

Telling children they have cardiomyopathy

Clinical psychologist Dr Kate Hawkins discusses telling children they have cardiomyopathy

It is natural to struggle with the idea of telling your child that he or she has cardiomyopathy. Parents want to protect their children from harm, so telling a child that he or she is unwell can be particularly distressing.

Why should I tell my child?

Parents of children with cardiomyopathy have the difficult task of helping them understand and cope with something they themselves may be struggling to accept. You might be worried about upsetting your child or fear that you will become too distressed to talk about it with him or her. In fact, talking to children about their illness will lessen their anxiety.

By the time a diagnosis has been confirmed by your doctor, your child is likely to have some awareness of the condition. He or she may have attended hospital appointments and undergone tests, and parents or other family members may also have received a diagnosis. But children still need to be told they have the illness and have their questions answered.



It is important to be open and honest with your child because children who are not told about their illness tend to imagine things that aren't true – for example, thinking their illness is a punishment for doing something wrong, or contagious. Being truthful prevents your child's trust from being shattered. And by talking openly about the condition, you will display healthy ways for your child to cope with his or her own thoughts and feelings about cardiomyopathy.

Who should tell my child?

This comes down to family circumstances and on the relationship you have with your child and your own feelings and attitudes. You may want to tell your child by yourself, or you may want your child's doctor to help explain the illness. Either way, you or someone close to your child should be with them when they are told for support, encouragement and love.

If you choose to tell your child, talking to others first will help you decide what to say. Your child's doctor or nurse can offer ideas, or you might want to contact other parents of children with cardiomyopathy – charities such as the CMA can put you in touch.

When should my child be told?

As parents, you probably have the best understanding of your child's personality and moods and will therefore be best placed to decide when your child should be told.

Try to choose a quiet time and place to create a calm, supportive atmosphere. Remember that your child, who is likely to have been seen by a specialist doctor and had tests, is likely to have an idea that something

is wrong. So don't delay too long as your child may imagine worse things than the truth and develop fears that are hard to dispel later. A long wait may also make the anticipation worse for you.

Find a time that is right for you

If you are feeling particularly distressed, your child is likely to pick up on this. There's no need to hide your feelings entirely though. Your child will probably have sensed you are upset, but talking openly and reassuring them that the doctors and nurses are there to help will give them confidence that they are okay.

Your doctor and nurse will give you information about the specific type of cardiomyopathy your child has and likely treatments. This will help to prepare you for any questions your child might have and make you both feel more secure.

Your child may still ask questions that you can't answer. It is all right to say you don't know. Explaining that you can ask the doctor or nurse to explain it to both of you will help to reassure your child and show how they can find things out about their condition as they get older.

What should I tell my child?

Telling your child about his or her cardiomyopathy is a personal matter, and family, cultural and religious beliefs will come into play. Exactly what you tell your child and how will also depend on your child's age and what he or she understands.

Children's grasp of illness is constantly evolving. So it is important to keep checking your child's understanding of what he or she has been told and dispel any myths that might have developed. It is important to let children know they are free to express themselves and they will be heard.

Young Children

For young children, it will be important to use simple ways to explain – for example, talking about the heart as a pump or engine – words that the child can relate to. Explain that the tests and treatments will help the engine to stay strong, or the pump to work better.

As children approach secondary school, they are less likely to believe that an illness is related to their own actions, and are more able to understand that trips to the doctor and medications will help them stay well.

Adolescents

Teenagers want to know how cardiomyopathy will change their life. Anticipate that they might be concerned about their peers' reactions or how much sport they are able to do.

They will start to understand they are not going to live forever. So fears about dying and the impact of cardiomyopathy on their future and independence may need to be addressed. Adolescents are also likely to have opinions about their care and should be consulted about treatment decisions.

Whatever your child's age, it is important to convey that, while there is something wrong with their heart, they are receiving treatment and regular check-ups, so there is no need to worry. Telling your child about cardiomyopathy is a building process. It may take weeks, months or years to absorb the information. And let the child know that no matter how difficult the subject is, he or she can always ask questions and share feelings.