

# Asking questions can help

Parents/carers have many questions in the last days of their child's life. This information sheet is to help you prepare by sharing similar questions that have also been asked by other parents/carers during this difficult time.

The questions below have been placed under specific headings to help you plan for information you may need. Please feel free to ask any questions that you need to, whether or not it is on the list. You will find that not all the questions under each of the headings are relevant. There may also be some that you may want to discuss with or without your child present. Some parents/carers differ in how much information they would like to be given, if this is the case please inform your Care Team.

We suggest that you look at the headings first and then decide whether you wish to read the questions about that topic.

## What to expect and what changes may occur in the last days of life

- What now?
- What can I expect may happen over the coming days?
- What changes will I see in my child?
- What should I do if my child won't eat very much or can't tolerate their feeds?
- If my child eats more, will this make them live longer?
- What can I do to continue to look after my child?
- Will my child go into a coma?
- How long will it be before my child dies?
- Will my child suffer or be in pain?
- How will I know when my child is about to die or has died?

## Family communication

- When should I call the rest of the family?
- What should I say to members of my family when I speak with them?
- What should I say if my child asks "am I dying"?
- What should I tell my child's brothers/sisters?
- How many people can come to visit my child?  
When can visitors come?
- What if I want to limit the number of visitors my child receives?
- How do I tell others about what is happening to my child?  
Can I get help with this?

## Care Team communication

- Who can I talk to if I am concerned about the care my child is receiving? What is a REACH call?
- How can I assist health professionals to talk to my child in a way that respects their personality/culture?
- How do I speak to a doctor if I have worries or questions?
- Can I get a second opinion?
- Will you be able to tell me when it is getting close to the time my child will die?
- What happens after my child dies? E.g. What happens to their body? How do we arrange a funeral?
- What will my child look like?
- What if I do not want to see my child after they have died?
- How long can I spend with my child after they have died?  
Can I hold or bath my child, or dress them in different clothes?
- What support is available to us after my child dies?

These are some of the many questions you may have. It is important that you feel you have all the information you need. Your Care Team is available to help with this.