



Becoming a LifeCircle Mentor

Have you cared for someone at end of life?

If so then you could use your wisdom and experience to become a LifeCircle Mentor to help others who are presently caring for someone in your community. If you or someone you know would like to become a LifeCircle Mentor, please contact us to learn more about our next Training Session, which will be:

- **Saturday 19, Sunday 20 and Saturday 26 May 2012**
- **9.00 am to 4.30 pm**
- **LifeCircle, Level 6 (Cancer Council Building)
153 Dowling Street, WOOLLOOMOOLOO**

LifeCircle Mentors:

- Have cared for someone through end of life (two years ago or more)
- Provide confidential, non-judgmental listening skills incorporating resources and skills to empower others to keep well and effectively manage complex and distressing issues
- Encourage people caring for loved ones to invite family, friends and community networks to help and support
- Remain in contact with the person caring for thirteen months post bereavement, or as required

How can I become involved?

- Have an hour or so per week to talk with someone caring for a loved one at end of life
- Learn more about and share with others the medical, palliative and community resources which can support families at this stressful time
- Call LifeCircle on (02) 9334 1393 or 1800 132 229 or contact Jamie at jamie@lifecircle.org.au for information about how to apply





LifeCircle Mentoring: Information for Health and Community Staff

LifeCircle Mentors provide *free peer support for people caring at home for someone one at the end of life*. Our Mentors are trained volunteers with personal experience of caring at end of life. Complementing services such as home-based palliative care and community nursing, **LifeCircle** Mentors focus solely *on the needs of the carer* and on building carers' capacity to care with less anxiety and greater confidence.

LifeCircle Mentors develop *an ongoing relationship with carers* through actively listening, emotional support, understanding and guidance about the practicalities of caring for someone at home at end of life, information about the dying process, and assistance linking with relevant services. *Carers are also supported to engage their personal network* of family, friends, neighbours and colleagues and involve them in the caring. Overall this range of support increases the opportunities for the dying person to live through their illness in the comfort of their own home with their families and friends. The **LifeCircle** Mentor can also provide ongoing carer support for up to a year after the death of the person being cared for.

LifeCircle undertakes a stringent selection process for Mentors, who are provided with training and ongoing support and education. Evaluation demonstrates that **LifeCircle** Mentoring results in improved quality of life and reduced anxiety for the carer, and a healthier bereavement for those engaged in the caring.

Health and Community Services Introductions

LifeCircle Mentors complement health and community services. If your clients are caring for someone choosing to live at home at the end of life they could be assisted by a **LifeCircle** Mentor.

Carers can link to a **LifeCircle** Mentor either by calling us themselves on **1300 364 673**, or by giving consent for a Service Provider to 'introduce' them to a **LifeCircle** coordinator. The introduction will be followed up by the coordinator within two working days and every effort will be made to match the carer with the most mutually compatible mentor.

To introduce a carer to **LifeCircle**, and for any additional information relating to **LifeCircle** mentoring, service providers may call the New South Wales Coordinator, **Jamie Parker-Smith** on **0406 606 446** or email: jamie@lifecircle.org.au

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.

The Carer's Guide

in preparation for the Final Farewell



HOMEHOSPICE

Community's Heart



Preparing for the final farewell

Notes for help in the time of caring for a loved one

To understand the final stages of life it is important to remember that dying is not a medical illness. It is not a condition that requires special technical equipment only found in hospitals in the hands of highly skilled professionals. Dying is a social event which belongs, when it is at all possible, within the family circle, in the home.

Death is the natural process by which we are separated from our physical body. It has finally become worn out, or perhaps is no longer able to function, and our physical life is no longer possible.

When the dying person is able to remain at home among loved ones a common observation is that there are fewer symptoms and less pain and discomfort. Usually the end of this process then is a very gentle release, a calm transition.

For each of us life is a unique journey of which dying is an inescapable, natural event. Our dying will be unique, as was our living.

These last weeks, days, hours together become more and more precious for loved ones. It is a time for closeness, a time for loved ones to be together in an even more intimate way than ever. Not just physically, but in mind and heart. It is a time for openness and honesty, expressing our emotions, affirming our love, trusting one another, a time for gratitude and forgiveness, a time for memories, a time for hope.

It is not a time for deception, for cracking hardy, for protecting one another from reality. Having shared so much through life, now is not the time for that. It is a time to be together in the most real way, to be authentic.

Physical closeness is one way we reassure the dying person of our nearness. Holding hands, stroking the forehead, gentle massage. Foot massage is almost always possible and a great way to help with pain relief.

Being in touch physically will make it more conducive to personal closeness, for sharing emotions, grieving together, sharing tears and memories. But allow for laughter, too, amid your tears. Both are helpful in the control of pain, the pain that is felt in the body. But, of more importance, is their need for the purpose of healing the person, soul pain. And while doing this you are also providing for your own needs, both in relation to your pain and your own healing in the bereavement time ahead.

Bear in mind the sense of hearing is the last sense to be lost. In fact it is heightened in the last stages of life. When death seems imminent and all communication seems to have been lost, assume the dying person can still hear you. You may want to ease their struggle with words that tell them they are free to go, that you understand, that you will be able to bear the loss.



Some are comforted by the belief that we do not die alone but that our dead loved ones come to comfort and assist us. Whatever about that, the shared experience of death can be as wonderful an experience as that of birth.

All that is not to deny that there is an enormous burden, physically and emotionally, on you at this time. If you are to care for your loved one in the way you want to, you must take best care of yourself. No trying to do everything yourself. No superhuman efforts that leave you exhausted, unable to think, sleepless and distressed. You have family, friends, neighbour, lots of people who have offered to assist you, who really want to share this labour of love with you. Use them. They will be grateful to be included and to be able to express their love practically. That way you will be free and better able to spend more time with your loved one.

Death naturally confronts us with questions of meaning and purpose, our worth as a person, destiny, life after death, the nature of man, all those spiritual matters we may or may not have dealt with.

Some may have found a faith in which their spirituality is nourished, a formal religious body to belong to. Bring that support into the home, especially if it is rich in ritual and tradition that can comfort and support the whole family. People praying together have a special kind of intimacy and bonding, and for the dying now taking leave of the body it means a profound solace and healing of the soul.

For those who have no formal religious affiliation, don't shy away from these concerns. Deal with them in your own simple, honest way together as a family. Ask help from anyone you may feel could help in such a situation.

As you reminisce and share your memories, as you look back on your struggles and express your love and gratitude and trust, as you nourish one another's courage between your tears, know that you are dealing with the spiritual aspect of life from which will come the rich legacy you will want to hold on to. For this reason some people actually record these times and talks, or later make notes to ensure their memory of them.

The dying journey

4 - 8 Weeks Before Death Occurs

Our dying is as individual as our living. The time taken and the way in which we leave our body is very similar to what happened at our birth.

These notes are a general guide as to the expected events which may occur. You may note your dying loved one experiencing some or all of these changes.

With the sometimes subtle, sometimes unexpressed awareness that death is approaching the dying person begins to withdraw from the world. People who are aware that they are dying become more concerned with their interior life. They lose interest in such things as television, or reading and making small talk, preferring intimacy with family and close friends who can just simply be with them.



Food and drink is not so necessary now as the person focuses away from those physical needs. This loss of desire to eat is one signal the person is preparing to leave. It would not be appropriate now to force food. At this time the energy needed is more of the spiritual nature, and it is this energy that is working deep within that person's being.

Sleeping also increases during this stage, and staying in bed longer as we see a gentle shutting down of the physical body. The key to helping your loved one is just to allow. Do only simple things: have sips of fluid constantly available, e.g., fruit juices, Sustagen Small ice blocks are pleasant to suck on and help a dry mouth. Feed only nibbles of semi-solids.

To make the bed really comfortable you may borrow a special mattress. Have lots of soft pillows.

Keep a thermos at the bedside during the night so you don't have to get up to prepare anything. If possible give one multivite a day to keep the skin healthy. To this end give a gentle massage with lovely oils.

Listening to favourite music softly playing is often the most pleasant activity for the dying person whose energies are at a low ebb.

Summary

That death is now approaching, and your loved one is aware of it, is indicated by

- their withdrawing from activity in the world
- physical changes (no interest in food, sleeping more)
- their increased focus on interior, or spiritual life.

I - 2 Weeks Before Death Occurs

Much of the time is spent sleeping now and there may be some disoriented times. Remember being sick yourself and sleeping much of the time? It's a very comfortable feeling to be in the dreamy state, but you lose track of time and events in the outside world.

Your loved one may still converse with you but may wake up somewhat distressed. You will quietly re-orient them with a gentle, calm voice, even identifying yourself by name. Encourage deep, slow breaths, the most useful tool for confused states, anxiety and pain causing restlessness.

You may help them relax with gentle massage or stroking, and playing gently some calming, pleasant music.

In this altered state of consciousness they may 'see' loved ones who have gone before them, they may have dreams that seem real to them. Don't be afraid to talk to them calmly about their experiences or to re-orient them when that is appropriate. Sharing of such dreams can help us understand a little of what it must be like to be between this world and the next.





All these physical changes are to be seen in terms of machinery that just isn't working properly any more. Everything is topsy turvy.

Skin colour may be very pale, greyish or jaundiced. Temperature can go up or down, and in the space of a few hours. They can be perspiring and feverish one minute, freezing the next.

Don't be alarmed, but just respond to those physical changes with common sense. A little fan and an open window does much to settle a feverish body and correct the sensation of difficulty in breathing. And in the case of the chills, a soft doona.

About this time breathing patterns change. Breathing may get very rapid, or irregular with pauses. Sometimes in sleep there is a kind of moaning sound which simply occurs as air passes in and out of the lungs over relaxed vocal chords. At this stage all these changes are likely to come and go.

What to do? Again, it is often very helpful to encourage steady, deep breathing, in and out. It's a good idea to practise this together at any time and as often as possible. Gentle stroking can be a good sedative, or reading to the patient, or playing soothing music.

Urine decreases, but due to advancing profound weakness incontinence may occur. Mattress protectors (or 'Depends') will protect and provide comfort, and these are provided by community nurses visiting the home.

Summary

As the dying process continues the physical changes are more marked:

- skin colour, texture
- breathing patterns
- increased sleepiness, weakness, more time in bed, tired all the time
- consciousness may vary, dreams may be vivid.

1 - 2 Days Before Death Occurs

This is the time when you and the family will want to be free to be with your loved one around the clock. Take it in shifts and have it all fine-tuned -two at the bedside while the others take brief rests. In this way you can all be fully involved in what can be for you a wondrous experience.

Often the patient has a sudden surge of energy. There may be lucid intervals when conversation is quite clear. There may be a request for a favourite food, even to be dressed. Usually these are very brief experiences and you can go along with those wishes as best you can, but then the patient settles back down as if satisfied, to continue on the journey.

There may be talk about wanting to go home. This may not be a reference to their earthly home.

The physical changes of the previous section are often accentuated. Restlessness may increase, often due to a lack of oxygen. Do some breathing exercises together, quietly talking, stroking to relax the patient. Your being there is their best reassurance.



Keep playing soft music throughout this phase, even till the time of death, making sure it is the kind of music conducive to the patient's calm and relaxed state.

Chest secretions may now begin to sound very rattly. This can be very disturbing for the loving carers, but not so for the patient. Prop the patient up with pillows if you can, and turn the head to one side. That will usually take care of the sounds. It is simply that profound weakness prevents chest secretions from being coughed up. Don't be alarmed. There is no need for fear of choking on these secretions. We do have medication which will dry these secretions up.

Sometimes the patient will make moaning sounds. These are not the result of pain but weak and loose vocal chords vibrating as air passes in and out.

Sometimes there is incontinence. Towards the last day or two, however, the intake of food and fluid will have dropped completely so that the elimination is minimal.

Colour changes may be noticed in the hands and feet as they take on a bluish cold-feeling effect. This may be associated with areas such as the back becoming mottled, a further indication of the slowing down of the circulation. The body shuts down the blood flow to non-vital areas at this stage to protect vital organs for as long as possible.

It is important to emphasise again that this is a very individual journey for each of us. Some take only minutes to die, others much longer. (Sometimes the dying person will be holding on because of fear, or the need to finish some business, or to await the arrival of an absent family member.)

As your loved one is actually now approaching closer to death you might move closer. Close enough to be heard. One of the great advantages of dying at home is in being able to be this close, this intimate; being allowed to go as far along this journey together as possible.

So, talk, pray, bring the family around the patient and talk together. Don't pass up this last opportunity to say the loving, healing, helpful things your loved one needs to hear - and you need to say.

Stay literally in touch, holding hands, embracing, stroking the forehead, so that your physical presence is felt.

If conscious during this time the dying person may well have taken the opportunity to say goodbye to family members and friends. Sometimes the patient lingers in this state for some time and people, for their own grieving, may want to return and say goodbye again. This can tire and distress the patient unnecessarily.

If at this time you would like your priest or minister present you will have anticipated this, you will have come to know what the dying person would want and you will have made some pre-arrangement. If you haven't been shy or reticent about this it won't have been left as an afterthought, and this ideally would not be the first visit.

Assume your words are heard and understood as you calmly express your love and reassurance, being very close and allowing yourself to say what you really want to say, allowing your tears as you allow nature to take its course and your loved one to continue on the journey.



Summary

This time of caring is what used to be called the death watch. It is a time of being with the dying person, with constancy and reverence, calmly accepting nature's process of the many physical changes taking place. There will be changes in the patient's breathing, confusion and restlessness, picking at the bedclothes. The extremities will become bluish, the chest rattly from secretions. There may be moaning sounds; and there may be lucid intervals, and evidence of much energy at times.

If you have been wise enough not to have exhausted yourself with chores over the previous days and weeks you will have energy and attention for this, the peak time of your caring. It will be over only when death occurs.

Minutes to hours before death occurs

By now your loved one may not be responding to you. Breathing has become extremely irregular, with long pauses. Chest secretions may be a problem and skin temperature will be very cold.

The patient may appear to be sleeping, although the eyelids may not be closed, as a measure of their weakness now. The mouth is open to allow for every shallow breaths.

You are now very close to the event. Say your goodbyes, if you can, but at least use the sense of touch to express your nearness. Your very presence is a loving reassurance.

Expressing your willingness to release them is further evidence of your love.

Hearing is the last sense we lose, and your loved one needs to hear your voice now more than ever.

You might tell them again to have no worries on your behalf, that you will be alright, that those they are leaving behind will care for one another, that you understand they have to leave you.

It may seem the dying person is ambivalent, wanting to go and yet wanting to stay. Sometimes this is an actual experience if the patient is still conscious.

What we mostly see with death actually occurring is nothing more dramatic than the cessation of breathing.

Breathing becomes shallow, and open-mouthed, a few more breaths..... and then, nothing.

Death has occurred.

Summary

You may share these very final stages of the journey even as far as the moment death is completed.

- The physical changes:
- eyes open - looking up, beyond
- skin temperature very cold
- breathing very irregular: stops, starts, goes rapid, then stops
- rattly chest, moaning sound
- consciousness fading



We labour, sometimes arduously, to enter this life in the process of being born. Just so, the process of leaving our physical body is one of labour. For some, in birth or in death, it is comparatively brief; for others it can be very long. That's just the way it is; not that one is more correct than the other. And we only speculate as to the reason for the difference.

When you have provided for your loved one to be able to die at home know that you have given a very great gift.

All the energy you have expended in doing the actual physical work will surely then be richly compensated for by the way your grieving is affected.

All that generous, loving care will have mysteriously generated a reward for you. You will have a deep sense of having given of your best. Your body may be tired, but your heart will be the stronger and the lighter for all the loving it has done.

You will be sad, of course, and you will still have to endure the pain of coming to terms with the loss. But you will be happy for having loved so well, so fully. And that will sustain you through your grieving.

You will have no need to fear.

Something else. Your gift was more widely appreciated as you allowed family, friends and neighbours to share the experience, the privilege. Your gift will have enriched your community in a special way, brought them closer to you and to one another, opened minds and hearts, and given them a new appreciation of life – and death.

They will be as grateful to you as you to them.

Your friends, intimately linked to you in this way, will be there for you in the grieving time ahead.

After death has occurred

Remember that you don't have to rush around to do anything.

Just take your time.

This is a time to be close to your family and grieve together.

When you're ready, call your doctor, who will need to write a death certificate.

Ask someone to call the funeral director. You will have given some thought to this already. Let the funeral director know when you would like the body removed. You may want some hours together still, or you may be ready sooner.

Meanwhile lie the body flat. Place some absorbent pads under the body and fold the arms over the chest.

If an open mouth is troubling you, fold a towel and place it under the chin.

Some want to wash the body, comb the hair or dress it. Others want to leave it the way it is. There is nothing you have to do.

Those present should feel free to go in or out of the room as they wish, to spend some grieving time. Children, especially, often want to see and feel death several times in order to take in the reality. Allow them to do this as they want, knowing there are no musts.



Once the funeral director has been and the remains have been taken away you will begin to realise how very tired you are. Don't oppose your body's need to rest now. Allow your close friends to look after you.

You may not be able to sleep despite being so tired. Just allow yourself to be still without trying to sleep or not to sleep.

Even through the tears and loss you will have a great sense of completion of your work of love.

As a daughter said, after the death of her father at home recently, "You know, I haven't had any children, but I feel as though I have just given birth."

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ON LOAN FROM HOME HOSPICE INC

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