
B/11 Aberdare Road
Nedlands WA 6009
Phone: (08) 9346 7355
www.mndawa.asn.au

The Motor Neurone Disease Association of WA encourages and enhances participation in normal life activities for people living with MND, recognising the need for quality of life and personal dignity. Motor Neurone Disease is a disease causing certain motor nerve cells to initially not work well and then to not work at all. This process can have a profound effect on an individual with a diagnosis of MND and their family and loved ones. The Motor Neurone Disease Association of Western Australia (MNDAWA) provides support, information, and a variety of links to services that can help reduce the impact of a diagnosis of MND.

Neurodegenerative Conditions Coordinated Care Program

Multiple Sclerosis Society of WA
Phone: (08) 9365 4888
Country callers: 1800 287 367
Email: enquiries@mswa.org.au
www.mswa.org.au

The program, funded by the WA Disability Services Commission, seeks to provide timely information and support for people with rapidly degenerating neurological conditions whose support needs will increase over time. Services include access to a loan pool of equipment and the program nurse. Referrals for this program may be received from support groups, service providers, the Disability Services Commission, neurologists, General Practitioners and self referral. People referred for NCCCP services must be eligible for Disability Services Commission funded services, and meet the specific program parameters in place see:

www.disability.wa.gov.au/forindividuals/servicesfunding/eligibilityoverview.html.

Please contact the NCCCP Program Coordinator on **9365 4889** to discuss the program in greater detail.

Office of the Public Advocate

Phone: (08) 9278 7300
Country: 1800 807 437
www.publicadvocate.wa.gov.au

The Office of the Public Advocate works to promote and protect the rights of more than 65,000 Western Australian adults with decision-making disabilities. The Office provides information to help families, friends, carers, health professionals, legal practitioners, primary care givers and accommodation service providers to meet the needs of adults with decision-making disabilities.

Contact the Office of the Public Advocate for detailed Information about Enduring Powers of Attorney and Enduring Powers of Guardianship. You can download forms from their website.

Public Trustee

565 Hay Street
PERTH WA 6000
New enquires: 1800 642 777
www.publictrustee.wa.gov.au

The Public Trustee offers independent, professional trustee and asset management services to the WA community. These include Will and Enduring Power of Attorney drafting, deceased estate administration, executor support, financial administration and trust management services. The Public Trustee is a statutory body that operates under the authority of the Parliament of Western Australia. The Public Trustee's commissions, fees and charges are regulated by the Parliament of Western Australia.

20. Metropolitan Palliative Care Services

The following is an alphabetical guide to palliative care services provided in the Perth metropolitan area. See Chapter 3 of this booklet for information on the sort of care available.

Armadale Kelmscott District Memorial Hospital

Palliative Care Service
3056 Albany Highway
Armadale WA 6112
Phone: 08 9391 2000

Bethesda Hospital

Palliative Care Unit
25 Queenslea Drive
Claremont WA 6010
Phone: (08) 9340 6300
Fax: (08) 9340 6491

A specialised interdisciplinary service providing inpatient palliative care. Admission is for symptom control, respite and care during the last stages of life. The unit has 14 publicly funded beds and the capacity to take privately insured persons over this number.

Fremantle Hospital

Palliative Care Service
Fremantle
Phone: (08) 9431 3333, pager: 4119
Fax: (08) 9431 2580

The Fremantle Hospital Palliative Care Service operates primarily as an inpatient consultative service.

Glengarry Private Hospital

Sandalwood Palliative Care Unit
53 Arnisdale Road
Duncraig WA 6023
Phone: (08) 9246 6395
Fax: (08) 9246 6398

The Sandalwood Palliative Care Unit has 10 private beds and offers symptom control, respite and care during the last stages of life.

Hollywood Private Hospital

Palliative Care Service
Nedlands
Phone: (08) 9346 6843 or (08) 9346 6842
Fax: (08) 9346 6404

This service provides inpatient care and a consultative service within Hollywood Private Hospital for veterans and private patients.

Kalamunda Hospital

Palliative Care Unit
Elizabeth Street
Kalamunda WA 6076
Phone: (08) 9293 2122
Fax: (08) 9293 2488

This unit consists of a multidisciplinary team. Admission is for symptom control, short term respite or care during the last stages of life.

Palliative Ambulatory Service North (PASN)

Phone (08) 9340 6390

Availability: 0800 to 1700 Monday to Friday

PASN is designed to meet identified gaps in access to specialist palliative care. The aim of the consultancy is to provide access to a visiting specialist palliative care team to secondary hospitals, correctional facilities, mental health and residential care facilities in the North Metropolitan Health Area.

Royal Perth Hospital

Palliative Care Service

Perth

Phone: (08) 9224 2788

Fax: (08) 9224 7012

Royal Perth Hospital Palliative Care Service is a multi-professional service that provides specialist palliative care through advisory, educational and direct care to patients and families within the acute hospital setting. The Nurse Practitioner can provide additional services to the South Metropolitan Area Health Region. Royal Perth Hospital also offers an outpatient Symptom Assessment Clinic twice per week.

Silver Chain Hospice Care Service

Phone: (08) 9242 0242

Fax: (08) 9444 7265

www.silverchain.org.au

The Silver Chain Hospice Care Service provides in-home palliative care supporting people with a life limiting illness, their families and carers in the Perth Metropolitan area. The Service works in close collaboration with the person's General Practitioner and all inpatient palliative care services in Perth.

Silver Chain also publishes an excellent booklet about loss and grief, discussing common issues and problems and listing a wide range of supports and resources, which you can download from www.silverchain.org.au/Brochures/.

<p>Palliative Care Nurse Consultancy Service Silver Chain Phone: (08) 9242 0101</p> <p>The nurse consultancy service offers a specialist palliative care advisory service to eligible metropolitan residential care facilities which provide 24 hour registered nursing care. The purpose is to assist the facility to increase their capacity to care for residents/persons who have a progressive, life limiting illness.</p>	<p>Rural Telephone Nurse Advisory Service Silver Chain Phone: 1800 420 102</p> <p>This service gives rural health professionals 24 hour access to prompt, convenient and free palliative care expertise from Silver Chain Hospice Care Nurse Consultants to support the needs of an individual.</p>
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Sir Charles Gairdner Hospital

Palliative Care Service

Nedlands

Phone: (08) 9346 2551

Fax: (08) 9346 1848

South Metropolitan Area Palliative Consultancy (SMAPC)

Phone: (08) 9366 1462

Email: smapc@health.wa.gov.au

Availability: 0800 to 1700 Monday to Friday

SMAPC is designed to meet identified gaps in access to specialist palliative care. The specialist consulting team visits secondary hospitals, correctional facilities, mental health and residential care facilities in the South Metropolitan Health Area.

St John of God Murdoch Community Hospice

100 Murdoch Drive
Murdoch WA 6150
Phone: (08) 9366 1366
Fax: (08) 9366 1367

This is a 20 bed specialist inpatient facility. Admission can be for symptom control, respite or end of life care. Admissions are open to both public and private patients and priorities are made on the basis of clinical need. Murdoch operates a day centre known as Footprints, which has a resource and information function, offers workshops and complementary therapies and other supportive services. The service also provides consultation to the patients of St John of God Murdoch Hospital and runs a medical outpatient clinic.

St John of God Hospital Subiaco

Palliative Care Service
Phone: (08) 9382 6111
Fax: (08) 6465 9382

The Palliative Care Service at St John of God Hospital Subiaco has a five bed palliative care unit and provides advice and support for patients in all areas of the hospital. The multi-disciplinary team runs outpatient clinics and a bereavement support program.

WA Paediatric Palliative Care Service (statewide service)

Child and Adolescent Health Service
Princess Margaret Hospital for Children
Roberts Road
Subiaco WA 6008
Phone: (08) 9340 8222

21. Country Palliative Care Services

Each region of Western Australia has a mix of services available. If palliative care services are not listed for your area, talk to your general practitioner, phone your local WA Country Health Service office (details of each office shown at the end of this section), or visit www.wacountry.health.wa.gov.au for more information. This is an alphabetical listing – check the name of your health region if you can't see your town or locality listed.

Albany Palliative Care Team

Albany Regional Hospital
Albany WA 6330
Phone: (08) 0429 379 145
Administrative Officer (Tue-Thu): (08) 9892 2380
Fax: (08) 9892 2580

Albany offers both a community and inpatient palliative care service in partnership with the patient's own GP or medical providers, with access to 24 hour support from Silver Chain. The Albany Hospice is a 4 bed unit located on the hospital grounds, offering symptom control, respite and terminal care, and is available for both public and private patients.

Avon Hospice Inc

Phone: (08) 9690 1338
Fax: (08) 9690 1319

Bunbury Palliative Care Service

St John of God Hospital
Cnr Bussell Highway and Robertson Drive
Bunbury WA 6230
Phone: (08) 9722 1790 (inpatient service)
Phone: (08) 9721 3374 (community service)
Fax: (08) 9792 5030

St John of God Hospital Bunbury has a purpose-built 10 bed inpatient palliative care unit. The multidisciplinary team also provides a 24-hour community palliative care service, day hospice program, outpatient clinics and bereavement follow-up. Referral from a doctor is required.

Busselton Hospice Unit

Craig Street
Busselton WA 6280
Phone: (08) 9751 1642
Fax: (08) 9751 1653

Busselton Palliative Care Service

Phone: (08) 9754 2880
Fax: (08) 9752 3758

Carnarvon Respite Palliative Care Unit

Phone: (08) 9941 0555 pager 403
Fax: (08) 9941 0556

Goldfields Regional Palliative Care Service

Phone: (08) 9080 5290

Kalgoorlie Hospital Palliative Care Unit

Medical Ward (B)
Locked Bag 7
Kalgoorlie WA 6433
Phone: (08) 9080 5340

Great Southern Regional Palliative Care Service

Phone: (08) 9892 2222 pager 122
Mobile: 0429 379 145

Kimberley Regional Palliative Care Service

Phone: (08) 9194 2325
Fax: (08) 9192 2282
Mobile: 0434 181 044

Midwest Regional Palliative Care Service

Phone: (08) 9956 2431
Fax: (08) 9956 2244
Mobile: 0407 949 040

Narrogin Cancer Support and Palliative Care Services

Phone: (08) 9881 0461
Fax: (08) 9881 0351

Peel Community Palliative Care Service

Phone: (08) 9531 7222
Fax: (08) 9531 7221

Pilbara Regional Palliative Care Service

Phone: (08) 9143 2333
Fax: (08) 9143 3274

St John of God Hospital Geraldton

Hermitage Street
Geraldton WA 6530
Phone: (08) 9965 8888
Fax: (08) 9964 2015

St John of God Geraldton has a purpose built inpatient palliative care unit. The service also offers a bereavement support program.

South West Regional Palliative Care Service

Phone: (08) 9722 1488
Fax: (08) 9722 1079
Email: wachs-swpalliativecare@health.wa.gov.au

Wagin Palliative Care

Phone: (08) 9861 1033

Wheatbelt Regional Palliative Care Service

Phone: (08) 9690 1780

Fax: (08) 9690 1601

WA Country Health Service Regional Offices

www.wacountry.health.wa.gov.au

- Kimberley Region - Phone: (08) 9194 1615
- Goldfields Region - Phone: (08) 9080 5710
- Pilbara Region - Phone: (08) 9158 1795
- Southwest Region - Phone: (08) 9781 2350
- Midwest Region - Phone: (08) 9956 2209
- Great Southern Region - Phone: (08) 9892 2662
- Wheatbelt Region - Phone: (08) 9621 0700
- WA Country Health Service Head Office - Toll Free: 1800 629 028

22. Appendices

The Western Australian Carers Charter

The *Carers Recognition Act 2004* came into effect on 1 January 2005 and is an important step in supporting the crucial and often difficult and complex role of carers.

The *Act* is aimed at changing the culture of service providers so that the impact on carers is considered when services are assessed, planned, delivered and reviewed.

A key part of the *Act* requires service providers to comply with the Western Australian *Carers Charter*. The *Charter* provides clear direction on how carers are to be treated and how carers are to be involved in the delivery of services. The *Act* also establishes the Carers Advisory Council which monitors compliance with the legislation and provides advice to the Government on matters relating to carers.

The *Carers Charter* reads:

1. Carers must be treated with respect and dignity.
2. The role of carers must be recognised by including carers in the assessment, planning delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
4. Complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

You can learn more about the *Carers Charter* online at www.communities.wa.gov.au, or contact:

The Carers Secretariat
Office for Seniors Interests and Carers
Level 7, Dumas House
2 Havelock Street
WEST PERTH WA 6005
Phone: (08) 6217 8518
Fax: (08) 9481 3886
Email: carersac@communities.wa.gov.au

Palliative Care WA Inc is subject to and supports the *Carers Charter*.

Complaints

The Health Consumers' Council WA Inc can advise and assist if you have a complaint about a health service:

Health Consumers Council WA Inc
GPO Box C134
Perth WA 6839
Phone: (08) 9221 3422
Fax: (08) 9221 5435
Freecall: 1800 620 780
www.hconc.org.au

The WA Department of Health complaints process is explained at www.health.wa.gov.au/compliments_complaints/index.cfm, or contact the Health and Disability Services Complaints Office:

GPO Box B61
PERTH WA 6838
Phone: (08) 9323 0600
Fax: (08) 9221 3675
Country Freecall: 1800 813 583
www.hadscow.wa.gov.au

Standards for providing quality palliative care for all Australians

The *Standards* were published by Palliative Care Australia in 2005 and describe quality care at the end of life.

1. Care decisions and care planning are each based on a respect for the uniqueness of the patient, their carer/s and family. The needs and wishes of the patient, their carer/s and family are acknowledged and guide decision-making and care planning.
2. The holistic needs of the patient, the carer/s and family are acknowledged in the assessment and care planning process, and strategies are developed to address those needs, in line with their wishes.
3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs of the patient, the carer/s and family.
4. Care is coordinated to minimise the burden on the patient, their carer/s and family.
5. The primary carer is provided with information, support and guidance about their role according to their needs and wishes.
6. The needs of dying patients are considered, their comfort maximised and their dignity preserved.
7. The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.
8. Formal mechanisms are in place to ensure that the patient, their carer/s and family have access to bereavement care, information and support services.
9. Community capacity to respond to the needs of people who have a life limiting illness, their carers and family is built through effective collaboration and partnerships.
10. Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.
11. The service is committed to quality improvement and research in clinical and management practices.
12. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
13. Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

The *Standards* are available from Palliative Care WA Inc or at the Palliative Care Australia website (www.palliativecare.org.au).

About Palliative Care WA Inc

Palliative Care WA Inc is the representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life. The aims of Palliative Care WA Inc are to:

- a) be a representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life
- b) promote the principles and practices of palliative care with the intention of enhancing the broader community's capacity to provide care and support at the end of life
- c) advocate for appropriate services and benefits for Western Australians confronting issues and problems commonly associated with the end of life
- d) advocate for appropriate palliative care education and training for all who provide care and support to people at the end of life
- e) promote the aims of the Association through cooperation and collaboration with stakeholders in palliative and end of life care
- f) act as a coordinating body and information resource for organisations and service agencies which provide care at the end of life and which promote the principles and practices of palliative care
- g) establish and maintain committees which are active in areas including, but not limited to, clinical services, standards and quality, education and community capacity building.

The organisation was established in 1986 (originally as the Hospice Support Organisation of WA Inc) and is managed by an Executive Committee elected from the membership. Annual membership costs a few dollars a year. Please download a membership form from www.palliativecarewa.asn.au/about_wa.php or call 1300 551 704 if you would like to join.

Funds are drawn from membership fees, donations, merchandise and event ticket sales, a grant from the WA Government and contributions from our key partner organisations. Please contact us for a confidential discussion if you would like to leave Palliative Care WA Inc a bequest.

Donation Slip

<p>In accord with privacy laws, Palliative Care WA Inc will only use your personal information to process your donation. We will protect your personal information, it will not be shared with any other organisation or published without your express agreement.</p>	<p>Please send your completed donation slip to: Palliative Care WA Inc 15 Bedbrook Place Shenton Park WA 6008 Fax: 1300 551 704</p>
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 Please complete and return this form if you would like to support the work of Palliative Care WA Inc.

My Details	
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My contact phone number ⇒	
Please send me Palliative Care WA Inc membership information ⇒	YES – NO
Please accept my tax-deductible donation ⇒	\$

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Palliative Care WA Inc gratefully acknowledges the organisations which have supported publication of this booklet.



www.silverchain.org.au



www.purslowefunerals.com.au



www.cancerwa.asn.au



www.afda.org.au



www.carersaustralia.org.au



www.supportiveandpalliativecare.org.au



www.brightwatergroup.com

Rotary Club of Fremantle
www.fremantlerotary.org

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Palliative Care WA Inc
15 Bedbrook Place
SHENTON PARK WA 6008
Phone/Fax: 1300 551 704
Email: pcwainc@palliativecarewa.asn.au
Internet: www.palliativecarewa.asn.au
ABN: 13 107 780 017