



May 23, 2012

Senators Siewert, Moore and Fierravanti-Wells
Senate Inquiry into Palliative Care in Australia
Community Affairs References Committee
Parliament House
Canberra ACT 2600

Dear Senators

Thank you once again for your thoughtful questions about our work and about how we might achieve a positive end of life experience for people in Australia, for those dying and those left behind.

I am enclosing information we promised to the committee, as follows:

'Bringing our Dying Home: Creating community at end of life,' by Horsfall, Noonan and Leonard, published by the University of Western Sydney, May 2011 based on the work of Home Hospice (now called LifeCircle)

'Dying Well at Home: Information for people caring for someone who is dying', the LifeCircle guide to people caring for loved ones, about what to expect in the final months

'The Carer's Guide in preparation for the Final Farewell', referred to by Oxana Paschuk, which has been replaced by 'Dying Well at Home'

LifeCircle Help Sheets available on our website. These will be published in one booklet for family carers and are currently given out at the appropriate time.

Social Return on Investment (SROI) Report on the Home Hospice Community Mentoring Program, written by Social Ventures Australia (based on the work of Home Hospice, now LifeCircle)

'Dying for Change' by UK Social Innovator Charles Leadbeater and Jake Garber, articulating what is required for people to live the kind of deaths that they want, highlighting community work done in Australia by LifeCircle; Charles Leadbeater launched the 'Bringing our Dying Home' report in Sydney in May 2011

Information about LifeCircle's June 14, 2012 Annual Conference, being held at NSW Parliament House, featuring key experts in the field (Dr. Kenneth Hillman, Dr. Richard Chye), social commentator Eva Cox, writer Stephanie Dowrick, ABC Radio Presenter Rachael Kohn

Information about becoming a LifeCircle Mentor, the Life Matters event, and LifeCircle brochures.

Please advise as to how we can be of further assistance in developing a positive end of life experience in Australia.

With sincere regards

~~Brynnie Goodwill~~
Chief Executive Officer



When Communities Get it Right: Living Well and Dying Well 2012 LifeCircle Conference

14 June 2012, 9am to 4.30pm, Strangers Function Room,
NSW Parliament House, Macquarie St Sydney



LifeCircle's 2012 Conference will bring people together to engage in conversations about dying and death, move from fear to knowledge and awareness of choices, and build pathways for a 'good end' for everyone.

Topics include: 'Engaging communities to care for loved ones', 'What it takes to live well and die well', 'Friends, families, networks and health care services working together'

Speakers include:

- Uncle Max Harrison, Yuin Elder, lore man, author: *My People's Dreaming*
- Eva Cox AO, Convenor, Women's Equity Think Tank
- Dr. Rachael Kohn, Producer/Presenter ABC: *The Spirit of Things*
- Prof Kenneth Hillman, Professor of Intensive Care, UNSW
- Dr. Richard Chye, Director, Palliative Care, SE Sydney, St Vincent's & Mater LHN
- Dr. Stephanie Dowrick, Writer and Social Commentator
- Dr. Andrew Penman AM, CEO, Cancer Council NSW
- The Honorable Marie Ficarra MLC, Parliamentary Secretary to the Premier of NSW

Space is limited so please register early to ensure your place.

Registration and information: www.lifecircle.org.au 1800 132 229





2012 Annual LifeCircle Conference

When community gets it right - living well and dying well

Thursday 14 June 2012 NSW Parliament House Strangers Function Room

8.30am	Registration, refreshment and music and introduction
9.00-9.30am	<p>Welcome to Country, Aunty Fay</p> <p>Sally Evans, Chairman, LifeCircle, <i>'Connected communities caring for loved ones'</i></p> <p>Stephen Kellaway, CEO, Olsen Funerals, Conference Sponsor</p> <p>The Hon Maria Ficcaro MLC Conference Host & Member NSW Legislative Assembly</p> <p>Brynnie Goodwill, CEO, LifeCircle, Master of Ceremonies</p>
9.30- 10.15am	<p>Opening Address by Uncle Max Harrison, Yuin Elder, Lore Man, author of <i>'My People's Dreaming'</i> entitled <i>'How do we feel when our loved ones pass over?'</i></p>
10.15-10.45am	Morning Tea
10.45-12.30am	<p>Panel Session: <i>Focus: Identifying the Issues - Dying Well: Is there no place like home? Practical Aspects and Barriers</i></p> <ul style="list-style-type: none"> - Eva Cox, AO, Convenor, Women's Equity Think Tank - Heidi Roland-Kenn, LifeCircle Mentor, Physiotherapist - Dr. Kenneth Hillman, Professor of Intensive Care, University of New South Wales - Rose Nean, Aboriginal Outreach Officer, Central GP Network with Veronica Saunders, Community Liaison Officer, Aboriginal Patterns of Care, CCNSW - Dr. Yvonne Luxford, CEO, Palliative Care Australia - Dr. Stephen Ginsborg, Director, Manly Warringah Division of General Practice Chair, Dr. Rachael Kohn, Producer / Presenter, Radio National, <i>'The Spirit of Things'</i>
	<p>Q & A <i>Focus: Identifying personal & professional barriers and how to overcome them</i></p> <p>Facilitator, Dr. Rachael Kohn, Producer / Presenter, Radio National, <i>'The Spirit of Things'</i></p>
12.30-1.30pm	Lunch
1.30 – 3.15pm	<p>Panel Session: <i>Focus: Generating Solutions - Creating change; strengthening the links between community and health care services</i></p> <ul style="list-style-type: none"> - Associate Professor Richard Chye, Northern Network Director, Palliative Care South East Sydney LHN & St Vincent's and Mater LHN - Dr. Andrew Penman AM, CEO, Cancer Council NSW - Jo Fowler, Regional Advisor, North Sydney and Central Coast, Motor Neuron Disease Association of NSW - Gerry Dixon, Clinical Nurse Consultant Palliative Care - The Hon. Maria Ficcaro, MLC Conference Host, Member NSW Legislative Assembly, Parliamentary Secretary to the Premier - Sally Evans, Chairman, LifeCircle
	<p>Q & A <i>Focus: Building and strengthening pathways between community and health services to create a 'good end'</i></p>
3.15– 3.45pm	Afternoon tea
3.45-4.15pm	<p>Closing Address by Dr. Stephanie Dowrick, Writer and Social Commentator entitled <i>'New meanings for hope: a gentle way forward'</i></p>
4.15-4.30 pm	Call to Action: Brynnie Goodwill, CEO, LifeCircle
4.30pm	Close

Dying well at home

Information for people caring for someone who is dying

Someone close to you is living through their final months, weeks or days. This may be an experience you have never encountered before.

This help sheet will help you to be aware of some of the changes which may take place as the dying person moves through the final stages of living. Being aware of what happens in these stages can help you and your family and friends live each day more fully with the person who is dying; it can relieve some of your fears and give you comfort when you know that the person you are caring for is progressing in a normal way towards their final moment. Finally this awareness can give you some ideas about how to respond to the changes that are taking place in the person you are caring for.

People die well in hospitals, hospices and in their own homes. Wherever the person you are caring for is dying, we hope this help sheet will make it possible for you and your family to surround the dying person with time, conversation, laughter, tears and love. It is written with dying at home in mind but we hope it will help you wherever you and the person you are caring for is living.

The final couple of months

The effects of dying on both the mental and physical state of each person are unique as they live their last few months, weeks and days. However there are some typical changes that might take place.

- **Withdrawing:** A person may start to withdraw from the wider world and become more preoccupied with personal and family matters, including reflections and memories. For example, a person who had been very interested in current affairs may no longer be interested in the daily news.
- **Finding busy activity or a group of people no longer easy to manage:** For example a large family gathering may be overwhelming despite evident pleasure in the event.
- **Irritability over daily busyness:** A person may feel that they need to take more time over each step in the day rather than rushing through a list of what used to be manageable tasks.
- **Anxiety and agitation:** A person may feel that they are running out of time to complete whatever has become important to them or they are fearful about what is ahead of them.
- **Sleepiness:** As the body's mental and physical functions deteriorate a person may need or may want to spend more time dozing or sleeping. Talking and being with others as well as eating and drinking may be exhausting.
- **Eating and Drinking:** The body's gentle process of shutting down means that a person may want less to eat and drink.

What can you do at this time?

For yourself

- Try not to respond to or be upset by unexpected irritability or frustration on the part of the person dying. You may have done nothing to cause it.
- Plan each day at the pace that is comfortable for the person dying and for you. It might be a very different schedule than you are all used to so give yourself permission to go with what seems to be important now rather than what you are used to achieving or expecting to happen.
- Be ready to abandon your daily plan and just enjoy the moment with the other person and all the important people in your life.
- Say “Yes!” to every offer of help from people who can support you at this time and enable you to prioritise what has become important in these final months. You will have plenty of time later to say thank you and to reciprocate. If you are having difficulty saying “Yes” it might help to reflect on how good you feel when someone lets you help them! Allow the people around you to enjoy that good feeling too.
- Find time to talk to whoever can help you if you are feeling unsure about how to cope from day to day or how to manage overwhelming emotions. A family member or friend, a LifeCircle mentor, a counsellor, religious leader or your GP can all support you on this journey.
- Don’t be afraid of talking about dying and death with whoever you need to including the person dying. It’s time to talk freely about what is happening and it feels good to allow laughter as well as tears. Don’t be afraid to include children—they need to understand and to feel that they are part of these momentous events.
- Do whatever you need to do to ensure that you are getting some sleep
 - Get help in overnight or respite care
 - Get help with the early morning routine of children and daily transport to day care, school, sport etc
 - Prepare a thermos, small snacks or lay out whatever you might need to find in the night so it is accessible and minimises disruption for you and your household.

For the person you are caring for

- Manage visitors (or allocate that task to someone else) at a pace which isn’t too tiring or too many at once. A visit may now consist of sitting and chatting around the bed while the person dozes and enjoys the companionship without participating very much in the conversation.
- Ensure that the person is able to sleep as much as they want to and prioritise other activities according to what each day brings.
- Small snacks and sips of liquid throughout the day may be more palatable than set meals at the usual times. Tastes may change or some foods may be easier to eat and preferred now.

- Reading to the person rather than expecting them to find the energy to hold a book or a magazine might become an important part of their day. They might prefer to listen to music. Bring household activities such as meal times into the person's room or move them into a living room even if they don't want to sit up and eat with the family.
- Provide extra pillows wherever the person is sitting or lying to ease sore or stiff spots. Pillows may also enable the person to enjoy watching the daily round without having to sit upright.

The final few weeks

As the body and brain prepare for death, more changes may be observed during the final weeks.

- **Withdrawing:** Social activity may now be impossible as the person dying is too exhausted or drowsy to participate in any social activities. They may still enjoy the sense of movement and chatter around them as they drift in and out so don't feel you should leave them alone or keep the house quiet. Ensure that they have a sense of movement and normality in the household remembering that the ebb and flow of daily routine is the reason you and your person want to be at home during these remarkable days.
- **Activity:** As the body and brain steadily shut down, the person may not be active in any way. There is information below about how to maintain comfort and hygiene at this time.
- **Anxiety, agitation and restlessness:** Chemical changes in the brain can affect thinking, awareness and emotion. The person might be confused and disoriented at this time. They may be unable to recognise their surroundings or familiar faces. This can be frightening for the person and upsetting for family and friends. They may also be restless or agitated at this time.
- **Sleep and consciousness:** The person may now be drifting in and out of consciousness and gradually becoming unable to respond even though they can probably hear what you are saying. They may dream vividly or be incoherent in what they say. Your presence can be of great comfort to them.
- **Eating and Drinking:** Your loved one may now refuse most or all food and drink. This is a natural change, as the body no longer needs nutrients. However the mouth and throat might be uncomfortably dry so sips of water or juice, sucking ice or gently moist mouth swabs can relieve those feelings. Cream for dry or cracked lips might also be very soothing.
- **Incontinence:** Sometimes people who are dying lose control of bladder and bowel because the muscles in those areas relax and no longer function normally. This can be both embarrassing and uncomfortable but can be managed with advice and perhaps equipment from a community or palliative care nurse. As less fluid is drunk, urine becomes stronger and darker in colour and there may be little faeces in these final few weeks as very little food is eaten.
- **Breathing:** Breathing patterns change as death approaches. Breathing may become rapid at times, or irregular with pauses between breaths. Moaning noises may sound disturbing but can simply be caused by air moving across weak vocal cords.

- **Skin and circulation;** As the body's circulation slows down the face, hands and feet in particular usually become cooler and sometimes more sensitive when touched. They may look bluish. A person's back may become mottled, as blood flow moves away from non-vital areas to protect vital organs for as long as necessary. Temperature may fluctuate between being too cold or too warm.

What can you do at this time?

For yourself

- Do whatever you need to do to ensure that you are getting some sleep
 - Get help in overnight so you can sleep knowing you will miss nothing momentous
 - Get help with the early morning routine of children and daily transport to day care, school, sport etc
 - Prepare a thermos, small snacks or lay out whatever you might need to find in the night so it is accessible and disruption for you and your loved one is minimised.
- Plan for what an emergency will look like for you and the dying person and think through the necessary steps and the implications of any emergency medical emergency intervention such as calling an ambulance and being moved to hospital. Take into account the dying person's wishes if you know what they are.
- Get all the information you need to help allay your fears and give you a feeling of control and calm in the face of the profound events awaiting you.
- Say everything you need to say to everyone important to you at this time and listen to whatever they need to say to you.
- Provide opportunities for all the important people to be involved to whatever extent is comfortable and appropriate.
- Don't feel guilty or neglectful about the person eating and drinking little or nothing at this stage. While providing food is a very powerful way to show love and concern, the refusal to eat and drink is a natural part of the dying process and is not uncomfortable for a dying person.

For the person you are caring for

- Comfort and rest will be priorities now, so plan visits and any activity, however small, according to what the person wants and needs.
- Settle agitation or distress with familiar surroundings, calm reassurance and stroking or gentle touch or massage. You may need to remind the person of your own name and assure them of your presence.
- Keep talking with the person, even if they appear to be sleeping or drifting in and out of consciousness. Assume they can hear you even if they can't respond. Bedside chat with family and friends can be comforting for everyone.

- Even though the person may be eating and drinking little or nothing now, make sure that cracked lips are soothed with lip cream and mouth is kept moist and fresh. Mouth care can be very important to the comfort of the person now.
- If incontinence is a problem, there are bed and personal products available to help you manage this. A community or palliative nurse or a pharmacist will be able to advise you. However, as food and fluid intake reduces this may now become less of a problem.
- Breathing may be increasingly erratic and noisy. This might sound alarming but once again this is probably normal and caused either by slack vocal cords or secretions collecting at the back of the throat that the dying person is no longer able to cough away. Propping up the bed head with pillows or laying a person on their side can help to drain secretions. A cool mist humidifier in the room may also help. Snoring and snuffling may also increase as jaw and throat muscles weaken and the tongue drops further back. In general the person is not lacking oxygen but just going through a natural process as the lungs and breathing shut down.
- Breathing distress (which may be due to confusion or agitation) is uncommon but can be aided by slow steady breathing together with the person in a rhythmic and calm way. A fan or airflow can also help as long as it doesn't make the person cold or shiver.

The final few days

What can you do at this time?

For yourself

- You, your family and friend may want to be constantly near the person dying now. This might mean enlisting help with anything and everything to keep the household running. It might also mean letting go of all other daily priorities or having alternate arrangements in place.
- Give yourself permission to radically change your priorities and your focus so that you can make the most of this precious time with and for whoever is now part of this journey towards death.
- Ask for the help you need so you can be free to do, feel and say exactly what is right for you at this time.
- Plan to sit with the dying person in shifts, if possible, so that everyone can both be involved and get some rest. Alternatively, rest or get some sleep near the dying person's bed.
- Be bold in saying what you want to say and doing what you want to do with and for the person dying. This is a time when powerful memories can be created which will form a cornerstone of the legacy that is being built for you and yours.
- Assume that what is said to and near the person can still be heard even if they are barely conscious or apparently unconscious.

For the person you are caring for

- There may be brief surges of energy with requests for particular meals or to get up and dressed. There may be a feeling of contentment as soon as the request is acknowledged without it having to be acted upon.
- Restlessness may increase and can be addressed in the same way as discussed earlier. It may be due to lack of oxygen or it may be due to confusion and disorientation. Calming reassurance and gentle stroking may work equally well to settle the person irrespective of what is causing the restlessness.
- There may be a sense that the person is waiting to complete unfinished business or for the arrival of someone special in their lives. You may be able to provide closure and encourage the person to let go when they are ready without having to wait unnecessarily.
- The skin may feel quite cold now and may be very sensitive to even the gentlest touch.
- Speak with the person as though they can hear and understand all that is said.
- Eyes may be partially closed and mouth may be open as muscles completely relax just before death.

The final breath

The final breaths a person takes can be intermittent with seemingly endless gaps between them. They can be surprisingly loud if fluid has been accumulating in the lungs. This is sometimes known as the death rattle. Do not be alarmed; this is often a normal part of the process.

Eventually the person will stop breathing altogether. There will be no pulse as the heart also stops beating. There may be a few muscle twitches, but that will stop quite quickly. The face will relax and the pupils will be large and still.

After death, the body goes through some more changes. As muscles are completely relaxed, body fluids may be expelled from the rectum, bladder or mouth, which can be upsetting if not expected.

What can you do at this time?

For yourself

- Remember that there is no hurry to do anything at all.
- Take the time you need to say goodbye, share this moment with the people around you and complete the journey of caring on which you embarked with the person who has just died.
- You may want to touch or hold the person or you may prefer not to. Make your own decisions about how you would like to spend this time and let others also make their own choices without impacting on each other.

For the person you are caring for

- You have just completed the enormous task of doing everything possible for the person who has just died. Allow yourself and your family to become the focus of concern and connectedness now.
- There is nothing more you need to do.

Immediately after death

There is no hurry to have the person's body taken out of the home. If the weather is very warm, keep the room as cool as possible. Muscles won't start to stiffen for some hours, so take your time. You might want to arrange the person's body straight on the bed and tidy any fluids away or place towels or pads underneath the body. If the person's mouth is slack and open, roll a small towel under their chin.

You may want to wash the person's body, comb or tidy hair or change their clothes. You may want to do nothing but sit or you may need to be outside or in the fresh air. Choose what is right for you and give yourself permission to do just that. Family, friends and especially children may want to be near the person, touching, stroking and holding them in order to make death and the nature of this farewell meaningful for them as well.

When you are ready, a doctor who has seen the person within the last 3 months can arrange a death certificate. You will need to advise them of the time of death. If a funeral director is taking the person's body, they will be able to remove the person's body after the death certificate is available. You can look at one of our other help sheets about planning a funeral if you are unsure about what happens next.

Once the person who has died has been taken out of the home, emotions may flood and overwhelm you and yours. You may be both exhausted and unable to sleep. Give yourself permission to feel proud of the ways in which you have accomplished a unique task. You have shared the gift of living well and dying well with the person who has just died and with everyone who has been a part of that person's life and death.

Next Steps

A **LifeCircle** Mentor has experience of caring for someone at the end of life. They help carers through these final months, weeks and days by staying in contact as a supportive listener with ideas to help carers on their journey of caring for someone who is dying. . If you would like more information about being matched with a Mentor, call **LifeCircle** on **1300 364 673**.

There are other help sheets in this series. They are all on the **LifeCircle** website **www.lifecircle.org.au**.

If you need emotional support or a listening ear call **LifeCircle** on **1300 364 673** to talk to one of our Telephone Counsellors.

This help sheet may be freely downloaded, copied or distributed on condition no change is made to the content. The information in this help sheet is not intended as a substitute for professional medical advice, diagnosis or treatment.

Thank you to Olsens Funerals for their support in producing this help sheet.



LifeCircle was established through the merger of Home Hospice and Life Goes On. We provide telephone counselling to people living with a serious illness and their families and friends and mentoring for people caring for someone who is at life's end. **LifeCircle** also holds Life Matters educational events that help people prepare for the later stages of life. Our dedicated staff and experienced, trained volunteers help thousands of Australians every year. **LifeCircle's** work in the community is free of charge due the generous support of private and corporate sponsors. For more information visit our website www.lifecircle.org.au or call 1300 364 673.