

Telling your children about your cardiomyopathy

Clinical psychologist Dr Sara O'Curry, from Great Ormond Street Hospital, advises parents with cardiomyopathy what to tell their children

Whether it's your health or your child's, the important thing is to talk to them from the beginning.

If you were diagnosed with cardiomyopathy before your child was born or when they were a baby, your child will grow up with cardiomyopathy as a normal part of life and not something to fear.

They might attend clinic with you, have seen you taking your medication and will certainly hear conversations you have with the extended family about your health.

If your child is older when you are diagnosed, they will have picked up that something is wrong, that you had to see the doctor and will certainly feel that you and the whole family are worried about something. The important thing is to check what your child understands about what is happening and to correct any misunderstandings.

Don't worry if you get a bit upset

At the time of diagnosis, when you may be in emotional turmoil it may be very hard for you to talk about it without getting upset. You might choose to have the conversation when you feel your feelings are under control. When you do get round to having the conversation, don't worry if you get a little upset.

Your child will have sensed your feelings already and explaining that you are a little anxious or sad (while at the same time reassuring them that you are being monitored and on medication and therefore not in danger) will help them to feel that there is nothing to be afraid of and, most importantly, that you are not keeping secrets from them.

Avoid secrets

Secrets make children feel very unsafe. They are likely to take the little bits of information they do know and imagine a much worse story, particularly if they feel you are keeping something from them.

Also, if you are able to have a conversation with your child about your health, they will feel more able to ask questions about it as they get older and not see it as a taboo subject.

This is really important as children's understanding of health changes significantly as they get older and if they ask you questions you will be able to set them straight. For example, a younger child might assume that cardiomyopathy is a punishment or that it is contagious. So it is very important that they feel able to check these things out with you.

Questions

If your child asks a questions you don't have an answer to, it is all right to say you don't know. Sometimes there isn't an answer and sometimes there might be but you don't have it. You can always write the question down and say you will ask your nurse specialist or cardiologist the next time you see them.



If they ask you whether you are going to die, it is probably best to explain that that is very unlikely because you are having regular check ups and are on medication, and to reassure them that there is no immediate danger.

This is important because children do not have the same concept of time as we have. So saying something philosophical like “we’re all going to die some day”, although true, may make your child think you are going today or next week.

In summary

Ultimately there isn’t a right or wrong way to talk to your child about your health. You have to do what suits your family style and beliefs. But in general, open, honest communication helps everyone to adjust and cope.