

# The Dying Process

Parents often wish to know the changes that may occur as death approaches. The dying process is often referred to as the terminal phase of illness. The body begins to shut down as major organ functions are progressively impaired. This is usually a gentle and undramatic series of physical changes which are not medical emergencies requiring invasive interventions.

## Preparing for a Child's Death

It is very important that the family is well supported at this time, this support may be the provision of information on what to expect, including the physical changes they are likely to see in their child. If their child is dying at home, 24-hour support from experienced staff that they know and trust is essential. Home visits by the GP, domiciliary nurse and the specialist liaison nurse, to assist with managing the child's symptoms are greatly appreciated by the family. This is a very emotionally draining and difficult time for the whole family and it is important to listen to their concerns and fears, and when necessary offer guidance and advice on how best to provide comfort to their dying child.

In our efforts to achieve a peaceful death for the child, it is essential that symptoms are closely monitored and there is ongoing assessment of the effectiveness of therapy given. Early detection of symptoms and appropriate treatment is crucial if we are to achieve a pain free and peaceful death for the child.

### Noisy / Rattly Breathing

Excessive secretions, or difficulty clearing pharyngeal secretions, will lead to noisy, gurgling, or "rattly" breathing. Generally this occurs during the terminal phase of the child's illness and is associated with a diminished conscious state.

It can be problematic for children with neurodegenerative diseases or brain stem lesions where swallowing is impaired. Positioning a child on their side or with their head slightly tilted down will allow some postural drainage and this may be all that is required. The child is usually unaware and untroubled by the noise and secretions, however reassurance and explanation to the family is essential as the noise can be very distressing.

Anticholinergic drugs, (e.g. hyoscine hydrobromide or glycopyrrolate), can be used to reduce the production of secretions. For children with chronic conditions, a portable suction machine at home may be of benefit.

### Incontinence

During the dying process, there may be a relaxation of the muscles of the gastrointestinal and urinary tracts resulting in incontinence of stool and urine. It is important to discuss this possibility with parents, including how they wish to manage incontinence. If the child is close to death, parents are often reluctant for a catheter to be inserted to drain urine and may choose to use incontinence pads or disposable incontinence draw sheets. Disposable draw sheets are also useful for diarrhoea. It is important for the family that their child's dignity is respected.

## Eye Changes

The pupils of a person who is dying may become fixed and dilated. Their eyes may become sunken or bulging and glazed. If eyes are bulging (which may occur in neuroblastoma), a small damp bandage placed upon the eye may provide some comfort. Eye secretions can be removed with a warm damp cloth.

## Restlessness and Agitation

Some children remain alert and responsive until the moment of death. Others may become confused, semiconscious or unconscious for several hours or days. Restlessness and agitation during the terminal phase is not uncommon and may be due to increasing pain, hypoxia, nausea, fear or anxiety. Agitation may be the child's only way of communicating distress. A calm peaceful environment and the presence of parents and family will assist in relieving the child's anxiety. The child's speech may become increasingly difficult to understand and words may be confused. Even if the child may not be able to communicate, they may be aware of the people around them. Hearing is the last sense to be lost and the family should be encouraged to talk to their child. They may also like to play their child's favourite music, read stories or just sit with and touch their child so the child knows they are not alone. These measures will assist in relieving anxiety.

Agitation and restlessness may continue if the cause is pain, hypoxia, nausea, or metabolic disturbances. Pain relief should be increased and this may be all that is required. If agitation continues, additional drugs may be required. Treatment is then directed at increasing sedation. At this stage oral medications may not be tolerated and alternative routes of medication are essential. Midazolam can be administered via the intranasal, buccal, intravenous or subcutaneous route. Clonazepam can be administered sublingually. Occasionally, there may also be indication for medication to be administered rectally (e.g. diazepam or paracetamol).

## Circulatory and Respiratory Changes

As the heart slows and the heartbeat is irregular, circulation of blood is decreased to the extremities. The child's hands, feet and face may be cold, pale and cyanotic. The child may also sweat profusely and feel damp to touch. Parents may wish to change the child's clothes and keep them warm with a blanket or doona. Respirations may be rapid, shallow and irregular. Respirations may also slow with periods of apnoea. This is called Cheyne-Stokes breathing and is common in the last hours or days of life. This breathing pattern is distressing for parents and family to witness, and they need reassurance that it is an expected part of the dying process and is not distressing for the child.

## After the Child Dies

It is important to inform parents that when death occurs the child may be incontinent of urine and stool. There may also be secretions from the mouth and nose, particularly if they roll their child to undress and wash them. Parents who are not aware of these possibilities may become distressed if this occurs.

It may be necessary to reassure parents that they can still touch their child and that nothing needs to be done in a hurry. They will probably wish to take some time to say their goodbyes. It is important to be aware that a person's religious, cultural or spiritual beliefs will influence how they want to spend this time.

Source: Queensland Government 2014, *A practical guide to palliative care in paediatrics*, Children's Health Queensland Hospital and Health Service, Brisbane.

