



What happens in the last days of life

This information sheet describes what to expect in the last days of your child's life, including the physical changes that may occur. It will include advice about how you can continue caring for your child during this time.

Many children who die, have very rare conditions. In their last days of life their signs and symptoms may present differently from that described below. For children with a severe developmental disability, some of the changes may not be as obvious as other children, however, most parents/carers notice a change in their child's level of alertness, their skin colour and their breathing. You may become aware of physical or behavioural changes that indicate your child is deteriorating and possibly entering the final phase of their illness. These changes include increased drowsiness, loss of interest in food, playtime, talking or physical weakness. Your child may have new difficulty swallowing (food, fluids or their own saliva). Symptoms such as pain or breathlessness may worsen and medicine doses or drugs may need to change or be given in another way to control the symptoms. Agitation, restlessness and confusion can also occur. This is not painful or distressing to the child but may be concerning for those at the bedside. Reassurance, a calm environment and in some circumstances, medicines can help alleviate these symptoms.

You and your Care Team may notice changes that indicate your child is entering what is called the preterminal phase. During this phase of their illness, your child may go into a coma-like state and their breathing may become irregular with long gaps between each breath. At this time their hands and feet may be cool or cold and their skin colour may be pale, mottled or blue. When your child is in this state, it is likely that they may only have hours or a day or two left to live.

The following suggestions are to help you care for your child during their last days of their life. It is also important to look after yourself during this difficult time. This information sheet will give ideas for how best to do this.

Communication

- **Asking questions:** If you have any questions, no matter how big or small, please ask the staff, even if they seem busy. If you would like to see a social worker for support please also ask the staff.

Helping staff to respect you and your child's wishes about their care:

- **Personal wishes, cultural and spiritual needs:** We would like to respect any specific personal wishes regarding care. We will also try to help arrange any specific cultural or religious needs you and your family have. Please let us know if there is anything we can do.
- **Location of care (your wishes about where care is provided):** If you want your child moved to a different location (home, Bear Cottage or a hospital closer to home) please ask your Care Team. However, if your child is close to death, it may be difficult to move them as they may become distressed or die on the way to the different location.
- **Comfort:** Please let your Care Team know if you feel your child is not comfortable. If your child is in hospital, the nursing staff will regularly assess your child to ensure they are not in pain or

experiencing other distressing symptoms. They will also ask you if there is anything you need.

Some ways to help your child be more comfortable include playing familiar music or TV shows, bringing in their favourite toys, pillow or doona. If you are able to, just being present will be of comfort.

Medicines: There may be frequent changes made to medicines so that your child will be as comfortable as possible. Medicine to help control problems that may occur, like pain or difficulty breathing, will be given as needed.

Caring for yourself: Caring for your dying child is one of the most stressful things anyone can go through. During this time, strong and upsetting emotions may occur such as anger and guilt. Dealing with other family members may also bring additional distress. Talking with your Care Team may be helpful during this difficult time.

Chaplains and Ministers are available to support you and your family for any spiritual or religious needs. Your Care Team may also spend time with you to discuss your spiritual beliefs if you wish. As hard as it is, it's important for you to continue to drink, eat and rest during this time.



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Changes which may occur before death and suggestions for parents/carers

Reduced need for food and drink: Food and drink are less important when a child is dying because the body is shutting down. Your child will be kept comfortable with mouth care.

Mouth care: Keep the lips and mouth moist with lip balm and swabs moistened in water. You may offer small sips of water or ice chips on a spoon if your child can swallow.

Restlessness and confusion: As an expected part of their dying process, your child may become increasingly confused and restless. This can take the form of moaning, calling out or trying to get out of bed. Medicines can be given to help keep your child comfortable and settled. Please talk with your Care Team if you have any concerns that your child is becoming increasingly confused or agitated.

Having someone familiar at the bedside to reassure and promote a calm environment may help with confusion. Keeping voices low and having soft lighting also helps.

Breathing and increased secretions: Changes in the breathing pattern are common, there may be several deep breaths taken that are followed by a gap in breathing. Saliva and mucus can collect and create a ‘rattling’ sound. Changes in breathing and the rattly sound are not usually distressing to the child who is dying.

Medication may be given to help dry out extra saliva. Repositioning your child may also help.

Circulation: Your child’s hands and feet can become cool, mottled and appear slightly blue in colour. Sometimes hands and feet can become hot and sweaty as well. Your child is usually unaware of these changes and they will not cause any suffering for your child.

There is no need to treat any of these changes. Although your child may feel cold to touch, they may not tolerate blankets. Use light blankets and keep the room a comfortable temperature.

Personal care and turns: Turning or moving your child on the bed is important to prevent pressure areas, soreness and stiffness from lying in the one position for too long. Your Care Team may be able to arrange a special air mattress to reduce the risk of pressure areas.

Eyecare: Eyecare is also important to keep a child comfortable. Eye drops can be used to keep the eyes moist during this time.

Bladder care: Sometimes an insertion of a tube into the bladder (called a catheter) is needed to relieve the feeling of bladder fullness. For most children, this is not needed as urine flow decreases or stops. Nappies or absorbent pads may also be used to keep your child comfortable.

Knowing how long your child has left to live

It is natural to want to know exactly how long your child will live. Your Care Team may be able to give some idea but it is usually impossible to be sure. Some children will stop waking up a few days before dying, however, others may die quite suddenly or even remain awake to some extent right up until they die.

How do I know when my child has died?

Often parents/carers have stated that their child looks peaceful after they have died. For some people, this may be the first experience of witnessing someone die and understandably this can cause anxiety.

Your child has died when their heart stops. This usually follows a few minutes after breathing stops. Babies and young children can take a long time between breaths (up to 15 minutes) and then start breathing again for a time. Usually, when this occurs, death will be soon.

If your child has stopped breathing, you do not need to do anything right away. At some stage, you will need to call your GP or Care Team but you can take your time with this. You and your family may want to spend this precious time in private with your child.

When you are ready, let your Care Team know and someone will come to check for a heartbeat, listen for breathing and check your child’s pupils. After this, the doctor or nurse will confirm that your child has died and confirm a time of death. There is paperwork that will be completed by the health professional who verifies your child’s death. This paperwork will need to be given to your chosen funeral director or may be done later at the funeral home in certain circumstances.

For further guidance regarding a child dying at home or in hospital, please see the information sheets:

- When a child dies at home
- When a child dies in hospital



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