



beat SCAD

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Information sheet

Talking to children about SCAD

Helping children understand Spontaneous Coronary Artery Dissection

Spontaneous Coronary Artery Dissection (SCAD) is an under-diagnosed 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.

SCAD not only affects the patient, but also their loved ones, including children.

This information sheet provides some advice on how to talk to children about SCAD. The information has been produced with the help of Catherine Beck, a SCAD patient and a former Registered Health Play Specialist. She worked with



families and children for many years at hospitals including Great Ormond Street Hospital for Children and University Hospitals of Leicester.

The emotional impact of SCAD on 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 age 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 happened and encourage them to tell you about how they feel now.

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.

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.



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.



Think about the best ways to communicate

Talking to children about SCAD should be honest and age appropriate.

As your child becomes older, there may be triggers that require 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 to provide your child with normality and reassurance.



Helpful tools

- Use play, interactive games, work sheets, art, and trusted websites.
- Call on supportive family and friends.
- If you have a particular medical concern, seek advice from your GP or health professional.

Further information

Beat SCAD

beatscad.org.uk
contactus@beatscad.org.uk

UK SCAD research project

Leicester Cardiovascular Biomedical Research Centre
scad.lcbru.le.ac.uk

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.

