Bethesda
health care

Caring in the Last Days of Life

Provided by the Metropolitan Palliative Care
Consultancy Service (MPaCCS)

This booklet has been compiled to help answer some of the questions that you may have about the dying process. Caregivers play an important role in providing comfort and support to someone entering their final stages of life.

Each experience is unique and no one can fully predict what it will be like or when it will occur. It is our goal to respect the dignity of each person by providing quality holistic palliative care.

Fatigue

You will find that over time your loved one will become increasingly tired and weak. It is common for people to begin to withdraw from friends and family and also what interested them in the past. This process may begin weeks or months before death. Your loved one may spend more time in bed and sleep for longer periods. Also with extreme fatigue there is less of a need to communicate with others. Touch and silence become more relevant.

What you can do:

- Plan activities and visits for times of the day when they are most alert.
- Because hearing remains intact even when people are unconscious, speak normally with a calm tone of voice.
- Identify yourself by name when you speak. Tell the person what you are going to do before you do it. For example: “Ed, this is Sue. I’m going to clean your mouth now.” This will be reassuring for them.
- Remember not to say anything in front of them that you wouldn’t say if he/she were awake.

Changes in Appetite

Near end of life it is natural for a person to lose interest in food or fluids. This is often one of the hardest concepts for caregivers to accept. The giving of food is often symbolic of loving and nurturing. To deprive someone of this may feel like neglect. As the body’s metabolism naturally begins to slow down, less nutrition is required. Weight loss is expected. This does not mean that the person is hungry or being “starved”.

Remember forcing a person to eat may cause nausea and vomiting.

What you can do:

- Let the person be the guide. He or she will let you know if they want food or fluids.
- Liquids are preferred to solids. Some people may find thickened liquids easier to swallow (dependent on speech pathologist assessment).
- The person needs to be in an upright and fully alert position when eating or drinking.

Changes in Breathing

Breathing patterns change for those nearing end of life, commonly gaps in breathing (Apnea - Slow breaths followed by rapid with gaps in between). These periods can last from 5-30 seconds. This type of breathing is not distressing, but is a response to the body's deterioration.

As the person is unable to cough due to a weakened gag reflex, secretions may build up at the back of the throat causing a "rattle". The sound is distressing to us but not a cause of discomfort to your loved one.

What you can do:

- Gently turning the person on his or her side may assist to drain the secretions.
- The nurse may administer prescribed medications that can dry excess secretions.
- If they are coughing on some saliva they may require some sedation. Ask the nurse to review.
- If breathing seems labored, your doctor may prescribe morphine or similar to ease shortness of breath. Ask your nurse to review.
- At this point, people are usually breathing with their mouth open. This will make the mouth dry; because of this frequent mouth care is important.

Physical Changes

Sometimes a person may become sweaty and clammy with or without a fever. As your loved one becomes weaker, his or her circulation decreases and you may notice that the arms and legs feel cool to touch and their skin colour may change. They may appear pale and have a grayish hue around the lips and fingers. This doesn't cause any discomfort for the person and is a natural part of the dying process.

What you can do:

- If they are hot use a fan or open a window if able.
- Apply blankets or remove as necessary.
- Gently reposition the person and provide gentle massage with creams.
- A tepid wash to refresh them.

Restlessness and Agitation

At times, the person you are caring for may appear restless. They may want to stand up, sit down, try to climb out of bed not knowing what they want. This is common and may be due to a variety of physical or psychological factors.

Restlessness may be caused in part by organ failure. Sometimes agitation can be a sign of physical discomfort, emotional or spiritual pain. The inability to pass urine or have the urge to have their bowels open will cause agitation. In some situations it may be appropriate for the nurse to place a catheter (a tube) into the bladder for comfort and use suppositories to have their bowels open.

What you can do:

- Let the nurse know if the person is agitated or restless. The nurse will assess for any underlying pain or discomfort.
- Continue with the medication regimen prescribed by the doctor.
- Utilise the social worker and/or chaplain to address concerns and provide emotional or spiritual support.
- Provide a reassuring presence by speaking slowly, calmly, and in a soothing way.
- Playing soft music.
- Holding hands or a light touch may be reassuring.
- Use bed rails or have someone sit with the person to keep him or her safe. Restraints may cause further agitation and are not encouraged. (You will have to sign a consent form for bed rails)
- It may be useful to limit visitors at this time and to minimise outside distractions (loud noises, radio or TV, ringing phones

Pain

Many people with a life limiting illness may experience pain. Pain can be due to reasons such as pressure sores, cancers, arthritis. There are a number of medications available that can be prescribed depending on the type of pain experienced.

The required dosage varies from person to person and the assessment of these medications regularly is needed to optimise pain management for the patient.

Regular repositioning of your loved one will also prevent discomfort. An air mattress may be applied to the bed to relieve pressure.

Medications may be delivered by injection using a 'butterfly' placed in the stomach or other areas to reduce the amount of needles the person gets. Use of a 'pain relieving patch' or syringe driver may be necessary to give an overall better cover of pain relief.

What you can do:

- Report to facility staff if you think your loved one is in pain. A nurse will come to review, and medicate as appropriate.
- Hot and cold packs may be helpful.
- Approach the patient in a calm and soothing manner. Gentle massage may help.
- Repositioning also may relieve pain if your loved one is restless.
- Ask your nurse or dr for advice.

Communication

Many people have questions about saying goodbye and wonder whether it is appropriate to do so.

When and how to say goodbye is a personal decision, there is no right or wrong way to do it. Some families have difficulty starting the conversation but find that once begun it is a wonderful privilege. Studies indicate that hearing is the last of the senses to be lost. They will be aware of your presence and voices around them which will provide comfort and reassurance for them.

What you can do:

- Take this opportunity while the person is alert to say or do what you need to.
- Some families may choose this time to say, “I am sorry,” share forgiveness and let go of the past
- Give the opportunity to people from afar to talk to your loved one by putting the phone near their ear.
- Remember tears are a normal and natural part of saying goodbye.

You can:

- Play soft music that the person enjoyed.
- Gentle massage, hand holding are all forms of communication.
- Consider a Priest or a Chaplain of chosen denomination to visit to speak as another source of support.
- Electric oil burners to diffuse pleasant scents through the air to create a calming environment.

Time of Death

Some people die when others are present. Some when they are alone. No one can accurately predict when death may occur. When the person has died, there will be no breathing or heartbeat. There will be no response to your voice or touch.

No matter how well prepared you are, death can still be a shock.

What you can do:

Let the staff know.

When a nurse or other team members visit, some of the things they may do are:

- Confirm the death
- Remove any tubes that are present
- Offer to bathe and prepare the body
- Call the funeral home, if you wish
- Provide support
- Notify the doctor.

Some choose to have the funeral home come right away, while other families may choose to wait for a period of time before calling.

Some of the ways in which you can honour your loved one are:

- Bathing and dressing the person in special clothes/ telling stories/sharing a spiritual or cultural ritual or playing special music.
- When the funeral directors come, you can decide whether you want to be present. The funeral home will liaise with you about making arrangements

Caring for Yourself

Caring for someone who is in the final weeks and days of life can be physically and emotionally demanding. It will feel overwhelming at times and leave you weary in body, mind, and spirit. In addition, some caregivers are often juggling other responsibilities such as work, household duties, caring for other family members, or addressing their own health concerns.

What you can do:

- Take a deep breath.
- Go outside for a few minutes; smell and feel the fresh air. Take a walk or sit outside.
- Drink plenty of fluids.
- Follow a well-balanced diet, eating at regular intervals.
- Determine if calls or visits are helpful or cause you more stress- limit these as a way of respecting your own needs and private time.
- Ask for help. Often family and friends want to help but do not know how - give them a list of tasks to be done, such as shopping, taking the dog for a walk etc.
- Share your concerns or feelings with facility staff, a trusted friend, Chaplain, or your palliative care link team.

A new journey begins

- Grief/loss and bereavement

Grief is a normal, natural and inevitable response to loss and it can affect every part of our lives. Grief can seem like a roller-coaster ride with ups and downs. Sometimes it can seem overwhelming and frightening. Grief allows us to gradually adjust to our loss and find a way of going on with our life without the person who has died.

Everyone experiences grief in their own way. There is no correct way to “grieve” and no way to “fix it”. Reactions to grief can manifest in different ways, mentally, emotionally, physically, behaviorally and spiritually.

Grief has no timeline. It is not unusual for grief to be felt over an extended period of time, even for many years. At first, people tend to feel grief more strongly. As time passes, we learn to manage. Sometimes after a period of feeling good, we find ourselves experiencing sadness, despair or anger. This is often the nature of grief, up and down and it may happen over and over.

Everyone grieves in their own way; some people express their grief in private and do not show it in public. We do not always know how people are grieving simply by what we see. Members of the same family can grieve differently. Some people express their grief through crying and talking. Others may be reluctant to talk and prefer to keep busy.

It is important to respect each other’s way of grieving. Being a carer for someone with a terminal condition can be quite isolating and exhausting. After the person has died you may find it very difficult to re-integrate into work, groups, clubs or activities you previously enjoyed. No one can take away the pain and sadness of grief, but knowing that people care can be comforting and healing for grieving people.

Sometimes, we may need to seek help. Counselling is one option, or you might consider joining a support group. Although the experience of grief is normal and an inevitable part of life, you may feel the need to seek additional support. Specialist palliative care services can help with accessing a bereavement counsellor or social worker. Also your general practitioner will be able to refer you to appropriate services.

Several organisations provide information or telephone counselling:

Alzheimer's Australia Helpline

1800 100 500

www.fightdementia.org.au

Beyond Blue

1300 22 4636

www.beyondblue.org.au

Cancer Council Western Australia Helpline

131 120

www.cancerwa.asn.au

Carers WA Australia Counselling Line

1800 007332

www.carersaustralia.com.au

Kids Helpline

(24/7): 1800 55 1800

www.kidshelp.com.au

Men's Line

(24/7): 1300 78 99 78

www.mensline.org.au

Metropolitan Palliative Care Consultancy Service

9217 1777

www.bethesda.org.au

Palliative Care Western Australia

1300 551 704

www.palliativecarewa.asn.au

Parent Line

1300 30 1300

www.parentline.com.au

Bethesda
health care

Government of **Western Australia**
Department of **Health**

For further information please contact:

Metropolitan Palliative Care Consultancy Service (MPaCCS)
Bethesda Hospital (08) 9217 1777
Monday - Friday 8am - 4pm
www.bethesda.org.au/mpaccs