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.

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 consciousness, 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.
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.