Topics covered in the parent resource *Caring Decisions*


- **Introduction**
  - How common are decisions about life support for children?
  - Why should I read this handbook?
  - Is this handbook relevant for my child?
  - How should I read this book?
  - Why am I being asked these questions? It is not given to me to decide about life
  - Starting a conversation with your child’s doctors
  - 'The bigger picture'
  - There is too much to think about...
  - I don’t understand...
  - Support at a stressful time
  - Terms used in this handbook

- **How do parents think about end of life decisions**

- **Life support treatment**
  - What is life support treatment?
  - Are there different types of life-support treatment?

- **Comfort treatment and palliative care**
  - What is comfort treatment and palliative care?
  - Is palliative care just for children who are dying?
  - Can a child have comfort treatment and life support treatment?

- **Stopping life support**
  - Why would doctors want to stop life support treatments for my child?
  - Are there different reasons for stopping or not starting life support treatment?
  - Is it legal to stop or not start life support treatment?
  - Is stopping treatment euthanasia?
  - What is futile medical treatment?
  - Futile treatment and the dying process
  - Questions you could ask

- **Stopping and not-starting**
  - Is there a difference between stopping treatment and not starting treatment?
  - What if I still feel uncomfortable stopping life support treatment for my child?
  - What is a ‘trial of life support treatment’?
  - Questions that you could ask your child’s doctors about treatment:

- **Different types of treatment**
  - Are decisions different for different life support treatments?
  - Is it OK to stop some life support treatments but continue others?
  - What is a DNAR or AND order?
  - If I agree to a DNAR order for my child will other people know?
• What will other people think of me if I agree to a DNAR for my child?
• If I agree to a DNAR will other treatment stop?
• What if I change my mind?
• What if I decide that I want doctors and nurses to provide CPR for my child?
• I want everything to be done
• Is it OK to stop artificial feeding?
• Is it legal to stop artificial feeding?

• **Doing what is best**
  • What is the right thing to do?
  • How do we work out what would be best?
  • Should I ask my child?
  • What if my child doesn't want life support treatment?

• **Quality of Life**
  • What is 'Quality of Life'?
  • Is it appropriate to use quality of life when making decisions for children?
  • Are all 'quality of life' decisions the same?
  • Are 'quality of life' decisions different in children?
  • What about the 'sanctity of life' approach? Isn't life sacred?
  • Is it discriminatory to stop life support treatment based on 'quality of life'?
  • Is quality of life a 'personal' decision?
  • Questions you could ask your doctor

• **Uncertainty**
  • Can the doctors be certain about what will happen for my child?
  • Questions you could ask your doctor about uncertainty
  • Ways to think about uncertainty
  • Is there a rush to make a decision? Do I need to decide now?
  • I have read about a new treatment/test on the internet...

• **Who decides about life support?**
  • Who makes the final decision about life support treatment?
  • What does shared decision-making mean?
  • Questions you might like to ask your doctor
  • Phrases that may be helpful
  • What if I don't want to decide?
  • Do parents need to consent to stopping treatment?
  • What would you do doctor?

• **Disagreement**
  • What should I do if the doctors don't agree about life support?
  • What should I do if I don't agree with my child's doctors about life support?
  • What should I do if my partner and I do not agree about life support treatment?
  • What should I do if others in my family do not agree about life support treatment?

• **Religion, culture and life support**
  • Is it against my religion to stop life support?
  • Is it playing God to stop life support?
What about the sanctity of life?
I don't want to stop life support because I am waiting for a miracle
Can I talk to my doctor about my cultural or religious beliefs?
Can I ask doctors to speak to my elder or religious advisor?
What do different religions say about stopping life support?

**After a decision**
- We have decided to continue life support. What will happen now?
- We have decided to stop or not start life support. What will happen now?
- What happens after a breathing tube is removed?
- If my child has morphine, will it stop him/her breathing?
- How long do we have?
- What about organ or tissue donation?
- What do I do about organising a funeral?

**Taboo questions**
- What if I had... If only I had...?
- Is it bad to wish for my child to die?
- Can't the doctors give my child something to put them out of their misery?
- Do doctors want to stop life support for my child because it costs too much?
- Is stopping life-support treatment giving up on my child?
- Is there no hope?
- The doctors cannot be right. They must have made a mistake.
- If I agree to stop life support, will people think I am a bad parent?
- Will we be abandoned?
- Will I be letting the doctors down if I agree to stopping or not starting life support?
- What about the rest of my family and their quality of life?
- I am afraid that I won't be able to cope if...
- 'Did I make the right decision?' Will I be able to live with myself?

**What to tell other people**
- Should I say anything?
- What do I tell other people about life support?
- What do I tell my other children?

**Further information**