

Palliative Care Information Service

# Palliative Caring at Home

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*We wish to acknowledge them for kindly allowing  
us to reproduce material from this publication.*

## *The Ultimate Gift of Love*

*A guide for carers who are caring for a terminally ill person  
at home.*



**Freecall: 1 800 772 273**  
**[www.pcis.org.au](http://www.pcis.org.au)**



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**DISCLAIMER**

The information contained in this booklet is for general guidance only. Whilst every effort has been made to ensure that the patient care recommendations in this book are correct and in keeping with accepted standards of practice at the time of publication, neither the authors nor the publisher can accept legal responsibility for any errors or omissions that may be made. It is the responsibility of the reader, before using any drug, technique or procedure to seek appropriate professional advice.

**Notes**

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## Fact Sheets

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Palliative Care Queensland have an extensive range of useful fact sheets for both carers and patients. These fact sheets can be obtained by calling them directly on **(07) 3391 2900** or by calling the Palliative Care Information Service on **1 800 772 273**.

Topics include:

- ◆ Refusing treatment: Clarifying your wishes about medical treatment
- ◆ Planning a funeral ahead of need
- ◆ Confusion and terminal restlessness
- ◆ Advanced Health Directives and appointing an Enduring Power of Attorney: Ensuring your wishes about medical treatment are followed
- ◆ Nutrition in Palliative Care
- ◆ Nausea and Vomiting
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- ◆ Helping Children when Someone has a Life-threatening Illness
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- ◆ Resources for Helping Children to Cope with Bereavement
- ◆ The Process of Dying
- ◆ Making a Will

## What do we do now?

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Facing the reality of a terminal illness is often a traumatic time for both you and the patient. Often, people ask questions such as:

- ◆ What will happen next?
- ◆ How long do we have?

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 in this case, the person may rapidly lose the ability to look after him or herself. Other people may be able to maintain a high degree of independence for some time, even though they are terminally ill.

We recognize that it can be very frustrating not knowing exactly how long the patient has to live. As it is so difficult to determine the time available to someone who is terminally ill, doctors may not be able to be specific.

## **What is Palliative Care?**

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Palliative Care aims to alleviate the problems that people may experience as their disease progresses; be they social, physical, emotional or spiritual. Palliative Care professionals are a team of specialist nurses, doctors, social workers, counsellors and volunteers. They work alongside GPs, visiting nurses and the other community organisations who often help manage the day-to-day treatment, to make sure that the patient gets the best care possible.

Palliative Care also provides emotional and spiritual support for the family and friends of the person who is dying. This support may be offered after the person has passed away, during what is termed the bereavement phase.

Palliative Care can be provided in the home, in an aged care facility, in an acute hospital or in a hospice. Caring at home is a big commitment on the part of the carer(s). If you are considering this role, it is a good idea to discuss this with your doctor, visiting nurse or palliative care professional. Don't feel guilty if you decide that you can't manage it. However, if you do decide to care for the person at home, there can be quite a lot of help available.

## **Palliative Care Queensland**

Palliative Care Queensland (PCQ) is the peak representative body for palliative care in Queensland. As well as supporting its own large membership base comprising mostly of health care providers, PCQ is the voice of palliative care in Queensland.

(07) 3391 2900

## **The Centre for Palliative Care Research and Education**

The Centre for Palliative Care Research and Education (CPCRE) is an organization that is responsible for supporting and promoting research and education within the palliative care industry. CPCRE is also responsible for ensuring that palliative care standards and best practice methods are accessible to all health care providers in Queensland.

(07) 3636 1449

### **Public Trustee**

The Public Trust Office is a self-funded State Government agency that provides Queenslanders with financial, trustee, legal, property and associated services. The office of the Public Trustee can give you more information about Powers of Attorney and Wills.

(07) 3213 9288 or [www.pt.qld.gov.au](http://www.pt.qld.gov.au)

### **Carers Queensland**

Carers Queensland is dedicated to supporting carers in Queensland through:

- ◆ the provision of tailored information and support, including referrals to appropriate services
- ◆ a counselling service specifically designed to meet the needs of carers. Carers Queensland provides both telephone and face-to-face counselling throughout the whole of Queensland
- ◆ community development, including linking carers into support groups

Carers Queensland is also committed to advancing the recognition of the role of carers. Carers provide unpaid support and assistance to a family member or friend who has a disability, physical or mental illness, or is frail aged.

For all of these services, carers can contact Carers Queensland's Commonwealth Carer Resource Centre between 9 am and 5 pm, Monday to Friday, on

1800 242 636.

### ***“If I really can't manage at home, can the patient spend the rest of their days in a hospice?”***

A hospice is not a long-term care facility so this would have to be assessed by the palliative care team. The main function of a hospice is as a centre 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.

It offers intensive nursing, medical and allied support. Not everyone needs this. If the person you are nursing is assessed as not requiring this level of care then you will be helped to find an alternative care facility; probably a nursing home or hostel. In Queensland, a person must be assessed by the Aged Care Assessment Team in order to qualify for nursing home or hostel placement.

### ***“But aren't nursing homes and hostels for old people?”***

There have been many changes to the care provided by nursing homes and hostels these days. In the main they cater for the frail elderly but they also provide palliative care for people of all ages. You may want to call nursing homes in your area to determine whether or not they provide a special palliative care service.

## **Caring at Home – Some Considerations**

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

### ***What things do I need to consider?***

Caring at home is a 24 hour a day, 7 days a week job. It is important that you are aware of your own limitations and exactly what help you can expect from others.

- ◆ What time do you have available? In the early days, the person you are caring for may be quite independent and may be able to be left alone for long periods. However, this could change rapidly.
- ◆ If you are employed, you may have to discuss with your employer the leave available to you. How much time you will need is hard to predict. In some instances, carer's leave may be available.
- ◆ 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, such as children, that cannot be put 'on hold'?

## **Queensland Cancer Fund**

The Queensland Cancer Fund (QCF) is the major advocacy organisation in Queensland for cancer. QCF performs many functions from advocacy to counselling, and offers a telephone based support service to those people facing cancer and related issues. In rare circumstances, the QCF may offer one-off financial support to individuals and organisations.

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## **The Office of the Adult Guardian**

For advice or further information about general Powers of Attorney for financial matters only, or Enduring Powers of Attorney for financial, personal and health matters, you can contact the Adult Guardian on:

1300 653 187

## **Aged Care Assessment Team**

These teams provide assessment, information, advice and assistance to older people who want to remain at home or who are thinking about moving to a hostel or nursing home. The client is assisted to clarify his or her needs and to identify the most appropriate care options. ACAT offices are located throughout Queensland including:

- ⇒ Brisbane (07) 3636 1203
- ⇒ Cairns (07) 4050 6446
- ⇒ Townsville (07) 4799 9050
- ⇒ Mackay (07) 4968 3823
- ⇒ Gold Coast (07) 5519 8412
- ⇒ Toowoomba (07) 4616 4925

## Information and Further Resources

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### **Palliative Care Information Service**

A free Queensland wide telephone information and referral service for people living with a life limiting illness and those who care for them. Information is provided about palliative care services in your area and how to access them.

1800 772 273

### **Commonwealth Respite & Carelink Centre**

The Commonwealth Respite & Carelink Centre (CRCC) provides responsive, timely and flexible respite which supports carers' needs in an emergency. The CRCC is a 24 hour, 7 days per week service that can also provide a range of planned, flexible, short term respite options based on individual need. A carer is a wife, husband, parent, son, daughter, friend or neighbour who gives a significant amount of time to care for someone who is frail with age or has dementia, has a disability or a chronic health condition or is in need of palliative care. The Commonwealth Respite & Carelink Centre is an Australian Government initiative.

1800 059 059

### **Commonwealth Carelink Centre**

Commonwealth Carelink Centres (CCC) are information centres for older people, people with disabilities and those who provide care and services. CCC provides free and confidential information on community aged care, disability and other support services available locally, intrastate or anywhere within Australia.

1800 052 222

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 important to discuss this with your health professional.

### ***What are the advantages?***

The advantages of caring for someone at home are:

#### **For the carer**

- ◆ being close to the patient
- ◆ not having to spend time making visits to hospital
- ◆ accepting the help of neighbours and friends
- ◆ ensuring the preferred wishes of the patient

#### **For the patient**

- ◆ being close to the carer
- ◆ being in familiar surroundings
- ◆ having familiar people around you
- ◆ 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 may have medical needs which cannot be met at home
- ◆ you live too far away from medical, nursing or support services
- ◆ your home may not be suitable for the type of care that is needed
- ◆ you do not feel you can manage

### **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 visiting nurse or palliative care worker will discuss with you what help is available and how to access it. For instance, an occupational therapist (OT) may be able to come into your home and make a detailed assessment of physical needs, recommending modifications in the home such as handrails, ramps etc., assessing what equipment may be necessary. You don't have to think of everything at once. You can reassess your needs at any time.

Some of the larger funeral directors offer bereavement groups and a limited counselling service. If there were difficulties surrounding the relationship with the person who died, you may want to visit a psychologist, social worker or counsellor. Local support groups, books and articles on the grief process can all help you through the pain of your loss. For information about bereavement services in your area, please telephone the Palliative Care Information Service during business hours on 1800 772 273.

## Bereavement Care

When the person that you have been caring for dies, although it may be an end to their suffering, it can also be a time of great loss and sadness for you. At this time you must remember to look after yourself physically, ensuring that you eat adequately and that you get enough rest. Initially you may only be able to cope with the basics, so try not to do too much at all in the first few months and if possible, delay any big decisions that need to be made.

You may react in a manner that is unpredictable, and this may seem quite alien to you. These reactive type feelings can include anger, anxiety, depression, relief and even guilt. They may be quite frightening, particularly if you think you shouldn't feel some of these things, however you need to be able to express what you are experiencing in some way. You will need support while you grieve, and a trusted friend or minister may be able to help, or you may even need the help of a professional bereavement counsellor. Remember, you are not mentally ill, you are grieving. Grief is normal.

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. You may find that it makes you feel better to go over the events leading up to and around the death with those that were there. If you think it may be helpful, you may even wish to contact a member of the palliative care team who cared for your loved one and talk with them.

### Who else 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, taking the children to school, 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 in the community who can give you time, for instance by sitting with the patient while you go out for a while.
- 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.
- If you belong to a church or community group they may have programs to help people who are sick. Ask what help they can provide.

The Commonwealth Respite & Carelink Centres can offer assistance to the carer, often by temporarily taking over the care of the patient whilst the carer has a break. Ask what help they can provide. (*See page 56 for contact details*)

## Outside Help

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

### **General Practitioner**

The patient's general practitioner (GP) is the best person to coordinate home medical 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 skilled advice from the palliative care team. In Queensland, palliative care cannot be provided at home unless there is a designated GP who can perform home visits when necessary. If your GP requires the support of a specialist palliative care physician, they can call the Palliative Care Information Service on 1800 772 273 during business hours.

### **Palliative Care Services**

Palliative Care Services provide specialist consultative care for those with a terminal illness, coordinating and supervising care wherever it is needed. Services provided include practical support, physical support and counselling.

The palliative care teams consist of doctors, nurses, social workers, counsellors, volunteers, administrative assistants and ancillary staff operating on a regional basis. The team can call on the expertise of other professionals such as physiotherapists, dietitians, occupational therapists and the clergy. In rural areas specially trained nurses coordinate palliative care.

## Funeral Arrangements

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If you are uncertain about what the patient would like, it is possible to raise this issue diplomatically with the patient before they die. Often this is done with the assistance of a counsellor from your palliative care team.

It is very important that you are made aware by the patient of such things as prepaid funeral arrangements, or whether there is a bond or funeral benefit payable with a private health fund. It is also important that you are made aware of the location of any documentation pertaining to these matters well in advance.

### *How much does a funeral cost?*

A simple funeral in Queensland typically costs between \$3500 to \$5500.

### *What if funeral arrangements have not been made?*

It is important to be clear about who will be charged for the funeral. If there is not enough money in the person's estate, the next of kin could be responsible. If you are the person arranging the funeral, then it is possible that you could be responsible for paying the fees.

In rare circumstances where there is no money available to pay for the funeral in Queensland, the Burial Assistance Fund may be of help.

one in advance to be ready at short notice if you wish.

The body can remain at home for several hours for relatives and friends to visit and say goodbye. If this is the case, leave the body in a natural position; there is no need to lay the body out in any formal way (unless there are religious or cultural reasons that require it). If you want to sponge your loved one first, this can be done prior to positioning the body. The visiting nursing service will help you with these preparations if you ask them.

Remember that there will be another opportunity for people to say goodbye at the funeral directors.

Contact the funeral director when you want the body attended to. They can usually come within a short period of time, and although it is possible to have the body removed at night, there may be an extra charge for this. If a funeral director has not been arranged prior to death, you can choose one from the 'Yellow Pages'. You may wish for someone else, like a friend or relative, to do this for you. The funeral director will make an appointment later that day or early the next to discuss arrangements and costs with you.

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

### **Other Medical Specialists**

Cancer patients can still benefit from cancer treatment even though the disease cannot be cured, and an oncologist (cancer specialist) may continue to see them or may even refer them to another specialist if the need arises. All specialists involved have an obligation to communicate with the GP, who is the coordinator of care, and who will need to know all the opinions and treatments that are being provided by the other doctors involved.

### **Visiting Nurses/Domiciliary Nursing Services (Blue Care, St Lukes, Ozcare)**

These nurses provide hands on nursing care and education in the home, each region having nurses with special skills in palliative care nursing. The visiting nurse will assess the situation and consult with you and the patient about the support needed, and what care they can provide. Nurses generally visit once a week at first, and then several times a week as the patient's needs increase. In the terminal phase of palliative care, the service may visit daily. Some services provide a 24 hour on-call service. It is common for some palliative care organizations to perform the role of the visiting nurses as well as providing a specialist palliative care consultancy.

**Private Nurses**

There are nursing agencies from which you can purchase private nursing or personal care to assist you in the home. Some of these agencies have nurses with experience in providing palliative care. Some health insurance funds provide a benefit for home nursing. Each fund is different however, so be sure to consult your health fund directly for details of your specific cover. For the contact details of the private nursing agencies in your area, please call the Palliative Care Information Service during business hours on 1800 772 273.

**Other Domiciliary Services**

Several types of domiciliary services can be contacted in order to access more practical home help or equipment. Anything from over-toilet chairs to hospital beds or lifting machinery can be hired for a small cost. Handymen can be accessed through community health centres to carry out modifications in the home, for example installing handrails in the bathroom or ramps over steps prior to the patient being referred to palliative care. There are also workers who can provide personal care such as help with showering and dressing, house cleaning or domestic duties. Ask your palliative care worker or visiting nurse for details.

**Allied Health Care Workers**

There are a range of allied health professionals who are available to assist you in your caring role. These include physiotherapists, podiatrists, occupational therapists, speech pathologists, psychologists, dietitians and of

**◆ *Change in colour***

As the blood circulation slows, the arms and legs become cool to the touch and may look mottled and dark. The patient'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 nurse them. There is no need to put on a lot of extra bedding or an electric blanket to warm the patient. This could just make them restless. A sheet and a couple of warm blankets or a doona should be sufficient.

**◆ *How will you know when your loved one has died?***

Although it is not hard to tell if a person has died, in an emotionally charged situation it may or may not be clear to those involved. The major signs that death has occurred are when breathing stops, and the muscles of the body relax.

**What to do when death occurs**

When you realize that your loved one has died, remember that there need be no rush. You do not have to do anything immediately, and most importantly there is no need to call the police or ambulance service. You may wish to call the doctor or visiting nurse to confirm that death has occurred. If the death occurs in the middle of the night, and you are comfortable with it, wait and call the patient's own doctor and your nursing service in the morning.

You may want a friend, minister or family to be with you at this time, so it may be a good idea to ask some-

loved ones to talk to the patient and encourage quiet conversation in the room to maintain awareness that people are in there, making sure that there are no distressing conversations within the person's hearing.

◆ ***Incontinence***

Incontinence (loss of control) of urine and bowel movements may occur when the person is very near death. Ensure that there are incontinence pads to maintain both comfort and hygiene.

◆ ***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.

As the patient's ability to swallow diminishes, saliva and secretions may collect at the back of the throat and make a noise as the patient breathes. This noise is commonly called the 'death rattle'. It is not distressing for the patient who is dying but may be distressing for you to hear. Sometimes elevating the head of the bed with pillows may be useful. The doctor may prescribe an injection to reduce the secretions, this can be highly effective if given early enough.

Sometimes as the patient is taking their last breaths they may seem to grimace. This is not an expression of discomfort, just a reaction of the muscles in the upper part of the body and face.

course, counsellors. These services generally operate from community health centres in Queensland, and a referral to these practitioners can be made by a health professional. These allied health workers will work in with the palliative care team to achieve the best outcome for all concerned.

**Hospice (In-Patient)**

Most palliative care services in Queensland are attached to inpatient facilities at either a general hospital ward or in a separate hospice building. These services are generally referred to as in-patient hospice services. In-patient hospice services provide specialist medical, nursing, psychological and social support for patients and their carers. Patients are usually only admitted to a hospice for symptom management, respite care, or at the end stage of their illness.

**Hospice in the Home (Outreach)**

In Queensland, hospice organizations provide home based palliative care that often is referred to as an outreach hospice service. These organizations do not have in-patient beds, but work from a central base going out to people's homes to perform palliative care and consultancy. The patient must be supported in the community by a GP who can perform home visits in order to qualify for this type of service. This type of community based care is the most common way that palliative care is delivered in Queensland.

**Public and Private Hospitals**

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

**Hostels and Nursing Homes**

Sometimes the patient's disease may progress slowly or may not be causing major discomfort, however, it is no longer possible to care for them at home. Hostels and nursing homes can provide some short-term respite or longer-term care for the patient. In order to access this type of residential care, an assessment needs to be completed by the Aged Care Assessment Team (ACAT).

**Community Packages**

There is also a facility that offers extended care at home with extra supports, using a 'community package'. In order to receive these packages, the patient needs to be specially assessed by ACAT. Generally, such packages are not used for palliative care patients as the patient's needs change too rapidly. There can also be a significant wait for some of these services, making them inappropriate for people in the terminal phase of their illness.

that comfort is the most important consideration at this stage.

**◆ *Not eating or drinking***

Interest in food and drink decreases to the point that nothing is taken at all. The patient will eventually lose the ability to swallow, as he or she may gag on drinks at this stage. Do not give fluids if this happens, as they will not be swallowed and will only gather 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 or Lanolin.

**◆ *Confusion, restlessness***

The patient 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 patient by talking calmly and identifying who you are. Avoid sudden noises or approaches, which can startle. Constant touching or stroking may be disturbing, but gently holding a hand is not. Have someone stay beside the patient as much as possible. In all cases of confusion or restlessness, talk to the nurse caring for your loved one, as there are medications that can be used in these cases to keep someone peaceful.

**◆ *Vision and hearing***

Vision may cloud; the patient 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

## The Approach of Death

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The approach of death in someone with an advanced illness is usually a gradual, peaceful process. 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 call the doctor or visiting nurse.

**Please note that if you call an ambulance they are duty bound to resuscitate anyone who appears to be dying. If you wish, the doctor can prepare a letter for you to give to the ambulance personnel instructing them not to engage in resuscitative measures if the patient dies during transportation.**

In some cases, administration of oxygen or analgesia by ambulance officers may be appropriate. Some nursing services have a specified form to indicate the most appropriate form of action to be taken by ambulance staff in such an event. Your nurse can provide you with this form.

### Signs and symptoms

Here are some comments on the changes that normally occur as death approaches, and what you can do:

#### ◆ *Drowsiness*

In the last days the patient may become drowsier and may spend a lot of time sleeping. You should move their position in bed from time to time, but remember

Ask your doctor, district nurse or palliative care worker for information about any of these services, or contact ACAT directly (*See page 31 for contact details*).

## Finances

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### *What costs may be involved in providing care at home?*

There will be costs attached to many of the services you can access. Don't be afraid to ask about the costs of services: it's better to know in advance than to receive a bill that you weren't expecting. In some cases you may be able to negotiate a reduction in fees if you feel your circumstances warrant it. If you are having financial difficulties, ask to see a social worker for advice. The following is a list of costs that may be involved in providing care at home.

#### ◆ *General Practitioners*

Most GPs will visit patients at home especially if they are unable to attend their surgery. Many will bulk bill for the visit, but some may charge a private fee for this service. All doctors have the right to determine their own billing regime. You need to check with the medical practice concerned, and ask what their usual policy is in this situation.

#### ◆ *The Palliative Care Service*

If you are being treated by a palliative care service or a home-based hospice, this service is generally free. Nursing, allied health, and medical consultancy are generally paid for using federal palliative care funding. In some cases, the service may ask you to make a donation for certain services such as counselling. For allied health services, palliative care funding may determine that only the initial or first few consultations are free.

This form can be obtained from the Office of the Public Advocate or your solicitor.

An Advanced Health Directive is a document which provides instructions about your choices for future health care and comes into effect only if you are unable to make your own decisions. If you wish to complete an Advanced Health Directive, your doctor may be the most appropriate person to help you. It is also important that you discuss the directive with your family and legal representative for personal/health matters. For more information about the Advanced Health Directive and Statutory Health Attorney contact the Office of the Adult Guardian (*See page 57 for contact details*).

## **Important questions to ask when putting affairs in order:**

### **◆ *Who can act on someone's behalf?***

The person chosen to act for another is usually called a Statutory Health Authority/Attorney. The person chosen cannot be a health professional involved directly or indirectly with their care. Usually the Statutory Health Authority/Attorney will be asked by the doctor to consent to treatment on behalf of the patient; the chosen person being close enough to the patient to understand what he/she may desire in such circumstances. This person is usually the spouse, parent, family member or friend of the patient, and may be called upon only if no Enduring Power of Attorney has been designated.

Statutory Health Authorities can say 'yes' or 'no' to treatment, but cannot refuse food or water for the person, nor can they refuse drugs that would ease pain or distress, or refuse treatment that would make the person well enough to make their own decisions. They cannot provide consent for withdrawing or withholding life sustaining treatment.

### **◆ *Can people write down their wishes rather than have a Medical Agent?***

In Queensland, it is possible to complete an Advanced Health Directive Form; a form that is designed to illustrate your desires regarding your own future medical treatment.

### **◆ *Visiting/Domiciliary Nursing Services***

In Queensland, visiting nursing services vary in cost. Although most of the expense is covered by the government, some services may charge a small fee for each visit. You need to check with the specific service to see how much the cost will be.

### **◆ *Private Home Nurses***

Fees vary across the different agencies and are based on daytime, night-time and weekend rates. Some private health insurance funds give rebates for home nursing; however, you need to contact your fund for details.

### **◆ *Equipment***

This is often loaned or hired to patients by the domiciliary nursing service or the palliative care service. If these services cannot supply the equipment required, you may be referred to a private company where the fees may be significantly higher. The cost of equipment may also be covered by some services as part of their funding arrangement with the government. In any case, please ask your visiting service exactly what the cost will be. The Queensland Cancer Fund may also loan equipment to palliative patients who have cancer.

### ***Dressings***

Dressings and the equipment used for injections are generally paid for by the patient, as they create a significant cost that visiting nursing services cannot absorb. Please speak with your visiting nurse if this creates a problem, as funding may be able to be obtained through the palliative care program.

◆ **Medications**

Some prescribed medications are not available from your local chemist. You may be able to obtain your medications from your hospital or through your palliative care service.

If the patient has a health care card, they will only pay a small fee for prescription medication provided that the drug concerned is listed on the Pharmaceutical Benefits Scheme (PBS). Your pharmacist can provide this information for you, or you can call the PBS hotline on:13 22 90

Items not listed on the PBS will be more expensive, however if the patient has private health insurance, the pharmacy component of that insurance may be used to claim a rebate for these items.

◆ **Respite**

The Commonwealth Respite & Carelink Centres may be able to assist with the cost of respite, as well as organising respite care. Speak to a Carer Support Officer to discuss your needs (*See page 56 for contact details*).

Enduring Power of Attorney (EPOA). This person is responsible for all decisions, including those relating to health care.

**The Adult Guardian**

An Adult Guardian can be appointed to make decisions for the patient when they are no longer able to do so, and when there is no Enduring Power of Attorney nominated. Such decisions are generally related to personal matters and can include:

- ◆ medical decisions
- ◆ where they live
- ◆ who they see

Details are available from the Office of the Adult Guardian.

**Consent to Medical Treatment and Palliative Care**

It is important that in any situation where medical treatment is required, that there is informed consent. The person undergoing the treatment proposed (or their guardian) must be given adequate information about both its advantages and disadvantages. It is also legal for any adult (or their guardian) to decline any medical treatment.

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## Putting Affairs in Order

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### **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 needs to make a will if they have money and property, otherwise the estate is shared out according to a formula in legislation. This may not be in accordance with what the person wanted. If a will has not been made it may prove difficult to raise the issue, especially if a patient has not come to terms with the progress of the illness. A social worker may feel more comfortable about talking to a patient in this situation and may help contact the Public Trustee or a solicitor for advice. The Public Trustee also has a visiting service for those unable to attend an appointment.

### **Power of Attorney/Enduring Power of Attorney**

The patient may want someone to manage his or her financial and/or medical affairs for them, now or in the future. You or someone else can be given 'Power of Attorney' to act on behalf of the patient. A solicitor, accountant or the Public Trustee can assist in completing the patient's instructions but there will be a charge involved. A Power of Attorney kit can be obtained from the post office, if you are interested in avoiding the cost of professional services.

In Queensland, there are two types of Powers of Attorney. The first type is known as the Power of Attorney (POA). This person is generally only responsible for financial concerns. The second type is referred to as an

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## What Financial Support is There?

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### ◆ **Centrelink**

As a carer there are two Centrelink payments that you may be able to access:

#### ◆ ***Carer Allowance***

Carer Allowance may be paid if you are living with, and looking after, a child or an adult with a disability or medical condition. From September 1, 2004, Carer Allowance can also be paid if you do not live with your adult carer but provide 20 hours per week personal care in their home. Eligibility for adults is based on a health professional's report of the level of care required. For children a doctor assesses their level of functioning compared with a child of the same age without a disability.

The Carer Allowance is not income and assets tested and may be paid in addition to another payment such as the Carer Payment or Age Pension. Australian residency requirements also apply.

#### ◆ ***Carer Payment***

The Carer Payment may be paid if you are providing constant care to a person in that person's own home. You are not required to live with the person you are caring for. To receive the Carer Payment for an adult, the person cared for must be receiving an income support payment from Centrelink, a Veterans' Affairs Service or Partner Service Pension, or meet special income and assets limits. Australian residency requirements also apply.

The Carer Payment may also be paid if you are providing full-time care to a profoundly disabled child or children. The Carer Payment is subject to an income and assets test. You can study or work for up to 20 hours per week and continue to receive the Carer Payment. Any income you earn may affect the amount of the Carer Payment paid.

You can continue to receive the Carer Allowance and/or Carer Payment for up to 63 days while the person you are caring for is in respite care as well as another 63 days if the person is temporarily in hospital. You can also receive the Carer Allowance and/or Carer Payment outside Australia for a temporary absence of up to 13 weeks.

For more information and to make a claim for the Carer Allowance or Carer Payment, you should call Centrelink on 13 27 17 or, visit your local Centrelink Customer Service Centre.

### **Other financial help**

Various disease specific support groups can offer limited financial support, often by way of one of payments to cover items such as utility bills or equipment. Ask your palliative care worker, visiting nurse or social worker if you wish to know more about these options.

Respite care is very hard to find, and must be planned well ahead of time in most instances.

### **When it's all too much**

It may be that the care demands are beyond your capacity to give and the patient needs more intensive care. Discuss this with the doctor or visiting nurse. It may be better that the person receives all the physical aspects of care from paid workers, leaving you with more time to offer them your love and personal and emotional support.

cases with the person you are caring for to see what they would prefer. You may have to indicate for how long, e.g., ten minutes. Don't be afraid to enforce this and remind them to leave if necessary.

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

### **Not Coping**

It is not a failure to feel that you have not met the expectations you gave yourself, or those placed on you. Most people in this situation have times when they feel like this. You may feel that you just want it all over and done with. It is important to talk; don't feel guilty about these thoughts. They reflect the strain you are experiencing, a strain which is inevitable and understandable. If you are having problems coping in your caring role, or if you feel you need someone to talk to, you may wish to contact Carers Queensland and speak with a counselor (*See page 58 for contact details*).

### **Respite Care**

Do you need a break? Respite care can usually be organised and, if you have a complete rest from the daily demands of care, you may feel a whole lot better. Your doctor, palliative care worker or social worker will help you find respite care when it is needed, or telephone the Commonwealth Respite & Carelink Centre (*See page 56 for contact details*).

### **Queensland Government Services**

Queensland Health have two schemes for which, as a carer, you may be eligible.

#### **◆ *Patient Travel Subsidy Scheme (PTSS)***

PTSS provides direct assistance to patients and in some cases their carers to enable them to access specialist medical services from which they are isolated. A subsidy is provided to approved patients and carers (escorts) to assist in the cost of travel and accommodation to the nearest specialist medical service that is more than 50 km from the patient's nearest hospital. For more information, please contact the Palliative Care Information Service on 1800 772 273.

#### **◆ *Medical Aids Subsidy Scheme (MASS)***

MASS provides eligible Queensland residents, with permanent and stabilised conditions or disabilities access to subsidisation for the provision of MASS endorsed aids and equipment. The range of MASS aids and equipment is selected primarily to assist people to live at home and avoid premature, or inappropriate residential care or hospitalisation. Aids and equipment are subsidised, either on a permanent loan basis, private ownership or through the purchase of consumables. For more information, please contact the Palliative Care Information Service on 1800 772 273.

## Practical Home Nursing

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### Preparing the Home

When caring for someone at home it will be helpful to consider some practical alterations that may make the job easier.

First, where is the person going to sleep or spend most of their time? If they have limited mobility, where would be the best place for the bed? The bedroom may not be the most efficient or suitable place to nurse someone. Changing the home can be disruptive. However, if everyone is going to feel comfortable and have their needs met, it is well worth it. The patient 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 patient wants to be 'in among things' or would prefer peace and quiet. You, and anyone else in the home, may also need space away from the demands of the bedside to relax and have private time. There should be significant discussion between everyone concerned in order to prepare the home environment.

If the person is mobile, it is often helpful to 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, TV control) so that they do not have to keep calling someone. You need to be prepared for changing needs as the patient's condition changes.

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.

### Physical Wellbeing

It is important to look after yourself physically. Make sure you are having:

- ◆ adequate sleep
- ◆ nutritious food regularly

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

### Time Out

It is also important to have some time to do things that you enjoy. If you need time to do this but you feel that you cannot leave the patient, ask a friend or relative to stay while you are absent. The Palliative Care Service have trained volunteers that you may be able to call upon if there is no-one else. Alternatively, speak to your local Commonwealth Respite and Carelink Centre about having a break or some 'time out' to do something for yourself (*See page 56 for contact details*).

### 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. Sometimes you may want to suggest to visitors that they stay for a short time only. It may be helpful to discuss these

## **Caring for Yourself**

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### **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. You do not have to feel guilty about accepting help from family and friends with shopping, cooking, housework or staying with the patient so you can do tasks outside the home or just have some time to yourself.

### **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 patient. The patient may display emotions that are difficult for you to accept, since sometimes their negative feelings are unloaded on those who are closest.

### **Fears**

You may feel unable to leave the patient 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, such as a member of your palliative care team.

### **Easing Up**

Sometimes carers may demand too much of themselves.

Below are some guidelines to help you prepare the home environment.

### **The Bed Area**

- ◆ 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 also need some bedside equipment in the future.
- ◆ Have the things that the person needs such as a clock, drinks, radio, torch, 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 patient may appreciate a radio, music centre or television. These help to maintain contact with the outside world and entertain the patient.
- ◆ A small chair near the bed is useful for visitors and for the patient to sit on while you make the bed.
- ◆ Room for a bedside commode might be necessary if the patient cannot get to the bathroom.
- ◆ A small table that can be positioned over the bed is useful for meals or other activities. These can be borrowed from your palliative care/visiting nursing service or hired from other equipment agencies.

These agencies also have specialised equipment that helps the patient 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 visiting 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 patient 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 can be used to overcome steps and strategically placed handrails may help the patient move around.

### **Bathroom**

A bathroom can feel very small once you try to fit in the patient, a shower chair, yourself and possibly the nurse as well. If modifications have to be made, your palliative care service will be able to refer you to someone who can help.

- ◆ If there is a drain hole in the floor of the bathroom, shower the patient 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.

Your visiting nurse may be able to provide a referral to these services.

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

- ◆ Is the therapy working for me?
- ◆ Do the therapies use up 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? To whom?
- ◆ What does my doctor know about the therapy and does he/ she support its use?

## **Complementary/Alternative Therapies**

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It is common and normal for individuals and families facing advanced illness to be willing to try all sorts of recommended remedies other than those offered by conventional medical practitioners.

It may be felt that conventional western medicine does not support all of the needs of a patient. On the whole, the palliative care team will be sympathetic to the patient'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.

'Natural therapies' (a common term used for non-medical treatments and therapies) fall into two main categories:

- ◆ alternative: replacing conventional therapies
- ◆ complementary: supplementing and adding to conventional treatment and care

Many health care workers and volunteers have incorporated several complementary practices into their care, including:

- ◆ massage
- ◆ some aspects of aromatherapy
- ◆ visualization
- ◆ relaxation
- ◆ therapeutic touch
- ◆ music therapy

- ◆ 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.

As you can see, there is a lot that can be done to make the job of caring much easier, and help is available with 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 terminal illness they will try to give you priority. Talk to the doctor, visiting nurse or palliative care worker if you are having problems.

### **Equipment**

The following is a list of equipment which may assist you in caring for the patient. Your visiting nurse or palliative care service can advise which equipment will assist in your particular circumstances.

- ◆ walking frames
- ◆ wheelchairs
- ◆ ramps, handrails
- ◆ shower chairs, commodes
- ◆ toilet raises, toilet surrounds - these assist in getting on and off the toilet
- ◆ Spenco or air mattresses

- ◆ goose necks, bed poles - these help the patient to move around, and get in and out of bed
- ◆ bed rails - these prevent the patient rolling out of bed
- ◆ bed tables
- ◆ waterproof mattress protectors
- ◆ bedpans and urinary bottles
- ◆ hospital beds, lifting machines if there are particular difficulties nursing the patient

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. Sometimes they are better tolerated chilled. The patient 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 the patient's food to be homemade, let your family and friends prepare meals for you instead. They could prepare food to put in the freezer or work out a roster to bring food on various days to relieve the burden for you. Other people will generally understand the stress you may be under, and if they want to help, let them.

If you are having great difficulty and have no one to help you, then you can ask the doctor, visiting nurse or palliative care worker to refer you to 'Meals on Wheels'. They can supply reasonably priced meals for both of you 5 days a week Monday to Friday, delivered at lunch time. There are also private companies that can supply gourmet meals or culturally specific meals.

The following is a list of reasons why people may lose their appetite:

◆ ***Odours***

Sometimes the smell of food preparation, such as frying, can be off-putting to the patient. 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 if you can, even if that was the person's pattern in the past. Large amounts of food are 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 'Crock-Pot'.

Ready packaged or canned food might be an option (soups, yoghurts, custards or even baby foods). Soups

## **Personal Care — the Practicalities**

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Like most people, the patient will feel fresher and more comfortable if their personal care such as washing or showering is attended to daily. However, individual preferences must be taken into account. Discuss their preferences with the person and respect them.

If the visiting nurse or care assistant is attending to personal care, you may wish to become their apprentice and learn how to do things yourself. The nurses are usually unable to visit daily.

### **Showering or Washing**

The patient may have a shower when the visiting nurse or care assistant attends and just a small wash will do on the other days. If you are attending to the patient'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 patient, an acceptable wash can be done in the bed, or on a chair.

Wherever you are carrying out the wash or shower, ensure that the patient has adequate privacy and that his or her dignity is maintained even if you think they are not aware. 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 soap substitutes or cologne may also help the patient enjoy it more, however avoid using real soap, as it may dry the patient's skin too much.

You can take care of the patient's personal needs in bed using a bowl of warm water plus face washers and towels. Another method of washing in bed with warm moist towels is called a 'hot towel bath'. The visiting nurse will be able to show you these methods.

### **Skin Care and Massage**

If the patient 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 patient 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 patient. You can use scented (or unscented if the patient prefers) oils, lotions and creams to massage dry skin and sore spots. Massage is often comforting for the patient 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 patient has a deep vein thrombosis (clot). If you are unsure, check with the doctor or visiting nurse.

### **Bed Linen**

If the patient 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 patient is in bed, ask the visiting 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), over the bottom sheet will limit any soiling due to incontinence, so you avoid making the whole bed.

## **Nutrition**

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

- ◆ tiredness
- ◆ pain
- ◆ nausea and vomiting
- ◆ depression
- ◆ sore, dry mouth or throat
- ◆ constipation
- ◆ alteration in taste
- ◆ diarrhoea

Although some of these causes can be reversed, the nutritional needs of a patient 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). Taste is often dulled and 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 patient.

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

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 patient may become restless 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 cannot communicate these needs.

Keep the patient safe from a fall or harm. Do not try to tie a restless patient into a bed or chair. This could frighten them and make them more restless. Sit with the patient and talk with them about the experience and try to reassure them. By treating things early, and by providing a good explanation to the patient, the outcome can be far better.

### **Shortness of Breath**

Shortness of breath is frightening and can be worsened by fear or anxiety, or unresolved emotional, family or spiritual issues. Your doctor will review your medications and discuss options for management with you. Oxygen is useful only if oxygen levels are low. The most effective treatment is usually Morphine used in conjunction with drugs to decrease anxiety. Relaxation techniques and breathing exercises can also help, your nurse or counsellor may be able to show you some of these techniques. Shortness of breath is most often caused by lung cancer, or pre-existing lung conditions such as emphysema, infection, anaemia, heart failure or fluid overload.

If the patient has an ongoing problem with incontinence, there are aids that can contain it and minimize mess and odour. Please talk to the visiting nurse or palliative care worker.

### **Manual Handling**

It is essential that a bed-bound patient is moved regularly; every two hours is the rule of thumb during the day, once or twice at night. However, pressure relieving mattresses can avoid the need for such frequent turning. If the patient is very sick and near to death, it may be better to move them much less frequently, if at all. The visiting nurse will advise you on these matters.

Depending on the degree of dependency of the patient, you will find yourself having to help them move. Bending and twisting while lifting can cause you injury, a nurse from your palliative care or visiting nursing service can teach you how to lift and move the patient in a way that minimises this risk. Learn the correct way to do things for your own safety.

### **Mouth Care**

Sick people are much more prone to oral 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, lozenges, or oral tablets. If the patient cannot swallow properly and debris is left in the mouth it

encourages infections of the salivary glands that appear as hard, hot, painful swellings around the jaws and cheeks. Antibiotics may be necessary; in either case, please refer to the doctor or visiting nurse.

For these reasons it is important to check the patient's mouth daily, and to help keep the mouth clean. Rather than a soft toothbrush, large swabs moistened with water can be used to keep the mouth moist and free of debris.

Dryness of the mouth can also be a problem. If the patient can swallow, they could try sucking small pieces of ice to keep the mouth moist. If they are 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 patient at night. Iced water is usually the most comfortable and refreshing.

### **Hair care when the patient is bed-bound**

It is quite possible to wash someone's hair in bed and it usually makes them feel so much better. If you have a plastic sheet, towels, jug and a bucket or bowl you are in business! Ask the visiting nurse to show you how to do it, giving a day or two's notice so that he/she can fit it in their schedule. It is also possible to have hair cut or permed at home. Look in the Yellow Pages for hair-dressers who have mobile services.

### **Weakness**

Weakness is common in the terminally ill patient. Treatment with tonics or vitamins will not help significantly. If there is anaemia, blood transfusions may bring temporary relief in some cases. Rest periods between outings and after visitors will 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 patient is not drinking but it is not usually a source of discomfort for them. In fact it prevents build up of saliva which is now an effort to swallow. It reduces noisy breathing in the back of the throat, leading to less coughing and vomiting. It also reduces the amount of urine the patient has to pass.

A dry mouth may be uncomfortable however, and if the patient 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. This can be easily administered in the home by the visiting nurses.

### **Confusion**

Confusion or delirium can occur in advanced illness. It is not a sign that the patient is 'going mad'. Confusion could be caused by medications or by one of several medical conditions. It is important to exclude causes that can be treated such as infection.

### **Nausea and Vomiting**

Nausea and vomiting can be troubling and may have a variety of causes. The doctor will investigate the cause and may give medication to alleviate the problem. It is helpful to reduce any odours that cause distress, for example, when preparing food. Nausea may be reduced by simple measures such as fresh air, adjusting the body position or by sipping fizzy drinks such as soda water.

### **Loss of Appetite and Weight**

Loss of appetite in advanced illness is common and it can be distressing for those who are providing care. There is not a lot that you can do however, so don't draw undue attention to the loss of weight. Some supplements such as Ensure or Sustagen may help the patient maintain an adequate caloric intake.

The person you are caring for may want to avoid looking in the mirror because the change in body image is upsetting. 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. Buying new clothes or adapting existing items so they fit will help the patient 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.

### **Nail Care and Shaving**

It is also important to help the patient 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 to maintain her beauty routine.

### **Clothing**

It is important that the patient is clothed comfortably and that clothes can be put on and removed with the minimum of fuss. On one hand it is not a good idea to wear night attire all day (unless the patient 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 track suits 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, perhaps you could organise this. Ask the visiting nurse or physiotherapist to check the patient's shoes or slippers to make sure they are suitable.

## Common Symptoms in Advanced Disease

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### Pain

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

Pain is best managed with regular analgesics (painkillers) 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 for times when the regular dose is not enough; these are called 'rescue' or 'breakthrough' doses.

Analgesia comes in various forms; tablets, syrups, suppositories, injections or skin patches. The doctor may prescribe Morphine or other 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 cancer. There is no risk of the person becoming addicted to these drugs when they are used to control pain.

Other medications such as antidepressants, steroids or milder painkillers may be used in conjunction with strong analgesics to achieve pain relief. For instance, you may be confused to find that the patient 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.

Analgesics, like all drugs, can have side effects as well as benefits. These may include constipation, nausea and vomiting, drowsiness and confusion. Talk to the doctor, visiting nurse or palliative care team member so that you understand the actions of each medication being prescribed, and what can be done if side effects occur.

Pain can be aggravated by social or emotional problems. Companionship and discussion of their fears and problems may do more to help the patient than medications alone.

### Constipation

Constipation is a very common problem in people with advanced disease, due to lack of mobility, poor diet and lack of fluid intake. Constipation makes other symptoms, especially pain, worse, and should be prevented. Strong analgesics like Morphine reduce bowel movement, and patients will often need to take laxatives (aperients). Even when someone is eating very little, a bowel action is expected at least every 3 days. If a patient has not had a bowel movement for 3 days or more, ask the visiting nurse for advice depending on their type of pain.

Encourage the patient to increase fluid intake, take prescribed aperients regularly, 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.