

Being with your child at the end of life's journey: knowing when death is near and how to ease the way with love

Dying is what happens as the body slows down in order to finally stop its work. It is the bridge between life and death. Dying is also readying the emotional self to let go. Your great gift to your child will be your calm presence as she prepares. We want you to know what to expect and helpful ways to respond during the final days and hours. In time you may be able to remember the last moments as a shared experience, as meaningful and dear as other significant spiritual times in your life.

Signs that the body is preparing for death:

Note: you may have seen some of these signs months before your child dies. The signs, themselves, do not necessarily mean death is close. However, these signs are almost always a part of dying.

* **Sleeps more and is difficult to waken**

Plan to talk to your child during those times when he seems most alert or awake. Even when your child is not sleeping he may seem withdrawn and "away." He may stare off into the distance. This is a normal part of letting go. Always speak softly and naturally even though there is no response. Never assume your child cannot hear; hearing is the last of the senses to be lost. Repeat the messages you want her to know into her last moments.

Hold or stroke his hand or cheek. Never shake an arm or shoulder in an effort to wake your child or pull him back to you. One way of "being with" your child in this "waking sleep" is to lie beside or sit close and breathe with your child. It will draw you together.

* **Eats and drinks less and less**

Offer spoonfuls of favourite foods and sips of drinks while your child is able to swallow. There is no point in coaxing food. Eating and digesting takes energy. The body will conserve its energy. A time will come when your child may hold food in the mouth but not swallow or refuse to have anything at all. This is a clear sign that you should stop feeding. You can still do mouth care to prevent thirst and dry mouth.

To be a calm presence:

- ♦ Speak in a slow, low voice
- ♦ Relax your shoulders
- ♦ Slow and deepen your breathing
- ♦ Slow down your movements.

For several months or weeks, you may have seen changes in the way your child's body and mind is working. In the days or hours before death, the body and mind will wind down even more. Think about a clock that slows to a stop. For some children death comes more suddenly.

* **Breathing patterns change**

Your child's breathing may become irregular. A common pattern is shallow breaths with rests of 5 to 30 seconds and up to a full minute between. Or, you may hear your child panting and then breathing may slow down further and further with long breaks between. Saliva and mucous may collect at the back of the throat causing a gurgle/rattle. This is because your child cannot swallow. You may find this disturbing but it is not a sign that your child is in distress. Stay with your child rather than running to make telephone calls or set emergency systems going. Lift her head, or turn her onto her side so the secretions dribble out if you want to. Gently wipe the mouth with a soft towel. After death there may be a "final sigh" or sound from the throat.

* **Body cools**

Your child's hands and arms, feet and then legs will feel cool. The skin may look pale and/or mottled blue. This is a normal sign that more blood is going to the most vital organs and less to the limbs. Cover with a warm but light blanket. Don't use one that is electric or pile heavy coverings onto your child.

* **Bowel and bladder is less controlled**

You will notice that there will be less and less urine flow and it will get darker as it gets less. As death gets close, the muscles will begin to relax and your child may lose bladder and bowel control. You may want to use incontinence pads or diapers and pad the bed with a towel. Discuss with your health care professional. If you are at home, supplies may be available from the program supporting your child's care.

* **Restlessness**

Your child may appear agitated and restless, pulling at sheets or clothing. She may repeat a phrase many times. Don't try to stop this. Rather, be a calm presence by lightly stroking the head and humming. Some people suggest that you talk quietly about staying beside her. Let her know that you are ready now to let her go. Say goodbye, or whatever words seem right.

* **Confusion about people, time and place**

Your child may seem not to know even close family. This is hard to accept, but try not to insist and badger the child to recognize someone, even you. Just say who you are in a soft, clear voice. Keep giving messages of comfort and love. There are many ways to be known. Hearing is the last sense to shut down.

* **Vision-like experiences**

Dying people sometimes speak to, or about, something or someone not present for you. Accept what your child sees as there for him at this moment. Do not try to find out more or correct him. If your child seems frightened just comfort and say again that you are beside him and will not leave him alone. Leave a soft light on in the room.

Parent voice:

We used singing and music to create calm for our child and ourselves. Music has always been a joy and comfort in our lives.

Preparing for the hour of death

Although you may be prepared for the dying, you may not be prepared for the death moments. It will help if you and your family can discuss what you want to happen at that time. These are some things to consider:

- * Who in the family wants to be present? Who will call them? (Keep a list of telephone numbers at hand.)
- * Who will take care of young children? What backup do you have if you can't reach them?
- * What about older siblings who choose not to be present. What is the plan?
- * What health professional will you call if you find, at the end, that you want a professional with you? What do you do if you cannot reach him?
- * Who will make the calls?

If you are in a hospital you can explain your plan to the staff. You can ask them to help you with the plan. For example, say if you want only your family in the room. Say when you want to hold your child in your arms. You can ask for your spiritual advisor to be called.

If you are at home and for any reason you cannot cope, call the ambulance. Make sure you give the DNR/DNAR form if you have one (see the handout [Critical choices about DNR/DNAR](#)). The ambulance will bring your child to the closest hospital. Do not try to bring her into the hospital yourself.

How will you know when death happens?

You will know your child has died when:

- ♦ there is no breath, no heartbeat;
- ♦ there may be a release of bowel and bladder;
- ♦ eyes do not move even if they are open;
- ♦ pupils are large;
- ♦ mouth falls open as the jaw relaxes.

Parent voice:

I can say quite honestly now, a few years after Megan's death, that no other experience has come close to the depth of feeling we shared as a family at the hour of Megan's death. It was as if we all felt the same common feeling – a feeling of wonder rather than fear. It was as if we were connected spirits. I can't describe it. I knew then what it meant to believe in a power greater than self.

This kind of death is not an emergency. Therefore no one needs to leave the child to do emergency care. Still, not having to think about what to do, but being able to refer to a plan, is very comforting.

Having a plan is helpful no matter where you are when your child dies.

Parent voice:

One thing that made our lives easier in the end was that we had a contract with a funeral home signed before our son's death. We had made some preliminary decisions about what we wanted. We made these plans while we could still sort of think about things. We knew the 24 hour telephone number to call after the doctor had come. We had even selected and paid for a family plot. It was such a comfort to have these things in place.

In the hours after the death

Take the time you need to say goodbye:

- ♦ Call others whom you know would like to come.
- ♦ Some people have washed and dressed their child in special clothes. While brushing their child's hair they cut a lock of hair to keep. Some people want to make a footprint. You may or may not want a final photograph.
- ♦ You may want to create a sickness free space:
 - take all medicine, oxygen, IV lines and medical equipment out of the room;
 - bring in some flowers;
 - put on some music;
 - light a candle.

Parent voice:

We took all the tubes out. We washed and dressed Nicholas. I wrapped him in a blanket and held him. I held him without tubes. It felt right. He had never been left alone in his life. I didn't want him alone now. His brothers and sisters all passed him from arms to arms. Many people had known him in the hospital and many came to say their goodbyes. Housekeeping staff came and pediatricians came and all held him. It was the best decision I could make.

If your child dies at home

Some families will call soon to their family physician so that he can come to sign the death certificate. (It is helpful to know ahead who will do this and what to do if you cannot reach your doctor. The death certificate must be completed before your child is taken to the funeral home.) Others will want to call a spiritual advisor or a friend first. Again, it will be easier if you have a clear plan so everyone in the family knows what his or her part is in the plan. Everyone can then follow through without having to think about what to do. Make things as simple for yourselves as possible. For example write important telephone numbers on a sheet of paper. Put down even the numbers you know by heart. Keep the list close to the phone.

When your family has said their goodbyes, and is ready, call the funeral home. They will come and take care of the body and help you arrange the funeral. They will come in a regular car or van rather than a hearse. If you have no arrangements with a funeral home you can call at the time. Ask your doctor or nurse to help you with this. Refer to the handout [Honouring the spirit and caring for your child after death](#) for a guide to preparing funerals and services.

If you have traditions that surround the hours after death, let staff know how they can help.

Parent voice:

We took our time before calling the funeral home. We realized that this would be the last time we had Meg at home. We called her grandparents and aunts and let them know they could come and be with her one last time if they wanted.

There is no right or wrong in this situation. You may not want to spend time with your child after death. You may prefer to keep only the memory of the living child.

Call the doctor who will pronounce death and fill in the death certificate

If you cannot reach him, call the back up you have arranged. You can also call your nurse for help with this (even if you are in hospital or hospice, this will be taken care of for you).

Arrange for your child to be taken out of the house

There is no rush. When you are ready call the funeral home. They will probably come in an ordinary van rather than a hearse.

Telephone numbers you need right away:

Doctor to pronounce death:

Name: _____

Phone#: _____

Back up phone #: _____

Person to care for children:

Name: _____

Phone #: _____

Back up phone #: _____

Name: _____

Phone #: _____

Funeral home:

Name: _____

Phone #: _____

Spiritual leader:

Name: _____

Phone #: _____

Friends and family:

If your child dies in the hospital

When you are ready to go (this may be minutes or hours), the nurse will continue to take care of your child until he is moved to the morgue. If you want to see him again before he leaves the morgue, talk to the social worker or hospital chaplain.

When you leave the hospital take with you whatever is precious. No one can guarantee the safety of those things you leave with your child. You will have another chance to place them with your child later.

End note:

Grieving is yet another challenge. May you have the strength and courage to meet it.

Parent voice:

When Jess died the nurse helped me bathe him. I brushed his hair and dressed him for the last time. I wish I had left after that. Being there while they put ID tags on him and wrapped him in a sheet are not helpful memories. Some things are not part of a parent's care. I think they are better left to the professionals.

This pamphlet is the result of a collaboration between
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