

What to expect in the final days

Many parents want to know what to expect as their child approaches their final days, however this information can be confronting to read or talk about. Others may not want to know or are too frightened to ask. This factsheet provides parents with accurate information about what to expect so that some of the common fears associated with a child's death can be reduced.

Preparing for Your Child's Death

What can we expect in the final days?

For the majority of parents, caring for their dying child will be their first close involvement with death. Parents are likely to have little knowledge of how their child may die and how to best manage this difficult and stressful time.

As your child's illness progresses, it usually becomes clear when death is approaching. The specific condition and its effect on the body will determine the symptoms that your child may experience. The following information is provided to assist in understanding the changes that may occur as the last days and hours approach. As every person is different, these are only guidelines. Your child may experience only one or two of these changes. The care team looking after your child will be able to give you specific details on the changes that are likely to happen.

If you are caring for your child at home, speak with your care team about who you should call if you have any questions, both during business hours and after-hours. Some hospitals, hospices and community nursing services have 24-hour support for their patients but it is best to speak to your care team.

Increased Sleeping

While some children remain responsive, many children spend more time asleep than awake. This increased sleeping is caused by a combination of factors. The progression of their illness can affect vital organs and will cause increased drowsiness. Medications to control pain may also contribute to increased sleep. Despite a loss of wakefulness, people at this stage can still hear and feel touch. You may want to play your child's favourite music and have familiar voices talking to them.

Restlessness and agitation

Some children become confused and agitated in the last few days of life, causing them to wake from sleep and become unsettled. This is not uncommon and can be caused by anxiety and fear, increased pain, nausea, decreased levels of oxygen or changes in their body's functions.

For children who are unable to speak at this time, displaying unsettled behaviour may be their only way of communicating that they are uncomfortable. It is important to check that there is no obvious reason for their distress. Examples can include a wet bed, hot or cold body temperatures or uncomfortable resting body position. Gently talking to your child and reassuring them that you are there will help in reducing anxiety. Simple measures like holding the hand and stroking their face can help to make them feel safe and secure.

Playing music or videos, or sharing stories or prayers may also be comforting.

If your child continues to be unsettled and distressed, it is important that you phone for advice, even if it is in the middle of the night. The distress may be from increased pain and their pain medication may need to be adjusted. This could be all that is needed. If the restlessness is from other causes then it may not be possible to correct these and instead the focus will need to be on ensuring your child is comfortable. This may be achieved by giving other medications. If it is not possible to give oral medications, then the medication can be given rectally or subcutaneously through a syringe driver. These medications will decrease agitation but may also have a sedative effect, making it difficult for your child to speak to you. It is likely that they will still be able to hear you and will be greatly comforted and reassured by hearing familiar voices and knowing that the family is there.

Loss of bladder and bowel control

On occasion, as a result of weakness or relaxation of the muscles to the bladder or bowel, children may lose the awareness of the need to go to the toilet. If this happens, there are options available to ensure that the child's dignity is maintained and that they are kept dry and comfortable. Parents may choose to use nappies, disposable incontinence pads or disposable draw sheets. In some situations a catheter into the bladder to drain urine may be considered.

Noisy/rattly breathing

As a child becomes more drowsy the level of consciousness or awareness decreases. As a result it may be more difficult to clear secretions from the mouth. This may make breathing sound noisy or 'rattly'. This noisy breathing will cause no pain to your child, however family may find it very upsetting. Sometimes lying your child on their side will reduce this sound and having music on in the background can also reduce the awareness of this. Medications can also be given through a syringe driver to help. If these methods are not helpful, a portable suction machine may help by gently removing excessive saliva from your child's mouth. If special equipment is required, the care team will assist you in learning how to use it.

Circulation and breathing changes

With further progression of your child's condition, circulation to the hands and feet is often reduced making them feel cool to touch, pale, bluish, or mottled in colour. Putting on their favourite socks and using a doona or blanket over their arms and legs can help. You may also want to stroke your child's face, as sensation to the hands is reduced with impaired circulation.

A change in the rate or depth of breathing can also occur. At times your child may even seem to stop breathing and then start breathing again. This is called "Cheyne-Stokes breathing" and may continue for a few hours or even longer until they die. This type of breathing causes no distress to your child however, it can be very distressing for you and your family to watch.

If your child has had irregular breathing it is often hard to know when breathing has finally stopped. Parents often have an awareness of when their child has died. The most important role for parents at this time is to just be with your child for as long as you want.

After your child has died

When a person dies the body changes over a period of hours. Your child will gradually feel cool to touch. The skin colour also changes and can look like bruises. The body will also become rigid. These changes will become more obvious with time.

At the time of death, some muscles in the body also relax and there may be loss from the bladder or bowel. There may also be some liquid from the mouth and nose. This can occur when you move your child for washing or undressing. Being aware of this helps you to be prepared when dressing your child in special clothes.

You can still touch your child and nothing needs to be done in a hurry. Sometimes, a person's religious, cultural or spiritual beliefs will influence how they want to spend this time. This is your personal time to be with your child and say goodbye.

Source: Queensland Government 2002, *Palliative Care for Children with Cancer — a Guide for Parents*, Royal Children's Hospital, Brisbane.