



The Royal
Children's
Hospital
Melbourne

Caring Decisions

A handbook for parents facing end-of-life decisions for their child

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ONLINE RESOURCE:

www.rch.org.au/caringdecisions

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All children's/parents' names have been changed.



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Who is this handbook for?

This handbook is for parents who may have to face decisions about life support treatment for their seriously ill child. You might have been given this handbook by your child's doctors or you might have found it by yourself. Perhaps you are worried about what is happening with your child and don't know where to look for help.

This handbook is also for people who would like to know more about how to support those who are facing end-of-life decisions for seriously ill children, for example friends or family, patients or clients.

How does this handbook help?

This handbook has some answers to questions that you may be facing. It also includes quotes and stories of some parents who have faced decisions about life support for their children. You can find more questions, and more detailed answers on our online resource at www.rch.org.au/caringdecisions

"This is the final chapter of the book. But we're going to make that chapter the best chapter we can ever make."

Nicky's story

Laurie's son Nicky was diagnosed with a brain tumour when he was two years old. Doctors told Laurie that Nicky's condition was very serious.

"The outlook wasn't very good when he was diagnosed. He did get to the stage where the tumour was removed... and we were quite hopeful but in about two months it came back."

Nicky had surgery and chemotherapy. His parents looked hard into different treatments. But Nicky's treatment wasn't working.

"It was easy to tell that it wasn't helping... having been through chemotherapy and hospital stays and just the invasiveness of it... we knew that we didn't want to make him go through pain that wasn't going to be helpful for him."

"It became apparent that it just wasn't working and there was nothing else that we could do besides keep him comfortable and take him home."

The palliative care team became involved and supported Nicky's family. He died at home eight months after diagnosis of his brain tumour.

What is life support treatment?

'Life support treatment' (or 'life support') is any medical treatment that is used to keep a child alive.

What is comfort treatment?

'Comfort treatment' is also called 'palliative care'. It refers to medicines or other care to make sure that a child is comfortable and not in pain.

Can a child have comfort treatment and life support treatment at the same time?

Yes. In fact it is very common for children to have medical treatment aimed at cure, life support treatment and comfort treatment all at the same time. However, when a medical treatment can't cure, and life support treatment isn't working, comfort treatment becomes the most important thing to provide.

"We were told there was no cure but he could be kept alive longer...but it would not be a way that would be comfortable for Eric, and it would be very invasive... so we just decided, we wanted to do it the gentle way... and hope that we can do that for as long as possible."

How common are decisions about life support for children?

When parents face decisions about life support treatment, they sometimes feel alone and frightened because it's something that they have never heard of or thought about. But many other parents have faced these decisions before.

Most families with a seriously ill child who dies have had to make a decision about life support. In Australia, when a child dies in hospital, 8 out of 10 times, parents and doctors have had to make a decision about life support. It is similar in the UK, Northern Europe, and the United States.

"You know, I had in my mind that at some point we would have to turn off something... but it was more a case of take away this, you take the IV and don't put it back in. It wasn't a case of us physically flicking a switch."

Are there different reasons for stopping life support treatment?

Yes. There are different reasons why doctors and parents may decide to stop life support treatments. Some reasons may include:

- Life support may not be working and is not helping a child
- Life support may not be able to save a child for long
- Treatment does more harm than good because of side effects
- Life support treatment does more harm than good because of a child's health condition

"It would not have been fair... ventilated the whole time. Existing on a machine. That wasn't Lucy."

"It would have been tortuous for him... Knowing how scared [he was]... We just wanted to help him.. We had to make the decision... But we knew it had to be done... he couldn't remain like that."

Is it OK to stop some life support treatments but continue others?

Yes. It depends on the type of treatment as well as on the reason for stopping treatment. When you are talking with your child's doctors and nurses about life support, you can work out together which treatments will be provided and which will not. Comfort treatments will always be provided if needed.

"How do you know when your child has had enough?

... she said you'll know when the time is right. And that day I knew it was right."

"Because we'd made the decision not to go down the intubation path, they continued with the CPAP."

Who makes the final decision about life support treatment?

Usually these decisions are made by the family and doctors and nurses together.

However, sometimes doctors make the final decision and sometimes families will decide. This depends on the type of decision, as well as on what families want.

For some families, such as Aboriginal families, it may be important for other members of the wider family or community to be involved in decisions.

You can let your child's doctor know how you would prefer decisions to be made.

"As his mother I have to make the decision for him and what's best for him."

"In our particular case... firstly we consulted with the professionals that we felt were relevant because we wanted their opinion. I think we probably brought something of a decision in our heads from the years of caring for her. But we didn't want to make that decision without being informed, we wanted to make an informed decision."

Lucy's story

Lucy had a severe accident leading to lack of oxygen to her brain. She was taken to hospital and transferred to a large intensive care unit. Her mother, Margaret was told by doctors that her outlook was very poor, and that if she survived she would likely be in a vegetative state. Margaret remembers the doctor telling her:

“Now I’ve given you the worst news I could ever give any parent and you’re going to need time to process this.”

Margaret felt sure that life support was not the right thing for Lucy.

“All I ever wanted for my daughter in life was for her to live a happy healthy life. I couldn’t give her that... but [I could give her] this, to let her go... so I let her go.”

Lucy’s family spent some time with her in the intensive care unit reading stories to her and saying goodbye. She died shortly after her breathing tube was removed.

What is a DNAR or an AND order?

Resuscitation (CPR) includes artificial breathing and heart massage. Like other life support treatments, CPR may not be helpful in some situations, or may do more harm than good.

When doctors and families have decided that CPR isn't the right thing for a child they will write that down so that other doctors and nurses know not to do this. This is sometimes called a 'Do Not Attempt Resuscitation' (DNAR) or 'Allow Natural Death' (AND) order.

Will I be a bad parent if I agree to a DNAR order for my child?

No. If life support is not helpful, or will do more harm than good, the best and most loving decision is to make sure that a child is kept comfortable. In countries like Australia, and the UK, most children who die after a long illness have a DNAR or similar instruction in place before they die.

If I agree to a DNAR will other treatment stop?

Not unless you and the doctors have decided to stop them.

"What were we doing it for? What were we hoping to achieve? What did we want?... [His illness] was never going to be fixed. So we didn't want to unduly prolong his suffering..."

"So I could clearly see then that it was no longer for him. And I think that was our line in the sand — if we are doing it for us rather than for him."

“I want everything to be done”

Sometimes when doctors talk to families about life support treatment, parents reply that they want “everything done”.

It is natural to feel this way. The doctors and nurses will do everything they can to help your child. But some treatments are not helpful. It is really important that doctors avoid doing things that would harm your child.

Can I talk to the doctors about my cultural or religious beliefs about life support?

Yes. If your culture or religion affects the way that you think about life support talk to your child’s doctor. They want to support you and your family to make the best decisions for your child.

For example, if it is important to you that someone outside your immediate family is part of decisions let the doctors know.

“We were like – you know, we’ll give her a chance and that’s our mentality.”

“In the end we realised she had a... [small] chance of survival after all the medical intervention and we decided that we chose quality over quantity which was a very hard decision to make. I don’t have the words to describe how we made those decisions but we did.”

Can the doctors be certain what will happen for my child?

It is often difficult to be sure what will happen for a child, but sometimes doctors and nurses have a high level of certainty about a child's future.

The medical team caring for your child will be able to give you an idea of what is most likely to happen, based on the medical facts available and their experience of caring for other children in similar situations.

"There's never a perfect decision. What's the best decision, given everything?"

"As much as a doctor can tell you an outcome of what's going to ultimately happen, they can never describe what it's going to be like for you... every person individually reacts... so independently to a condition or illness."

What is 'quality of life'?

'Quality of life' is a measure of the balance of good things and bad things in someone's life. For example, pleasure, comfort, happiness, or satisfaction balanced against pain, discomfort, frustration or sadness.

Is it appropriate to assess quality of life when making decisions for children?

Yes. It is important to assess a child's quality of life when we are making decisions about their medical treatment. All medical treatment has risks and benefits. Sometimes treatment can do more harm than good. Doctors need to consider the impact of treatment on a child's quality of life.

"I had decided it was going to be quality over quantity. That a good life didn't necessarily have to be a long one."

What should I do if I don't agree with my child's doctors about life support treatment?

Parents' views are important. Tell the doctors your views about life support treatment, and what you would like to happen for your child. Doctors will do their best to respect your views and may be able to follow your wishes.

If you are finding it difficult to explain your wishes to the doctors you can ask for someone else to come with you, for example a family member, friend, Aboriginal liaison officer or social worker. If English is not your first language, you can ask for an interpreter if it would help.

If doctors are not able or willing to follow your wishes about treatment you might consider asking for a second opinion or for review by a hospital ethics committee. If you have tried those things and still cannot reach an agreement with the doctors about what would be best for your child you may like to seek legal advice about what other options you have available.

"As much as you want to do everything possible for your child, you need to... make decisions that will work for you in the long term.

Having made the decision you need to resist beating yourself up and questioning it and second-guessing.

Our son's doctor advised us to remember: *you made the best decisions you could, with the information you had then.*"

Don't be afraid to ask questions

Don't be afraid to ask questions of your child's doctors.

Some questions that you could ask include:

- What makes you think that life support treatment will not work for my child?
.....
- Is there a chance that medical treatment could work?
If so, how big or small is that chance?
.....
- Is there anything else that could happen?
How likely or unlikely is it that this could happen instead?
.....
- Is there any way of becoming more sure about the outcome for my child?
.....
- What are the risks and benefits of life support treatment for my child?
.....
- If my child survives, what would everyday life be like?
.....
- Is there any scientific evidence on quality of life in this condition?
.....
- Is there a support group for the problems that my child is facing?
.....
- I need to understand what life would be like for my child and my family.
Is there anyone I could talk to?
.....

Online resource

Our online resource has more information on issues discussed here as well as additional topics including:

- How do parents think about end-of-life decisions?
.....
- Life support treatment
.....
- Comfort treatment and palliative care
.....
- Stopping life support
.....
- Different types of treatment.
.....
- Doing what is best
.....
- Quality of life
.....
- Uncertainty
.....
- Who decides about life support?
.....
- Disagreement
.....
- Religion, culture and life support
.....
- After a decision
.....
- Taboo questions
.....
- What to tell other people (including other children)
.....
- Further information, links, reading list
.....

Visit www.rch.org.au/caringdecisions



Notes

Online resource:

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