

Caring for someone in the final stages of a life threatening illness

Latrobe Community Health Service
Palliative Care Service



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LATROBE COMMUNITY HEALTH SERVICE
PALLIATIVE CARE SERVICE

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Introduction

This booklet is intended to provide some assistance and support for those who are caring for someone in the final stages of a life threatening illness. There are some areas that maybe considered difficult to talk about, however we have attempted to address these with a level of sensitivity and integrity yet with honesty. We have developed this booklet to give families and carers information and strategies to assist them in being better prepared when someone they love is dying.



Preparing Yourself

COMMUNICATION

If you are considering looking after someone at home in the advanced stages of a life threatening illness then you need to be prepared to have open and honest discussions with your Doctor, the Palliative Care Service and with your loved one. It is likely that you will feel a range of different emotions at different stages and it is important that you have support around you to enable you to talk about your concerns. Open and honest communication with your loved one's Doctor and the Palliative Care Service is a priority.

BEING PREPARED FOR WHAT MIGHT HAPPEN

It is important that as a carer you are prepared for situations that might occur in regards to physical and emotional changes. It is likely that the person you are caring for will experience a range of symptoms and you need to have open and frank discussions with the Doctor and the Palliative Care Service about how these symptoms can be managed in the home environment.

MEDICATION CHANGES

The Palliative Care Service in discussion with the Doctor may assess that the person requires a change in medication in order to better manage a range of symptoms. The staff will discuss with you any need for medication changes

and how to go about accessing these medications. It is important in the advanced stages that you have support around you to ensure that any new medication required can be picked up from the Pharmacy at short notice.

GIVING YOURSELF A BREAK

Looking after someone at home who is in the advanced stages of a life threatening illness can be extremely demanding and very exhausting. It is crucial that you have a support network around you such as other family members and friends. Depending on the person's symptoms and condition you might need to assist them with hygiene needs such as a sponge bath in bed or lifting and turning the person in bed.

It is important that you make sure you have planned breaks to give yourself a rest – ask other family members and friends to help out so that you can have some time to look after yourself as well as your loved one. The Palliative Care Service can also discuss with you the option of Carer Respite support.

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Prepare Important Documents

ADVANCE CARE PLAN

It is important that you and your loved one have planned in advance for any problems that might occur. It can be very difficult and challenging for family members, carers and friends to make decisions on behalf of a person if there has not been a discussion about it previously. For further information refer to the Advance Care Plan section in the booklet "Palliative Care – Information for Clients, Families and Carers" or discuss this with the Palliative Care team.



FUNERAL ARRANGEMENTS

Discussing and planning a funeral can be a confronting discussion but one that is important. Some people feel comfortable to have this discussion about their own funeral arrangements and others don't so it is important that the dying person is given the opportunity to have this conversation if they want to. If possible it is important to have this discussion so that you don't feel you have to make uninformed decisions after the person has died in regard to issues and preferences such as burial, cremation, ceremonies and any special requests.

If you are feeling unable to do this yourself then it is important you talk with the Palliative Care team to help you prepare and to identify other relatives or friends who may be able to help you.

Looking after Someone Dying at Home

It is important that before you make the decision to look after someone at home who is dying you fully understand what this means. Most people have never done this before and therefore have no knowledge or understanding of what the challenges might be. It is also important to remember that this can be a significantly valuable and rewarding experience.

Making a decision about where to die is extremely difficult and one that may change over time. The most important basis for making this decision is about where the person and the carer feel most comfortable and supported.

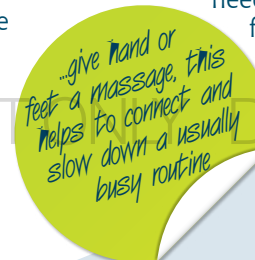
Caring at home for someone who is dying is physically and emotionally challenging and it is important that you give yourself the permission to change your mind about certain decisions if you wish and to try and be as flexible as possible without feeling guilty. Probably the most significant thing to remember is that you need to keep monitoring how you are feeling and coping and talk this through with the Doctor and Palliative Care Service.

It is important to make sure that the physical demands of looking after someone

who is dying are balanced with the need to spend time emotionally with the person. The Palliative Care team can talk with you about what options there are for Carer Respite either in your home or in a health care environment. The Palliative Care team can also talk with you about what other options there are if you feel that you are no longer able or wish to care for your loved one at home.

When making the decision to care for someone at home who is dying it is imperative that you have a strong support network around you including a Doctor who is prepared to play an active role in the person's care and other family and friends who can not only emotionally support you but also provide you with physical assistance as you need it. You may need to consider other issues such as the physical layout of your home, practical support the person requires and if you are comfortable with support people, such as nurses who you don't know, coming into your home.

The best way to approach making these important decisions is not to do it on your own but with other people such as the Doctor, Palliative Care Service, other family members and friends, and support from any particular groups such as your church or your workplace. No-one can really tell you exactly how things will be but remember that you need to be flexible and prepared for change at short notice.



HOW WILL I FEEL CONTINUING TO LIVE IN MY HOME AFTER MY LOVED ONE HAS DIED?

The Palliative Care team can talk through with you how you might feel continuing to live in your home after your loved one has died. People have a mixed range of emotions about this so it is important to talk about how you might be feeling. You may need to consider that there might be certain places in your home or events that occur that might raise strong emotions for you and how you might deal with it when it occurs.



Practical Caring at Home

Maintaining someone's hygiene is important but this needs to be done based on what the person wants and what they can cope with. The Palliative Care Service can help guide you on this and there are a few helpful hints below: How to help

- If the person is able to bath or shower, talk with the Palliative Care Service about the need for any special equipment such as bath boards, shower chairs or rails
- Don't make water too warm in a bath as this can make the person sleepy and potentially cause difficulties for the person to get out of the bath
- If the person is not able to get out of bed, then a sponge bath can be given in bed. This can be done with simply a face washer, towel and warm water. The Palliative Care staff can talk with you and show you how to do this if you wish. A person will often feel better after a wash even if it is just face, hands and the genital area.

FLUIDS AND MOUTH CARE

Maintaining good mouth care is imperative in the final stages of a life threatening illness. If your loved one is unable to manage their own mouth and dental care (such as brushing and flossing), then they will need some

assistance to do this. It is also common for people in the advanced stages of an illness to experience a dry mouth. If the person is unable to swallow safely then do not give them fluids – speak with the Palliative Care staff about what you can do in this situation.

If the person can swallow fluids try giving them a range of different drinks and encourage them to sip slowly – using a straw can sometimes be helpful. It is important that you do not force your loved one to drink if they do not want to or are unable to.

It is important that care of the mouth is done regularly and more so if the person's mouth is very dry.

- Try and encourage the person to rinse their mouth every few hours and particularly after meals Avoid using mouth washes that contain alcohol as this can dry the mouth more. There are some mouth washes that have a pain relieving affect so it can sometimes be helpful to use them half an hour prior to meals Sometimes it can help to leave dentures out if the person has them (except if the person is eating). Often a person's lips can become very dry so it is important to keep these moist by using things such as lip balm.

If the person is safely able to suck, then using ice cubes and hard lollies can sometimes assist in moistening the mouth Managing the person in bed

When someone is in the final stages they will more than likely spend a lot of time in bed. If this is the case then

they will need assistance to change their position on a regular basis to ensure that their skin doesn't break down from pressure and that they don't develop "pressure sores".

Being able to change position is important but if the person is not expected to live for more than a few hours then it is not considered necessary to continually move the person as this can potentially cause more distress. Some people may experience pain when moving so it is important to talk with the Doctor and the Palliative Care staff about whether medication can be given before the person is moved to make it easier for them.

Managing someone in bed can be physically demanding so it is imperative that you have support from other family and friends to assist you with this as necessary. The Palliative Care staff can advise you on particular methods and equipment available to assist in moving someone in bed.

TOILETING AND CONTINENCE

Assisting someone to use the toilet or managing someone who is incontinent of urine or faeces can be emotionally confronting as well as physically challenging. Not everyone loses control of their bladder or bowels but it can happen and most often people will need assistance with some form of toileting. The Palliative Care staff can discuss with you the support and types of equipment that maybe useful such as commode chairs, bedpans and catheters if necessary.

CONFUSION, DELIRIUM AND TERMINAL RESTLESSNESS

Sometimes in the very advanced stages of a life threatening illness a person can become confused. Confusion can be caused by a number of issues such as infections, lack of oxygen to the brain and pain. If confusion occurs it can be very difficult and upsetting for both the person and their carers. People can experience confusion differently depending on the individual and the reason; but some common signs are restlessness, agitation, hallucinations, disorientation, inappropriate comments, difficulty in sleeping and loss of memory. It is important to talk with the Doctor and the Palliative Care Service if you are concerned about the person's confusion, however the following strategies may also assist you in managing this type of situation:

- Try to make situations and tasks as easy and simple as possible to avoid further confusion
- It is pointless trying to argue, debate, disagree or contradict a person who is confused – this may make them feel more threatened and defensive. Acknowledge what they are saying and let them know you will try and help out
- When speaking with the person try and remain calm and speak slowly in a non-threatening way reminding them of who you are and where they are
- Familiar faces and people, diaries, clocks and calendars can all help remind the person of their

surroundings – however it is also important not to have too many people around as this can cause more confusion

- Make sure that the person has familiar things around them and uses their glasses and hearing aids if need be

Treatment for Confusion and Delirium

As previously indicated there can be a range of reasons why a person may become confused. Most often medication can assist greatly in managing the symptoms of confusion, delirium and terminal restlessness. For example, if a person has an infection then they may be treated with antibiotics to decrease the confusion associated with the infection. You may also decide that as part of the person's Advance Care Plan that you will manage the confusion as it is because you do not wish to give the person any further medication or treatment. Again, it is important that you discuss this with the Doctor and Palliative Care Service so the right medication can be prescribed if necessary.

Physical & Psychological Changes

If you are going to care for someone at home who is dying it is important that you are aware of some of the physical changes a person will experience. Again, everyone's experience is different, however there are some similarities or generalisations we can highlight. Over a period of time the body becomes more fatigued and weak and the body's systems gradually begin to shut down. It is not uncommon in the last few days for someone to have lost a lot of weight and be sleeping for long periods of time. Along with physical changes the person will generally become less alert and will not interact socially or emotionally with you as much as previously.

CAN THE PERSON HEAR WHAT I'M SAYING?

Nobody really knows whether a dying person who is not conscious can hear what we say to them. However, it is a medical fact that a person's hearing is a very strong function. Therefore, it is important that you speak regularly and honestly with your loved one. It is im-

portant that you do not have regrets because you didn't say the things that you might want to - we would encourage you to take the time to have those conversations and to allow yourself the privacy if there are other family members and friends around.

It is important to remember that if we assume the person can hear us then we should make sure that any conversations we don't want them to hear should be outside of the room.

SHOULD I BE DOING SOMETHING?

Sometimes it is not necessary to do anything other than just be there for your loved one. Being able to support one another and other family and friends is the most important thing to do. Many peoples' experience is that they go on doing normal and routine things like sharing meals, talking and sharing stories and reminiscing.

Changes Near the End

Shortly before a person dies there can be obvious changes in a person's functioning including:

- Changes in the person's circulation which can mean the person's body is cool to touch and it can sometimes change colour and look slightly blotchy
- There will generally be a decrease in the amount of urine and faeces a person produces
- A person's breathing may become noisy, irregular and there may be long pauses between breaths
- Sometimes when death is near there can be an unexpected improvement in the person's alertness, communication and ability to interact with others – there is no explanation for this and it can sometimes occur on more than one occasion

What to do When Someone Dies

No-one can really tell you how you might feel when your loved one dies. Often when someone has been unwell for a period of time we think we might have prepared ourselves for the moment they die, however the emotions you feel at this time will generally be intense and varied. How you respond will be right for you and remember that it is completely normal and perfectly acceptable for you and other family members and friends to respond very emotionally – you do not have to control your emotions or be seen to be "holding it together".

You need to be prepared so that you will know when someone has died. There are several signs to indicate that someone has died including:

- The person has stopped breathing and there will be no heartbeat (you will not be able to feel a

pulse beating)

- There will be no movement and the person's muscles will look like they have relaxed
- The person's eyes will not respond to light or stimuli
- Sometimes after death the person may have a few minor muscle twitches but these do not last long
- A little while after the person has died there can be other changes to the person's body such as a release of urine, faeces or saliva and the body will be cool to touch. After several hours the person's body will start to stiffen and the colour will change.

It is important that you do what you feel is right for you at this point. There is absolutely no reason why you can't continue to talk to and touch your loved one. It is completely your decision whether you want anyone else there with you and for how long you want your loved one to stay in the home. Most importantly, you need to feel like you have had the opportunity to say your good-byes.

After a person dies some people wish to assist with washing and dressing their loved one in particular items of clothing or identifying sentimental items they want to go with the person. Other people may have particular cultural or religious desires they wish to observe. Again, there is no right or wrong in this regard and it is entirely your choice what you wish to do. However, you may need to be clear with the Funeral Directors of any particular wishes you have.



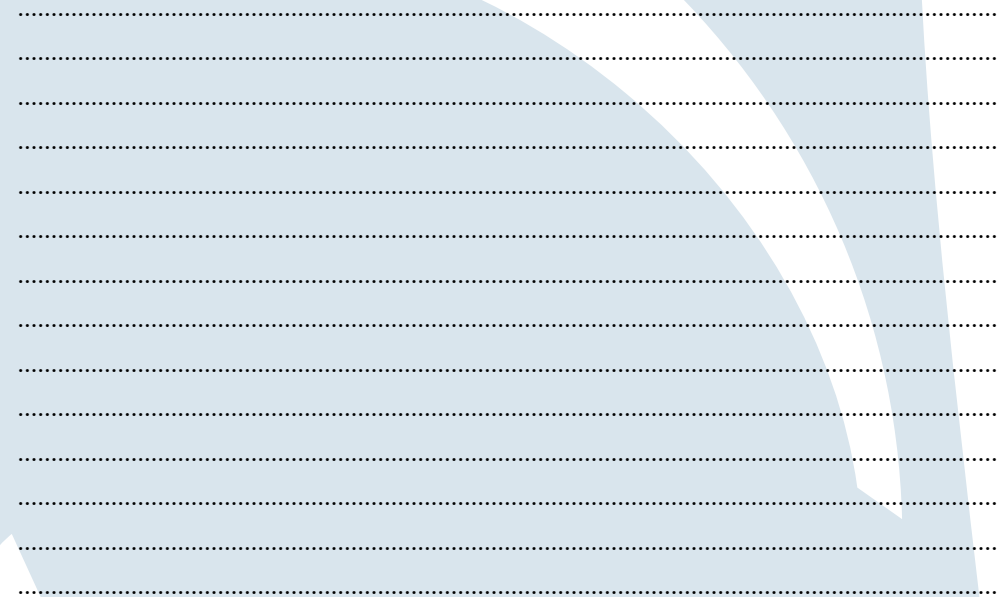
When someone has died you need to feel reassured that you do not need to do anything in a hurry if you do not wish to. It is particularly important at this time to make sure that you have other family members and friends around you to assist where possible. You may not feel up to calling other relatives, the Doctor or the Funeral Directors so let other family and friends help you with this.

When someone dies at home the person's Doctor will need to arrange for a Death Certificate to be issued. You need to establish with the person's Doctor whether they will visit at home to certify the person has died. It is recommended that you speak with the Doctor and the Palliative Care Service earlier on about this.

You will also be required to contact the nominated Funeral Director but keep in mind that it is up to you when you want them to come. Some family members and friends may want them to come straight away and others may wish for them to wait until later in the day and/or the following day if the person died during the night.

If you are unsure about anything it is important to talk this through with a member of the Palliative Care Service.

My Notes



My Contacts

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For information visit

www.lchs.com.au

Or Free Call

1800 242 696

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