

# Transcript Topic 3

## Caring for children with life-limiting illnesses

### Emily's story



#### Emily's story 1 min 33 sec

**Jacob:** You're feeding the dog Ryan.

**Ryan:** No I'm not. I did it last night.

**Jacob:** Yeh, but if you do it last night then you do it in the morning as well.

**Melissa:** Ryan, you're feeding the dog. Jacob, can you get upstairs and clean your teeth and get ready for school as quickly as possible.

**Jacob:** But I've got to eat my breakfast.

**Melissa:** After you've finished your breakfast then okay.

**Melissa:** (to Robert) Emily had a really really bad night last night. She is a lot paler than usual. She's really keen to go to school today but this breathing has got me really worried.

**Robert:** Yeh, you're right, she's not looking too good.

**Robert:** You breathin' a bit hard today Princess? Emily nods.

**Melissa:** I am going to have to take her in to town to see the doc.

**Robert:** Okay love, look that heifer's got into Darren's paddock again. You right to take the boys to the school bus?

**Melissa:** Yeh, yeh – of course. See you this arv.

**Robert:** Righto, drive safely. (To Emily) Love ya princess. (To sons) Boys, behave for your mother.

Okay? Righto. See you gang. Have a good day.

**Melissa:** Bye.

**Jacob:** See you dad.

**Ryan:** You're feeding the dog.


[Melissa, Emily, Jacob and Ryan in the car.]

**Melissa:** OK boys, school bus is here. I'll pick you up at usual time this afternoon. Okay?

**Jacob & Ryan:** Okay, see you mum.

**Melissa:** Be good. See you.

**Melissa:** (to Emily) You alright in the back there darling? It's not going to be long.

 **Emily's review**  
3 min 43 sec

**Margaret:** Hi Emily, come in and have a seat.

**Margaret:** So Emily, you sound as though you are having trouble breathing today.

**Emily:** I couldn't sleep last night and it hurts to breathe in too much. I really wanted to go to school today but Mum said I am not allowed to.

**Melissa:** Emily has been going to school lately but on Monday when she came home she looked so pale and she just wasn't at all herself. By yesterday she was having trouble breathing when she was talking. It's bad, like the last time she was unwell but it just seems to have happened so much faster this time. She is using oxygen like you suggested for when her breathing gets like this and when she uses it she does seem to be a bit better.

**Margaret:** I am glad to hear that the oxygen has helped. Emily, I see that you used your walker to come in today. Does it help with your breathing when you are walking for longer distances?

**Emily:** I have to walk slowly and sometimes I feel dizzy.

**Margaret:** It's good that you have found it helpful. Right, well, I think I'll have a listen to your chest.

**Margaret:** Emily, it looks and sounds as though your heart is having trouble pumping the blood around your body today, which is why you are having trouble breathing. I'll have a look and see what other medications we can use and I'll speak to Dr Greg from your cardiology team. I think I'll also speak to another team in Brisbane, they work specifically with children, and see if we can help with your shortness of breath. They're called the paediatric palliative care team.

**Emily:** I know the palliative care team! That's just for old people! Like Grandma in the hospital before she died.

**Margaret:** Well, palliative care teams work with people of all ages, not just when they are dying. They help you to do the things that matter to you when you are getting more unwell. (Pause) You remember a while ago I spoke with you about how one day your heart might not be strong enough and we might need some additional help to keep you comfortable? Well, Emily we are worried now that you are getting sicker more often and we know that your heart is getting weaker and weaker. Together with the Brisbane team our aim is to keep your heart working as well as it can and to keep you comfortable no matter what....

**Melissa:** Does this mean we are going to have to drive to Brisbane? I don't think that Emily can handle that drive and Robert is just so busy and then there's the boys and the farm and..


**Margaret:** No. I can speak with the team in Brisbane by organising a meeting via the computer. Just like everyone's there in the room with you. For now I think it's important that you stay home from school and keep using the oxygen when you need to. I will give you a call after I have spoken to the teams in Brisbane and I'll organise a time for you to speak to Chenoa, she's the nurse with the paediatric palliative care service. She is in a similar role to Hannah but for palliative care instead of cardiac.

Chenoa and the doctor with the team are incredibly knowledgeable and they love working with kids. I think you will find them to be a great help and you can ask them any questions you may have. (Pauses) I know this is a lot to take in.... but,well...how do you feel about this as a plan?

**Melissa & Emily:** Okay.

[Melissa and Emily in car.]

**Melissa:** We should just make it in time to pick up your brothers.

 **Emily's case conference**  
6 min 32 sec

**Hannah:** Can you hear me Margaret?

**Margaret:** Oh hello, there you are! Well done Hannah. Can everyone see and hear us all the way out there?

**Hannah:** We can hear you loud and clear.

**Margaret:** Hi everyone, and our thanks for agreeing to meet with myself, Di, our Director of Nursing, and Alan from the Royal Flying Doctor Service to discuss Emily's case today. I'm very keen to hear any suggestions you may have about Emily's management and ongoing care.

**Hannah:** Good morning Margaret. I believe you know Greg and Ben from the Paediatric Cardiology team.

**Greg & Ben:** Hello.

**Margaret:** Yes hello again!

**Hannah:** And I'd like to introduce you to Chenoa from the Paediatric Palliative Care Service.

**Chenoa:** Thanks Hannah. With me here today is Amanda our Paediatric Palliative Consultant and Tuyen, our Social Worker.

**Amanda:** Hello.

**Chenoa:** Amanda would you like to take it from here?

**Amanda:** Hi Margaret, I am sorry to hear that Emily is unable to have more surgery and that she is not able to have a heart transplant. As you know, our team would like to work with you and the cardiology team to give her the best quality of life

we can, and also to support the family as much as we can. One area we'd like to focus on is pain management and other symptoms. Are any of these an issue for Emily?

**Margaret:** She is having increasing difficulty breathing.

**Amanda:** I see here that Emily already uses oxygen at home when she is breathless. Does Emily also have a portable oxygen cylinder that she can use when she is away from the house?

**Margaret:** Well, Emily had an exacerbation of her condition about 6 months ago, which is when we first ordered the oxygen. Her breathlessness seemed to settle down for quite a few months after that. I was surprised at how soon it is now since her last episode. She has recommenced using the oxygen this week with moderate effectiveness. I would like to organise a mobile oxygen cylinder, because they mentioned on their visit that it helps Emily when she uses oxygen. She has two large standing cylinders because they live out of town and often rely on a generator or solar power.

I know Emily is keen to get back to school to see her friends. It would be helpful for the palliative care team to connect with school about the care of the oxygen equipment.

**Tuyen:** What about Emily's parents? How are they coping with things?

**Margaret:** Emily's parents own a large cattle property out of town. Robert works seven days a week on the property and Melissa has had to get a job in town two days a week to help them financially. They also have two other children, Jacob and Ryan who are six and eight years old. They can be a bit of a handful.

Emily has had quite a bit of time away from school lately and I know that Melissa has been helping with her school work as well. When they came in yesterday, Melissa looked tired and physically run down. To be honest I don't know how Dad is coping. I never see him and I rarely get the chance to ask Melissa when she brings Emily in to see me... even how she is managing all of this to be honest. I would really like to assess this properly and see if we can provide some support financially as well as emotionally.

**Tuyen:** Margaret, I will talk to Chenoa and Hannah. We will discuss what further assistance and financial support might be available. It is often what we see; as you describe, the dad is busy trying to financially support the family and it can be difficult to get his perspective. We can connect with them at home with an adult's only conversation to explore some of their shared and individual concerns.

**Amanda:** Margaret, have you had a conversation with Emily and her family that her condition will deteriorate? I realise this can be difficult to do and she may have periods of stability but it is likely they will see a steady decline. The time frame we are dealing with in terms of life expectancy is still uncertain.

As you know with complex heart disease, it is possible that Emily could have a cardiac episode or even an infection such as influenza within the next 12 months and not recover.

It will be important now to manage both her physical symptoms, such as pain and shortness of breath, as well as provide practical and emotional support.

It would also be a good idea to discuss a plan about what to do if Emily should have a sudden deterioration. This could include a sudden worsening of her symptoms, as well as an arrhythmia, which could cause a very sudden decline and possibly even sudden death. We have developed a resuscitation plan to assist with this discussion, and would be happy to share this with you. Again, I acknowledge this will be a very tough series of conversations for you to have with the family.

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### Emily's case conference *continued*

**Margaret:** Yes, it is a very difficult time. I mentioned to Emily and Melissa that I would be including the paediatric palliative care service in her care and explained what that means. Emily was upset by this. I explained to her what you do as a service. I haven't spoken to them directly about Emily's condition deteriorating and what that may include but I am sure they are very aware of it. I have found it hard to discuss. I am not really sure what to say to them. From the things that Emily has been saying recently, I think she knows she is going to die but doesn't seem to want to talk about it in front of her mum. I get the same feeling that Melissa doesn't want to admit it in front of Emily.

**Chenoa:** Yes it is hard to discuss but it is an important conversation to have. It is actually not uncommon for parents or children to understand the seriousness of the illness and know that death will happen, but they just don't like discussing it. We will set up a family meeting on line with you, Emily and Melissa. We would like it if you could organise it so that Robert can be involved as well and then we can all sit together and discuss what is likely to happen and what steps to take.

**Margaret:** Well that sounds like a great approach and I'm sure we all look forward to meeting and planning together again soon...

### Emily's progression 1 min 3 sec

**Emily:** Mum, have a look at the funny email that Chenoa sent me for my birthday.

**Melissa:** Well you don't turn twelve every day, do you? That is a funny birthday message. When you reply to Chenoa, tell her thank you and that we have spoken to your teacher and we've organised for you to visit your school friends tomorrow. You can go in your wheelchair and we will attach the portable oxygen.

**Emily:** Mum, there was also a birthday card from Pop today. Do you think Grandma is looking down from her star and wishing me a happy birthday too?

**Melissa:** I am sure she is darling.

**Emily:** Go away brats!