

Helping children understand Spontaneous Coronary Artery Dissection

A parent's illness can be traumatic for children, who can be fearful, scared, blame themselves or express other emotions and behaviours. It is important to talk to children about SCAD, but hard to know how. The information below aims to help adults discuss SCAD with children.

The way children respond emotionally to a parent having a SCAD can vary depending on the individual child. Very young children may not be able to verbalise their feelings and will often communicate through their behaviour.

School-aged children may or may not be able to verbalise their feelings. Some may feel traumatised; they could worry the person who has had a SCAD may die, they may blame themselves, or feel they should have done or do more to help. They may worry about upsetting their parents, be over-vigilant and reluctant to spend time away from you.

Find out what your child knows

You know your child best so talk to them about what has happened and encourage them to tell you about how they feel now and what they understand about what has happened.

Consider your child's age and developmental level. If they find it difficult to talk about what has happened use play/activities to start conversations.

What is SCAD?

Spontaneous Coronary Artery Dissection (SCAD) is a rare heart condition that cannot be predicted or prevented – yet.

It affects people with few or none of the normal risk factors for heart disease. A tear or a bruise develops in a coronary artery resulting in a blockage that prevents normal blood flow.

SCAD affects young, fit people, mainly women, with no cardiac risk factors. SCAD can happen during or soon after pregnancy.



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Pick a good time to talk

Ask your child if they feel OK to talk about SCAD. Consider if they are ready to hear you and ensure there are no distractions.

Look for visual clues when talking together. For example, if they get very upset, agitated or refuse to talk, take a break or leave it for another time.

They may be fearful about upsetting you so support them with this. Provide them with reassurance and encourage them to ask or write down anything they would like to know.

Be honest about your SCAD

It's important to be truthful about what has happened, even though it will be scary and emotional.

Children may not grasp what you are saying immediately so be prepared for them to ask the same or more questions over and over again, sometimes hoping the answer will be different.

Give them time to absorb the information and check later that they have understood what you've told them.

It is important to understand there is no rush; often questions and comments from children happen at random times, so stay aware and let them know they can talk to you at any time.

Think about the best ways to communicate

Talking to children about SCAD should be age appropriate. For example, use simple, truthful words with younger children

and if you don't know the answer to a question, tell them. School-aged children may be helped by listening to you read a book out loud about the illness of a parent.

The British Heart Foundation 'My Dad's heart attack' may be useful for under-11s. Although not specific to SCAD, it helps explain heart attacks, medications, angiograms and more.

Teenagers may try to hide their emotions, which may manifest in physical symptoms such as headaches or stomach aches. Directing them to peer support groups and encouraging them to talk to their friends may be an option. Teenagers are old enough to understand more complex answers about what SCAD is, so don't be afraid of using scientific language and encourage them to ask questions.

As your child becomes older, there may be triggers that require you to give them further reassurance and answers to their concerns/questions. For example, your child may hear stories in the media or have conversations with their peer group or teachers about heart conditions/heart attacks.

It is important to continue to parent using the boundaries and routines you had in place before your SCAD, as much as possible. This will provide your child with normality and reassurance.

Be aware of their emotions

Your child may experience different reactions and emotions, such as disbelief or anger, perhaps directed at you. These responses are normal.

They may have feelings of abandonment and be worried about who will look after them, keep them safe and loved, so try to reassure them that even if you are not well enough to do that, there is a plan in place.

They may have thoughts that what has happened to you is somehow their fault, so they will need reassurance that SCAD comes out of the blue and is no-one's fault.

Look out for warning signs of problems

Other than the normal reactions to a trauma, look out for warning signs that your child may be having problems processing or dealing with the information. Sleeping or eating problems, school work suffering, risky actions that may indicate suicidal thoughts, aggressive or withdrawn behaviour and extreme fears are some things to watch out for.

Let them be kids!

Try not to overburden children with your illness or with taking on more responsibility than they need to. Older children may feel they have to step into a parent's shoes and look after younger siblings. Give them permission to be kids and have fun!



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Things to remember



Find out what they know and are feeling



Pick a good time to talk



Think about the best way to communicate

- Having a SCAD should not be trivialised by anyone nor does it define who you are.
- Being a parent and a SCAD survivor is not always straightforward – be kind to yourself.
- Talking to children about SCAD could benefit the whole family.
- Support is available – call on family and friends and see the further information section below.
- If you have a particular medical concern, seek advice from your GP or health professional.

The leaflet has been produced with the help of Catherine Beck, a SCAD survivor and a Registered Health Play Specialist. She has worked with families and children for many years at hospitals including Great Ormond Street Hospital for Children and University Hospitals of Leicester. If parents would like to talk to Catherine, please email contactus@beatscad.org.uk

Further information

Beat SCAD

beatscad.org.uk
contactus@beatscad.org.uk
Youtube: bit.ly/1TXhiLV

UK SCAD research project at the Leicester NIHR Biomedical Research Centre*
scad.lcbru.le.ac.uk

Talking to children about SCAD video, Catherine Beck youtu.be/ZShzLad5ks8

British Heart Foundation

bit.ly/1LaOgys/bit.ly/1T345Aj

*The SCAD research project received initial funding from a BHF grant. Since the grant ended, the project is being funded by the Leicester NIHR BRC and Beat SCAD.

What SCAD parents say...

We asked some SCAD patients how their children reacted to their illness and how they, as parents, faced the challenges this raised.

You always die after a heart attack... don't you?

During a school run with four children aged six to 10 in my car, one of them told us all how their Dad had been on the Tube the day before when someone had had a heart attack and died. One of the other children said. "Yeah, you always die when you have a heart attack". I realised that this was a perfect opportunity to say something. So I took a deep breath and said: "Well, actually,

that's not quite right. Do you remember when Mummy had a problem with her heart and spent time in hospital two years ago? Well, I had a heart attack and I got better again. And as you all can see, I am very much alive and well now." There were a couple of "Oh, OK then" type comments and someone changed the subject and we carried on with our journey!

"My son was very scared when I was taken to hospital. When I came home I told him what had happened in a basic way. He said he was afraid to be alone with me in case it happened again."

"My son got very protective and when his friends started jumping out in front of me one day, he was really upset. He said: 'Don't do that, you'll give my Mum a heart attack.'"

He missed me at bedtime

Thankfully, my six-year-old son was not traumatised by the event itself. He was old enough to know that he was not being abandoned by me when I had to go to hospital. He could understand the simple facts (explained in an age-appropriate way), but didn't have the emotional development to really understand what was going on and to get scared.

He understood that I had to go to hospital and that I had to stay there while the doctors made me better again. He missed me a lot – particularly at bedtime.

Cuddly and concerned that I might die

When I came home from hospital my six-year-old was very cuddly and kept asking if it would happen again and if I would have to go away again. He was also very concerned about me. If he saw me looking tired or unwell he would worry. He would ask me if I had to go back to hospital. He would ask me if I might die.

I tried to find a book written from a child's point of view about a parent being ill, but the only books I could find were ones explaining to children what might happen to them if they had to go to hospital... So I decided to write a book specifically for him, from his own perspective (as I understood it) in order to help him understand his feelings.

I can't draw, so I did it with stick figures. I got a blank book from an arts/crafts shop and planned out my storyline. He absolutely loved being given the book. We read it together and I used it as a tool to get him to talk. As the weeks and months progressed, I would sometimes catch him looking

at the book on his own. Sometimes I chose the book as our bedtime book. I regularly talked about my illness and gave him lots of opportunities to ask me anything about it at all.

The book gave him the chance to think, to process his thoughts and to ask lots of questions – which we answered truthfully but carefully. He knew I had a problem with my heart and that the doctors made me better.

Three years on, the book is still around but not read so often. My son remembers that I had a problem with my heart, but does not seem overly concerned about my health.

