

DYING AT **HOME**



The Carers Guide in Preparation for the Final Farewell

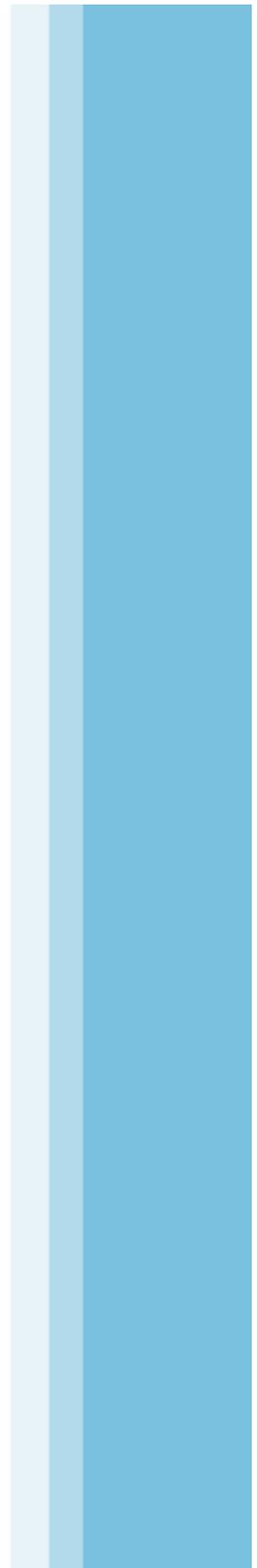
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PREPARING FOR THE FINAL FAREWELL

Notes to help in caring for a loved one at the end of life

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 is 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 soul pain, the pain felt in the person. Both laughter and tears shared authentically can help with the healing. 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, know that 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 deceased 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, neighbours, lots of people who have offered to assist you, who really want to share this labour of love with you. Invite 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

This is simply a general guide as to how nature usually proceeds towards the end of life. It is not a prediction, the time may vary.

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.

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, as is 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.

IN 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 (less interest in food, sleeping more)
- their increased focus on interior, or spiritual life.

1 - 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.

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 absorbent pads will protect and provide comfort, and these are provided by community nurses visiting the home.

IN 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.

Be aware your loved one is still living. You need to be sharing your living presence. Ensure someone is present at all times, if at all possible, at the bedside, in touch with your loved one literally. Share your living still, your breathing, talking, praying, singing – whatever. Be close. This is your last loving gift, and your heart is fully in your giving.

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 dying person 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 dying person 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 your dying loved ones 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 your dying loved one. Prop the dying person 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 dying person 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 dying loved one 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 dying person 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 dying person unnecessarily.

If at this time you would like to connect with your religious or cultural tradition 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 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 dying person'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, skin temperature 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 very 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; your loved one needs to hear your voice now more than ever.

Reassure your loved one not to worry about you, that those being left behind will care for one another, that you understand this parting has to happen.

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...
Your loved one has left their body. Death has occurred.

SUMMARY

You may share these 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, becomes 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

Be still. Take your time to experience this profound moment.

Be aware of those who have shared this experience with you. Extend your care to one another, appreciate their love and now their grief and sadness.

Be grateful for the opportunity to have loved and served in such intimacy at such a special time.

Be unhurried with your memories of your loved one. Be free with your emotions and your embraces with those you are comforting. You may even have your own rituals to express yourselves when words cannot. You may have a tradition of special prayers to be said together after death.

Take time to reflect without distraction. There is no hurry.

Know that you can remain together at home for as long as you want. There are no rules, only the family's wishes to guide the next steps.

Only when you are ready, call your doctor, who will need to write a death certificate.

When you are ready call the funeral director. You will have given some thought to this already. Let the funeral director know when you would like

your loved ones body removed. You may want some hours together, even days in your tradition, 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 and allow the room to cool. Cover the body with a sheet only.

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 other than to observe your cultural traditions.

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. Having children, even very young children, involved in caring does so much to remove fear and encourage understanding that death is part of life.

Once the funeral director has been and your loved one's body has 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, "You know, I haven't had any children, but I feel as though I have just given birth."

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