



A guide to care for those with a terminal condition:

Honouring the choices of Aboriginal and Torres Strait Islander people in the ACT community

You matter because you are you.

You matter to the last moment of your life and

we will do all we can, not only to help you die peacefully,

but to live until you die

Dame Cicely Saunders

About the Author

ACT Health is committed to supporting and improving the cultural appropriateness of palliative care services for Aboriginal people in the ACT and increasing awareness in the Aboriginal and Torres Strait Islander communities of available palliative care services.

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Kerry is a descendant from the Merriam people in the Torres Strait and has been recognised both nationally and internationally for her contribution to the sexual and reproductive health of Indigenous Australians in particular, and for her commitment to health service development and delivery. In Kerry's professional career, she has been the Executive Director of health service and political agencies including the most remote area Aboriginal medical service in Australia; and been a representative on a range of local, state and national Councils and Committees.

Kerry has been contracted by the World Health Organisation and the World Bank to work with communities in Asia and the Pacific region. She is a Fellow of the Sir Gustav Nossal Leadership in Health Reform, having supervised the development and implementation of national strategies and engaged health systems in developmental issues; and was one of the top 10 finalists in the Health and Medical Research section for the Bulletin Magazine 'SMART 100' in 2004.

Kerry has chaired a number of Boards and Committees, including the International Advisory Committee for Sexual Health and Family Planning Australia, the National Indigenous Australians Sexual Health Committee and ACT Health Promotion Grants.

Kerry's extensive program work has been replicated across Australia, targeting community members, health care workers and other service providers alike. Kerry is a Visiting Research Fellow with the Australian Institute of Aboriginal and Torres Strait Islander Studies, and will shortly be completing her PhD at the Australian National University.

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Foreword

Aboriginal and Torres Strait Islander people are intimate with death. We are largely involved in the support of people who are dying and in the grieving processes that follow a death in the community. Funerals have been identified as a key time when families and friends catch up, spend time together and perform the rites and rituals that are important during that time. Sadly, many of our people die quickly, due either to a late diagnosis of their chronic and complex condition or because of injury or physical trauma. Many families in communities have been affected in this way; people have died without the opportunity for medical intervention, for families to say their goodbyes or time to accept and reflect on happy times at the end of their life.

More often than not, Aboriginal and Torres Strait Islander people in and around Canberra are isolated from loved ones at the time of death. People have relocated to the ACT for work and are separated from family and kinship structures back home. This can be doubly problematic. In the instance when someone loved passes away in other cities or communities, people have to negotiate with their workplaces for time off to attend funerals and often cannot afford to take their whole family with them. People from other places who pass away in Canberra often wish to be transported home after their death so that families and friends can say the proper farewells.

Dealing with death can be incredibly stressful for everyone involved. Grief is particularly debilitating for some people, activated not only by the death of a loved one, but also compounding trauma from this, their parents and their grandparents lifetimes. Many Aboriginal and Torres Strait Islander people in Canberra are hospitalised in acute settings at the time of death. During this time there are many opportunities for families and friends to provide care, love and support to that person through palliative care approaches. The World Health Organisation describes palliative care as life affirming, and regards dying as a normal part of life. Death is not hurried up or postponed by palliative care; rather palliative care offers a support system to help people live as actively as possible until death.¹

This booklet is for those who are assisting a person living with a terminal condition, and who is no longer responding to a cure. The booklet outlines what to expect with palliative care, identifies some roles and responsibilities in the palliative care process and outlines steps you can take to access palliative care in the ACT. This booklet is a guide on how to care for those with a terminal condition, by honouring their choices. It is primarily for the information of Aboriginal and Torres Strait Islander people in the ACT community.

You can be supported to provide palliative care at home, at one of the hospitals, in a hospice or in an aged care home. Palliative care can also be supported by Winnunga Nimmityjah Aboriginal Health Service, Clare Holland House, the ACT Palliative Care Society, Carers ACT, and the Aboriginal Liaison Service at the Canberra Hospital or by a General Practitioner.

This booklet is dedicated to all the people who have taught us about the value of life by allowing us to honour their death.

Kerry Arabena

1 Clare Holland House Presentation, *Death, Dying and Grieving in our Community: A Palliative approach for Aboriginal and Torres Strait Islander peoples in the ACT*. Workshop Folder, 2006.

Kim's story

'Our journey had begun to face this monster of a disease and we had very few choices but to do this together as a family, whether we wanted to or not...'

When my husband Dennis and I visited Winnunga to see Doctor Pete to find what this 'Motor Neurone Disease' was all about, it changed our lives forever in one blow!

We had never heard of the disease that crept into our lives and after two years took the life of my husband at just 40 years of age. We have three children, good jobs and our life was great. This wasn't in our plan; it was not supposed to happen to us. I ran out of the surgery and lost it.

Dennis' strength from the time we found out was amazing. If I was in his position I doubt I could have handled the situation that he faced with such bravery and thought for other people. Our journey had begun to face this monster of a disease and we had very few choices but to do this together as a family, whether we wanted to or not.

I didn't want to read up on the disease. I just wanted it to go away and I wanted my husband to be well again. I didn't want other people asking me to explain about the disease and I didn't want to see in other people's eyes how much Dennis had deteriorated. To me, we were always going to beat this, end of story!

While I was thinking this, I also knew deep down that it was important that family and friends had the opportunity to spend quality time with Dennis, without making it into a big deal. There was so much to think about; his feelings, my children's feelings, our family's feelings, our friend's feelings and of course my feelings as his wife who simply couldn't cope if he wasn't around. It wasn't an option and I refused to make it one.

Dennis' love was Gudan Gulwan Youth Centre. He was the Chairperson and I was the Director there and I had to continue to work. It was difficult, but we needed to have an income to survive. My heart wasn't there but I did it. I continued to listen to everyone's problems with gritted teeth.

Dennis' parents moved up to Canberra from the south coast and our nephew moved in with us to assist, as Dennis required 24 hour care once he was in the wheelchair and lost use of his hands and eventually his legs. There was a lot of lifting to be done, showering and feeding, but we were going to do it and I didn't want any help. This was my responsibility and it was Dennis' wish that he didn't want strange people coming in and showering him and neither did I. You see the helplessness you feel is overwhelming because you just want to be able to fix it, make things disappear and stop the hurt for your

family and the more you try to do that, the more things just don't work out. It's not intentional, just happens that way. Our house burnt down while we were away on a family trip and my coping skills were simply non-existent at this stage. We coped. We had to! I look back and wonder how we managed to get through any of this.

In early 2003, it had become apparent that we all needed a bit of help. It was then that we come in contact with Clare Holland House and the palliative care team.

Dennis was hospitalised after being sick with the flu and of course due to this terminal condition and being bedridden, his strength deteriorated even more. It took him a long time to recover from the flu and the disease was taking over. But to me, this 'tower of strength' I saw in the hospital bed was still going to beat this.

I spent all day by his side and didn't leave until late at night, to go home. I could not sleep, so many things going through my head. I wanted him to come home.

When the doctors and staff finally gave us the all clear to bring him home, I will never forget the nurse saying to me. 'They go home, but they always come back'. My thoughts and reaction to that was, 'Sorry love, my husband ain't coming back here. He's going to be alright!'

We only managed four days at home and it wasn't working because Dennis got too weak and I cried until I didn't think I had any more energy to give. I had failed my husband and my children and everyone else that cared for Dennis. I couldn't cope and it was the most devastating 'reality check' that I had to admit to. He was going back to the hospice.

I went with Dennis in the ambulance and we both cried all the way to the hospice that day. This is when I knew that all wasn't ok and as a grown woman who had others to think about, I had to come to terms with this without showing my husband how 'gutted' I really did feel.

He knew me too well and would turn to me regularly as the days passed sitting with him at the hospice, saying that I needed to be strong. I held his hand and looked him in his eyes and told him that I would be strong and not to worry about that. Inside my stomach was churning and I wanted to scream, lose it and say, 'I'm not this strong woman that you think I am! I'm feeling weak and I don't want to do this by myself! You're the strong one, not me! Stop thinking I can cope when I can't and don't want to!'

Thoughts of, 'Why are you doing this to me? Come on fight it! I really need you to fight!' The selfishness takes over and as horrible as it sounds that's exactly what I was thinking. 'Why me? Why our family? Why my kids? It wasn't fair and I struggled to see any positives at that stage.

This is where the palliative care team came into play; they were simply fantastic. I was pulled into the doctor's office one morning and I heard the words I had been hoping I would never hear; 'Dennis is weakening and he is in the final stages of the disease.' I left that office numb, walked outside and rang my parents. I wanted them to make this go away, I needed them and they came straight away.

When I went back to Dennis' room and told him what the doctor had said, he instantly didn't want me to tell the kids. We talked and cried and I told him that I had to tell the kids; they had a right to know. He was against it but I knew I had to do this. I had to walk through that door and tell them. I did it and I could feel their disbelief and their hurt. My body was aching and exhausted. Later that night, as I lay in my bed, I thought death is a natural progression. We all die. It happens to people everyday. 'Come on girl! Pull yourself together' I thought, as Dennis and our kids need me. This isn't about how I was feeling. It was much more than that.

How do you deal with death? Even the thought of it scared me. There were so many visitors. I just hung around in my own world with Dennis being my whole priority. I left the room and gave his family all the time they needed and his mates of course. I remember sitting outside crying and one of the other patients came to me, put his hand on my shoulder and then left me alone. He knew what I was going through and that comforted me somehow. You get to know the other patients in the hospice and the thing that I found comforting is that they knew without having to say anything. We were all in this together, this fight for life.

I cannot thank hospice staff enough for their understanding that Aboriginal families need to have visitors, a lot of visitors, with sometimes 15-20 people around.

They moved Dennis to a larger room with a lounge and fridge. This enabled me to sleep over at night. I didn't want to leave him and mum and dad were there for the kids, which I appreciated more than they know.

Dennis was experiencing a lot of pain and I needed to be there. One episode lasted for two hours. Two hours of intense pain and I couldn't stop it, no one could and I will never ever deal with the look in my husband's eyes that night. I couldn't do anything to help him and that hurt the most. All of sudden, I was the protector of him and my kids. It was a role that was forced upon me, I didn't ask for it; it just happens that way. I wanted my husband back. He was our protector and he did a much better job than I could ever do. I was failing miserably.

It was also great that the staff left us alone when there were visitors. Especially near the end when Uncle Ossie Cruise came for prayer. Then it happened. I was there to experience Dennis' last breath, which was beautiful. Well now it is, it wasn't at the time. The pain I felt for my kids spread throughout my body, a dull ache that didn't let up. The community gathered around the family and we said our goodbyes.

The grieving was something else, another hurdle to overcome. There's a little poem that I have on my cabinet at work that simply states 'I know God won't give me more than I can handle, I just wish he didn't trust me so much'. True words. I didn't handle my grief with a lot of grace. The anger consumed me while I attempted to carry on. I shut myself away from everyone, which was my way of coping. There is no wrong way and definitely no right way. Each individual has to cope as they see fit.

We are approaching Dennis' fourth anniversary come September, and as a family we have all dealt with his death in our own individual way. There is light at the end of the tunnel and only time can heal you. I am blessed to have shared my time with Dennis, and to have had the opportunity to have three children whom I love very much. For that, I am truly grateful. He still gives me strength everyday. Dennis' memory will never fade in our hearts.

Kim Davison

1. What is palliative care?

A person needs palliative care when they are living with a terminal condition and are no longer responding to a cure. Palliative care affirms life and regards dying as a normal part of life. Death is not hurried up or postponed by palliative care; rather palliative care offers a support system to help people live as actively as possible until death.

2. What does palliative care offer?

Palliative care also recognises the support needed by the person's family and can involve families and friends as palliative caregivers.

Palliative care helps a person with a terminal condition to face a number of changes that often happen in the process of dying. These changes include physical changes in their body, spiritual changes in the way they think about their future, social changes and emotional changes too.

A person who has a terminal condition also experiences changes in their independence, in their mobility, and in their relationships with others. For people with a terminal condition, their families and friends, palliative care offers:

Comfort – to the person; their family and friends and to the caregivers;

Compassion – an understanding and acceptance of feelings;

Concern – for the person's pain and suffering, for the family's frustrations and grief, and for the caregivers; and

Choices – for people to retain dignity and maintain control while they and their caregivers are experiencing the physical, spiritual, emotional and social changes of a terminal condition.

Palliative care can be offered at home, at one of the hospitals, in a hospice or at an aged care home. Palliative care can also be supported by Winnunga Nimmityjah Aboriginal Health Service, Clare Holland House, the ACT Palliative Care Association, Carers ACT, an Aboriginal Liaison Officer, or a General Practitioner.

3. What would I be doing if I were providing palliative care?

You would be helping the person with a terminal condition to maintain a sense of dignity, privacy and control.

'...Dennis required 24 hour care once he was in the wheelchair and lost use of his hands and eventually his legs. There was a lot of lifting to be done; showering and feeding; but we were going to do it and I didn't want any help. This was my responsibility and it was Dennis' wish that he didn't want strange people coming in and showering him and neither did I...'

3.1 Helping a person maintain mobility

A good deal of your time would be spent helping that person deal with their physical changes and would involve activities like:

- Helping the person get around;
- Getting them in and out of bed;
- Helping them get in and out of a wheelchair;
- Helping them get to a bathroom;
- Moving them from a bed to a chair and back to a bed;
- Making them comfortable in their resting positions;
- Making sure their bedding is clean, dry and comfortable; and
- Supporting people to sit up in bed, lie down or lay on their sides as they normally do for sleep.

3.2 Helping with food, nutrition, medication and mouth care

Many people who have a terminal condition feel less hungry and thirsty as their bodies become less able to process food. This could also be due to the progression of the condition, the effects of medication, or the person may have a sore mouth. You may notice the person eats very little, is disinterested in food or may feel unable to eat. They may refuse solids and only drink liquids. They may also lose a lot of weight. If you were providing palliative care you would be:

- Giving the person smaller portions of foods that are soft, nutritious and easy to eat;
- Making sure that they can take medication without feeling too ill;
- Supporting them if they felt like vomiting or were having difficulty in keeping their food down; and
- Helping that person with mouth care, i.e. cleaning their mouth, teeth and/or dentures, lubricating their lips or bringing them ice to suck.

3.3 Providing personal care

A sensitive area of palliative care is providing someone with personal care. There are many aspects to personal care; some of them can be a cause of embarrassment, whilst others can become small acts of love.

Personal care would involve helping the person with a bath or shower (e.g. giving the person a bed bath, helping to lift the person in and out of the bath), providing general hair care (including brushing, combing or washing their hair) and perhaps giving them gentle back massages or rubbing the skin where they have been lying down, to increase circulation.

You may also help the person use a bedpan or a urinal if they are bed ridden. If a person is unable to control their bladder or bowel movements you would be helping them to change regularly and making sure the person's skin is clean and dry. Skin care becomes especially important to prevent bedsores and other painful skin conditions.

You may also be asked to provide some help for people to brush their teeth, trim their fingernails and maybe give someone a good footbath too.

3.4 Making sure the person is comfortable

There are many physical changes that happen due to the progression of the terminal condition. The person may experience an increase in pain, difficulty in breathing (from feeling anxious or breathless), sore areas and breaks in the skin, constipation, or feelings of weakness. They may also experience changing levels of awareness when death is near, and their ability to think and respond clearly can be affected.

Some people feel pain but try to deny it. It is important to look for signs of pain so it can be treated and managed if possible. Pain can affect moods, thoughts and emotions. Pain management is an important aspect of palliative care.

'...Dennis was experiencing a lot of pain and I needed to be there. One episode lasted for two hours. Two hours of intense pain and I couldn't stop it, no one could and I will never ever deal with the look in my husbands eyes that night. I couldn't do anything to help him and that hurt the most...'

To make the person comfortable you may be required to reduce the amount and type of distractions such as TV, radio, or too many visitors. You may also work with a palliative care worker to manage the person's pain with different treatments, be there to talk with them, or help them practice meditation and relaxation exercises. The person can be helped with some small changes to their diet, and all people involved in caring could benefit from introducing new equipment for example lifting equipment to help get a person in and out of a bath, mobility aids such as a wheelchair or a walker, or a humidifier to help their breathing.

3.5 Participating as part of a care team

You may also have the opportunity to participate as part of a care team. This team will talk about the goals of care, work to solve problems as they come up, prepare for changes, plan for crisis, provide support and keep communication channels open between the person, family, friends and caregivers.

'...This is where the palliative care team came into play, they were simply fantastic...'

As well as the personal and medical needs, there will also be other practical needs to be met. Cleaning the house, cooking the food, doing laundry, shopping, taking care of kids and pets, organising visitors and looking after equipment; are some of the ways families, extended families, friends and agency support people can help and feel like they have a role.

3.6 Looking after yourself

'One of the best things you can do for your loved one during this time is to take care of yourself...'

You will also need to look after yourself during this time. Seeing your loved one unwell can absorb a lot of energy. You are at risk of becoming emotionally, mentally and physically exhausted. It is important to know that your wellbeing is as important as that of the dying person. You are likely to experience a range of emotions; all of them are normal. These feelings occur in response to the losses you are now experiencing.

Sleep may not come easily, but try to rest. While you may not feel like eating, attend to your nutritional needs. Time away from your loved one is essential if you are to avoid mental exhaustion. Ask other people to stay with the person to give you a chance to re-energise.

As palliative care involves a lot of assisted lifting, it is important to learn how to do this properly. You can develop good relationships with people who work in palliative care, and find people that you can talk to about the emotions and issues that you, your family and your friends experience. It is important to find ways to relax, and to deal with your own feelings as well as those of others.

4. What are the cultural values that services in the ACT respect?

Making space for cultural practices, such as:

- Allowing family and extended families to be with the person at the time of dying;
- Giving families and extended families the opportunity to fulfil cultural roles and responsibilities;
- Attending to smoking ceremonies and other cleansing rituals; and
- Honouring and respecting family and individual choices.

There may be a desire to return to country.

There may be wailing or other ways of expressing grief that are cultural.

There may be drumming or some other cultural form of music that will be important for the person and the family.

5. How do I deal with the social and emotional needs of the person dying, myself and others?

Someone you love is dying and it feels as if a part of you is dying too. It is not easy to think about what all this means. What will life be like without them? What will happen to you in the future? What will become of your relationship? These are probably only some of your questions. You are probably also wondering about the period just ahead of you. What will you say to your loved one? What will you talk about? What should you not talk about? How should you act? What can you do that will best help them? And how can you best help yourself? The dying person will be as they've always been, only more so. The one who is dying needs you to reach out.

'...I also knew deep down that it was important that family and friends had the opportunity to spend quality time with Dennis, without making it into a big deal. There was so much to think about, his feelings, my children's feelings, our family's feelings, our friend's feelings and of course my feelings as his wife who simply couldn't cope if he wasn't around, it wasn't an option and I refused to make it one...'

You will notice that everyone has different emotional reactions to the terminal condition, and may have special emotional needs at the same time as caring for the emotional and social needs of the person with the terminal condition. These emotional reactions will change over time.

The first reactions to the news of a terminal condition can be shock, anger, denial, and fear. The person dying may blame others, or you may blame yourself.

'...Dennis' strength from the time we found out was amazing. If I was in his position I doubt I could have handled the situation that he faced with such bravery and thought for other people...'

Later, as you start to adjust to the news, you and the person who has the terminal condition may want to talk more about your feelings, and you may want to become more organised to give the needed care.

You are likely to be feeling many different emotions near the end, for example sadness, anxiety, anger, or you may try to hide your feelings. You may also feel frustrated because your care isn't making the dying person feel better, or frustrated with and jealous of other members of your family who appear closer to the person with the terminal condition. All of these feelings are legitimate. Different people deal with their feelings in different ways.

'...You see, the helplessness you feel is overwhelming because you just want to be able to fix it, make things disappear and stop the hurt for your family and the more you try to do that, the more things just don't work out...'

It is important to know that you will experience a range of feelings, and that these will change over time. Try to find someone you can talk to about these feelings, especially if they are making you feel tired, irritable or stressed.

The person with a terminal condition may experience feeling lonely, afraid, in pain, confused, sad, angry, or at peace.

The emotional needs of the dying person may be:

- Companionship;
- Spiritual comfort;
- The opportunity to talk to loved ones and express his/her feelings;
- The opportunity for loved ones to listen to his/her last words of love and wisdom and special requests;
- Someone to make sure their last wishes are carried out; and
- Help in giving away his/her personal things.

The important thing is to listen, be patient, honest, gentle and sensitive. It is important to accept people's reactions, respect personal beliefs and ensure confidentiality during this time.

6. How do I care for the spiritual aspects of the person?

All people have spiritual needs. These needs may become stronger when people are at the end of their life and for those who are struggling with an incurable terminal condition.

A person with a terminal condition may have the need to look back on life events and accomplishments, make peace, practice forgiveness, ready oneself for the afterlife, and take part in rituals.

A person may have many questions that are overwhelming and that you may feel unable to answer. If this is the case it may be important to talk to a leader from the spiritual tradition, an Elder from the community or the palliative care workers.

It is important to note that a person's spiritual or religious beliefs may affect the decisions they make, but it is important to respect whatever the person and family believes and finds comforting.

'...It was also great that the staff (at Clare Holland House) left us alone when there were visitors. Especially near the end when Uncle Ossie Cruise came for prayer. Then it happened. I was there to experience Dennis' last breath, which was beautiful. Well now it is. It wasn't at the time. The pain I felt for my kids spread throughout my body, a dull ache that didn't let up. The community gathered around the family and we said our goodbyes...'

At the end of life, some people may need some help letting go. Each person is unique. They may need silence, a room full of people, praying or rituals.

7. Who can help me support someone to die with dignity?

Volunteers and health care providers working in the field know that palliative care is about valuing every moment of life. They will not support any action that has the intention of shortening a person's life and will respect every individual, regardless of sex, age, race, intellectual or socio-economic standing. They recognise that the individual and the family are entitled to make informed decisions about care, and have the upmost respect for the confidentiality of all information arising out of the provision of care. Palliative care workers believe in empowerment of the individual, the family and the community and have respect in the faith, belief system and culture of each individual. They understand about the need for respecting the rule of law and will work within the law of each person's country wherever possible.

Palliative care aims to:

- Look after the physical needs of the person;
- Reduce or prevent pain and other symptoms of the person's terminal condition;
- Provide counselling and emotional support for the person who is ill;
- Provide grief and bereavement counselling for family and friends while the person is sick; and
- Offer follow-up counselling after their death.

7.1 Who provides palliative care?

Palliative care is provided by a team which can include:

- Doctors;
- Nurses;
- Counsellors;
- Carers;
- Volunteers;
- Aboriginal Liaison Officers; and
- Allied Health Practitioners

7.2 Where to find palliative care services

Palliative care can be offered at home, in a hospital or at a hospice. A hospice is where specially trained staff cares for people with a terminal condition in a place more like a home than a hospital. As far as possible, the person and their family and friends choose where the care is given.

Some people receive all their palliative care in a hospice or in hospital (in a hospice ward or unit). Others are only admitted to a hospital or hospice for a brief stay. This service offers:

- Relief from pain and other upsetting symptoms; and
- A short break (respite) for family or friends who are caring for the person at home.

There are special programs to help people who want to be looked after at home. They are known as community-based programs and they provide:

- Medical support;
- Nursing care (usually available 24 hours a day);
- Equipment loan;
- Counselling; and
- Bereavement services.

7.3 Who refers people for palliative care?

People are referred by:

- Doctors;
- Nurses or other healthcare providers;
- The person themselves, or their families or friends; and
- Community services, such as home help.

After the referral is made, a hospice and palliative care worker visits the sick person in their home. The worker will help the person and the family and friends who are caring for them, to decide which services they need.

7.4 Dying at home

While most death occurs in a hospital, much of the process of dying occurs within the home. The responsibilities of a family caregiver may encompass some or all of the following:

- Personal care (hygiene, feeding);
- Domestic care (cleaning, meal preparation);
- Auxiliary care (shopping, transportation);
- Social care (informal counselling, emotional support, talking);
- Nursing care (administering medication, changing catheters); and
- Planning care (establishing and coordinating support for the patient).

For family palliative caregivers, the physical, emotional, financial and social impact of providing care for a dying relative is made more difficult by issues such as:

- Becoming as housebound as the person dying;
- Managing multiple roles and more responsibilities; and
- Being unable to work as much, this can cause financial problems.

The benefits of home-based palliative care include a sense of normality, choice and comfort for the dying person and for the family members involved in their care. Death at home is commonly viewed as a more dignified and comfortable experience than death in a hospital. Meeting the needs of families is central to providing good palliative care at home.

7.5 Dying in hospitals

Most people still die in hospitals. For Aboriginal and Torres Strait Islander people, hospitals can seem like alienating, dangerous places. The goal of palliative care in the ACT hospital sector is to develop family capacity to help those who have a terminal condition. In order to reach this goal, the workers in ACT hospitals:

- Consider the families and others as part of a palliative care team;
- Manage symptoms and pain;
- Provide education and training for families;
- Contribute to the decision making process;
- Support the dying person; and
- Provide advocacy, information and interpretation services.

At the Canberra Hospital there are no dedicated palliative care beds. However, there is a palliative care team who will assist Aboriginal and Torres Strait Islander people to die with peace and dignity. Referrals to home-based and hospice-based services are available through the ACT hospital system.

7.6 Dying at a hospice

The hospice in the ACT is called Clare Holland House. The hospice can provide a home-based palliative care service, an inpatient unit, a hospital consultancy service and also a bereavement service.

Home-based palliative care includes home visits, 24 hours on call, and a focus on symptom management, education, some care coordination, psychological and emotional support and equipment.

The inpatient unit has 19 dedicated beds and people can be admitted for symptom management, respite care and end of life care.

The bereavement service was developed over the last few years in conjunction with the ACT Palliative Care Society, and provides information, support and counselling.

8. Why does planning ahead help?

No matter how much we prepare, the moment of death will arrive in its own time and in its own way. The experience of dying is different for every person and for every family. Sometimes, planning ahead can help make sure that you feel that you are helping during this final stage. Families can get involved in activities like:

Choosing a place for a person to spend their last days;

- Knowing what the person's wishes are; (*The person and the family may make funeral arrangements ahead of time*)
- Ensuring that affairs are in order; and
- Finding out who to call when death happens and who will pronounce the person dead and sign the death certificate.

It is important that the person's wishes are known and respected. Planning ahead will reduce the number of decisions that will need to be made right after death and provide an opportunity to talk about arrangements, concerns and feelings. Planning ahead will also reduce family stress during the early time of grief.

8.1 A checklist to help you prepare

1. Who needs to be there at the time of death?
2. Who will wash and dress the body? What will they be dressed in?
3. Are there any special spiritual rites or activities that need to be attended to?
4. Are there any last letters or words that people want to have said?
5. Is the person an organ donor? If so, who needs to be advised?
6. What things can be done to make sure the funeral is reflective of the person's needs?
 - Is there time to get the person involved in a funeral fund to help pay for the costs of the funeral?
 - Does the person want to be buried close to someone? Do they want their ashes scattered at a special place?
 - What kind of music do they want to play, what hymns will be sung?
 - Is there a need for people to say a few words? Who will those people be and what do they want to say?

Who will arrange the invitations to the funeral and put the notice in the paper.

Is there anyone the person does not want to come to the funeral?

Do people need to arrange accommodation for families and friends who will attend?

Who will be the pallbearers?

Is there a special charity that the person wants monies and gifts to be donated to, rather than people buying flowers?

What will the inscription on the headstone or plaque say?

7. Ensure that affairs are in order:

Make sure their legal and financial affairs are attended to;

Ensure there is an executor for any wills or last testaments and that the executor has been informed of their roles and responsibilities;

Close off bank accounts;

Inform Centrelink, Housing and/or other agencies and attend to their superannuation funds; and

If the person has died at home, then make sure all the utilities have been turned off and the last bills paid.

8. Gifting of household and personal effects is important:

There may be personal items that the person wants someone specific to have.

Try to attend to this wish;

Clothes could be packed away and given to family, friends or to a charity; and

Other property may need to be given away or sold.

9. Buying food and preparing for the wake and other feasting activities:

There may be activities like mowing the lawns, cleaning the house, arranging extra chairs and tables, getting in extra eskies or hiring a hall in order to fulfil family obligations and to respect people who have come from a long way; and

There may be traditional dances from the person's home community that will need to be performed.

10. Adoption or caring for children and/or pets:

Families and friends may also have to make the decision to take care of or adopt young children of those who have passed away, or be identified as a person who can care for those children. This is a time of adjustment for families. There will be traditional, legal and logistical issues to be discussed with the appropriate people; and

It is essential to hold discussions with the person who is dying about these issues, so that there are more opportunities for them to discuss what will happen and how.

9. What is the dying experience?

It is hard to say what people experience when they are dying. Palliative care approaches make people feel supported through to their death. Palliative care honours the person's choice.

Dying is much more than a medical event. It is a time for exchanging love, for reconciliation and transformation. It is a chance for a dying person's loved ones to become compassionate companions on a journey of continuous discovery.

Fear is only natural. Doubt is to be expected. Whether we are making the bed or confined to it, we will come to know and appreciate the preciousness of life.

Each person's death is as unique as their birth. No one technique can fit every situation, but the following tips can serve as a guide during a loved one's final days.

9.1 Some of the signs that death is near and what you can do

A person may spend more and more time sleeping and it may be harder and harder to wake that person up. The person may seem confused about the time and place and the identity of people around them, including close and familiar people.

The person may make restless, repetitive movements such as pulling at the bed linen or clothing. This may be due to less oxygen getting to the brain. Don't interfere with or restrain these movements but maintain speaking quietly and naturally. You can do things to help like lightly massage their forehead, read to the person or play soothing music.

Their hands, arms, feet and then legs may become cooler to the touch. Their face may become paler, and the feet and legs may become a purple blue mottle colour. This is normal and indicates that the body is shutting down.

There may be loud gurgling sounds coming from the person's throat or chest. This is because the person is unable to swallow, and doesn't mean that they are uncomfortable. You can turn the person on their side and wipe the mouth with a moist cloth.

Breathing may be irregular and may stop for 20–30 second periods. They may experience periods of rapid, shallow pant-like breathing and after death there may be a 'last sigh' or gurgling sound. These are common patterns.

The person may seem unresponsive, withdrawn or in a comatose-like state. This shows the preparation for release, and the beginning of letting go. Since hearing remains all the way to the end, speak to the person in a normal tone, identify yourself by name when you speak, hold the person's hand and say what ever will help him or her to let go.

The person may only want to be with just a few or only one person. This is also a sign of preparation for release. If you are not part of this, it does not mean that you are unloved or unimportant. It means you have already fulfilled your tasks and it is time for you to leave and let go.

The person may speak or claim to have spoken to a person already dead, or to see places or people not visible to you. This is not a drug reaction or hallucination. The person is detaching from this life, and preparing for the transition so that it will not be frightening. Accept what the person is saying. Avoid explaining away or arguing. The experience is real to your loved one and is normal and common.

9.2 How you will know when death has happened

- Your loved one is entirely unresponsive;
- He/she will not be breathing;
- The pulse and the heartbeat will stop;
- Your loved ones eyes will be fixed in one direction; they may be opened or closed;
- There will be no movement;
- The person's mouth may be open and their jaw may be slack; and
- There will be no pain.

9.3 What to do if you think death has happened

- Remain calm;
- Allow tears and feelings to come;
- Breathe deeply and encourage everyone to do the same;
- Allow everyone to be in physical contact with others: i.e. hug, hold hands or link arms;
- Gather around the person and send blessings and love in silence or speaking out loud;
- Ceremonies or prayers according to tradition;
- Warming drinks might help;
- Reassure the family that they can do whatever feels right for them; and
- Call family and health care providers according to the plan.

9.4 Supporting someone who is dying

Be yourself

Relate to the person, not the terminal condition. Bring both your strength and vulnerability to the bedside. People who are dying continue to need intimate and honest relationships.

Empathise

The greatest gift we can offer one another is our undivided attention. Listen without judgement or an agenda. Be aware of feelings and non-verbal cues. Respect the personal truths which the dying person may be discovering.

Show human kindness

Details do matter. A cool cloth on a perspiring brow, holding the hand of a frightened person or listening to a lifetime of stories. When offered with attention and love, these ordinary activities convey caring and acceptance and build trust.

Keep it simple

Have confidence in the healing power of human presence. Particularly in the final days, slow down and leave room for silence. Reduce distractions. Create a calm and receptive environment. Honour the spiritual dimensions of dying. Let go of control and be willing to acknowledge ignorance in the face of this extraordinary mystery.

10. Agencies, resources and further information is available from:

ACT Palliative Care Society

PO Box 88

Civic Square ACT 2608

Telephone: (02) 6273 9606

Canberra Hospital Aboriginal Liaison Officer (ALO)

Building 3, The Canberra Hospital,
Yamba Drive, Garran ACT 2605

Telephone: (02) 6244 2222

Calvary Health Care ACT

Mary Potter Circuit

Bruce ACT 2617

Telephone: (02) 6201 6111

Canberra Hospital – Palliative Care

Capital Region Cancer Service

Yamba Drive

Garran ACT 2605

Telephone: (02) 6244 2222

Carers ACT – Belconnen Office

Ground Floor, Churches Centre,

54 Benjamin Way

Belconnen ACT 2617

Telephone: (02) 6296 9900

Carers ACT – Torrens Office

1 Torrens Place

Torrens ACT 2607

Telephone: (02) 6296 9900

Clare Holland House

5 Menindee Drive

Barton ACT 2600

Telephone: (02) 6273 0336

Ngunnawal Aboriginal Corporation

147 Meehan Street

Yass NSW 2582

Telephone: (02) 6226 3799

Queanbeyan Community Health

Antill Street

Queanbeyan NSW 2620

Telephone: (02) 6298 9233

Winnunga Nimmityjah Aboriginal Health Services

63 Boolimba Street

Narrabundah ACT 2604

Telephone: (02) 6284 6220

Yass Community Health

Sheahan House

143 Meehan Street

Yass NSW 2582

Telephone: (02) 6221 2111

Further Information

This information is available from ACT Government Health Information – Palliative Care <http://www.health.act.gov.au/>

Bereavement Care Centre

The Bereavement Care Centre <http://www.bereavementcare.com.au> offers a range of resources – books to videos and articles – to help you through the process of grief. Phone the Bereavement Care Centre on 1300 654 556.

CareSearch

The CareSearch website <http://www.caresearch.com.au> provides palliative care information for the person and their carers, families and friends.

Child grief and loss

Children grieve – and this can happen at an early age – but not in the same way as adults. Children are likely to show their grief in less direct ways than adults. Phone Parentline on 6287 3833 for further information.

Clare Holland House hospice

The ACT hospice Clare Holland House – by Canberra’s Lake Burley Griffin – focuses on the person and their family members. Every effort is made to meet all needs whether physical, emotional, social or spiritual. Tel: (02) 6273 0336.

GriefLink

GriefLink <http://www.grieflink.asn.au/> is an invaluable information resource on death-related grief for the community and health professionals. The site is based in South Australia so information about support services is not specific to ACT.

National Centre for Childhood Grief

The National Centre for Childhood Grief, in Sydney, provides loving support in a safe place where children grieving a death can share their experience as they learn to live with its impact on their lives. The centre also provides education and training for individuals, schools and other organisations handling the grief of children and young people. Call the National Centre for Childhood Grief on 1300 654 556 or email: help@childhoodgrief.org.au

Palliative Care Australia

Palliative Care Australia <http://pallcare.org.au> is the national peak body representing the interests of palliative care service providers including anyone with an interest in palliative care both nationally and internationally.

