

## Taking your child home to die

This information sheet is to help you decide whether to take your child home from the hospital to die during the last days/weeks of their life. It is important to talk with your Care Team to gain as much information as possible when deciding if home is the best place of care. If you have questions please do not hesitate to ask.

Your Care Team can work with your child's primary team to identify specific supports in your home area to achieve your wish of having your child at home to die. However, if your child is very close to death it may not be possible to move them without causing distress or having the risk that they might die on the way home. Your Care Team will talk with you about any of these concerns.

This time is very difficult for families and your Care Team will understand if you change your mind about taking your child home to die.

### Who is available to provide the care?

The care requirements of a child who is dying are considered on an individual basis. It is very important to consider the type of care your child is requiring by nursing staff in the hospital and whether you would feel confident to do this at home. Do you have family or friends who can help with this care? For example, washing your child may require two people. If you wish to take your child home but feel you would need help with your child's personal care, please talk to your Care Team so that they can help identify if extra support is available in your local area.

**Equipment:** Your Care Team will help you by advising what equipment your child may need, and how quickly this can be delivered. They will also tell you what it may cost. Items may include a hospital bed or other equipment to help with comfort and positioning.

**Medicines:** Ask your Care Team about medicines which are important to keep your child comfortable. If you decide to take your child home, the team will organise medicines and a written plan so that you know how and when to use them. You will also be given a contact number so that you have someone to ring if you have questions. Depending on your child's condition, medicines may be given by mouth or through their usual feeding tube. Often in the last days of life, a child may have difficulty swallowing or absorbing medications and therefore it may be necessary to give medication subcutaneously. In order for this to happen, a health professional will insert a small tube (called a catheter) under the skin for the medicine to be given. Where possible, your child will be referred to a Community Palliative Care Team who will support you to care for your child at home and ensure they are comfortable.

**General Practitioner (GP):** A GP will need to be available to support you at home. If you do not have a GP and need help finding one speak to your Care Team. If possible a GP or their after-hours service should be available to attend your home after your child has died to confirm their death. There will need to be a plan for the GP or Care Team to complete a death certificate following death.

### Written plan

It is helpful to have documentation that states that your child has a life-limiting illness and is not to have resuscitation. A resuscitation plan will generally be included with your child's palliative care management plan to ensure they are kept comfortable. In the event that you decide to return to the hospital or go to Bear Cottage, a Palliative Care Ambulance Plan may also be helpful. If you would like further information, talk to your Care Team regarding these options.

### How do I know when my child has 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 death will occur soon after this.

Often parents/carers have stated that their child looks peaceful after they have died.

## What should you do?

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.

After your child has died, you will have been given the contact details of a health service or GP that you can call to let them know your child has died. A health professional (doctor, ambulance officer or suitably trained nurse) will need to come to your house and verify in writing that your child has died.

They will come to listen for a heartbeat, breathing and check your child's pupils. After this, the doctor or nurse will confirm that your

child has died and document the 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.

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For further guidance regarding a child dying at home and planning a funeral, please see the information sheets:

- When a child dies at home
- Arranging a funeral for a baby
- Arranging a funeral for a child or adolescent