



beat SCAD

Spontaneous Coronary Artery Dissection

# SCAD for Patients

## A warm welcome!

*If you've had a SCAD, you will no doubt have lots of questions about what happened and what the future holds. We know a SCAD diagnosis can be scary, but we hope you find this booklet helpful. It summarises some of the information on our website and we've included QR codes that link to relevant pages, so do scan them to find out more.*

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## What is SCAD?

Spontaneous Coronary Artery Dissection (SCAD) is a bruise (sometimes called a tear) that develops in the wall of a coronary (heart) artery, creating a 'false lumen', which compresses the artery (the true lumen) and prevents normal blood flow. This leads to a heart attack and occasionally heart failure or cardiac arrest. SCAD, very rarely, can be fatal. See page 4 for a more in-depth explanation.

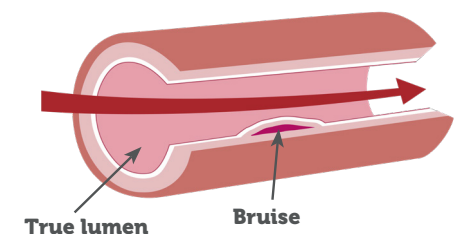
The cause of false lumen formation is unclear but growing evidence suggests that micro-vessels within the artery wall haemorrhage, creating a bruise (called an intramural haematoma), which causes vessel narrowing and sometimes ruptures to form a dissection flap.

SCAD is an uncommon heart condition that can't be predicted or prevented – yet.

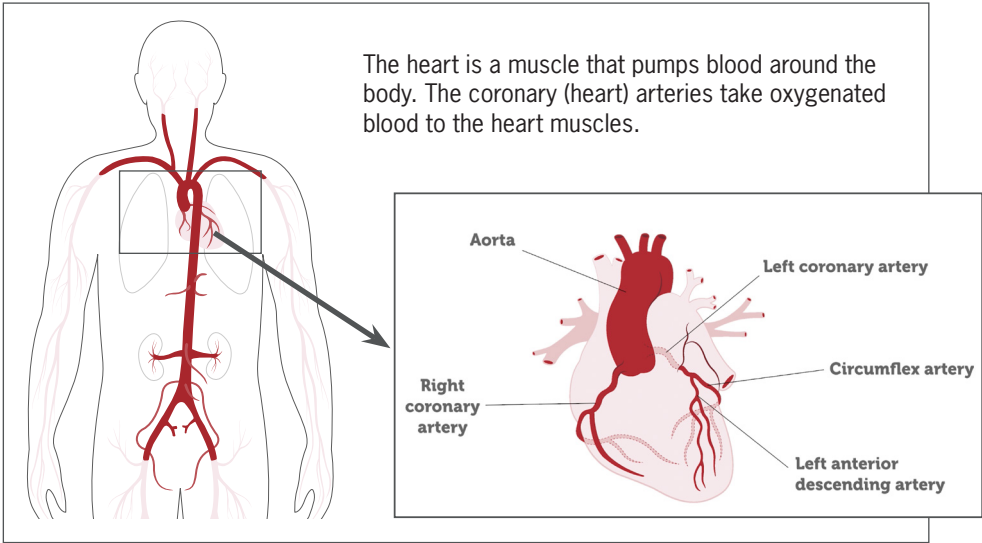
Patients may have few or none of the traditional risk factors associated with 'normal' heart disease (atherosclerosis).

Some associations have been described with: pregnancy and post-partum, menopause, Fibromuscular Dysplasia (FMD), hereditary connective tissue disorders, extreme stress, extreme exercise or emotional stress.

What is SCAD?

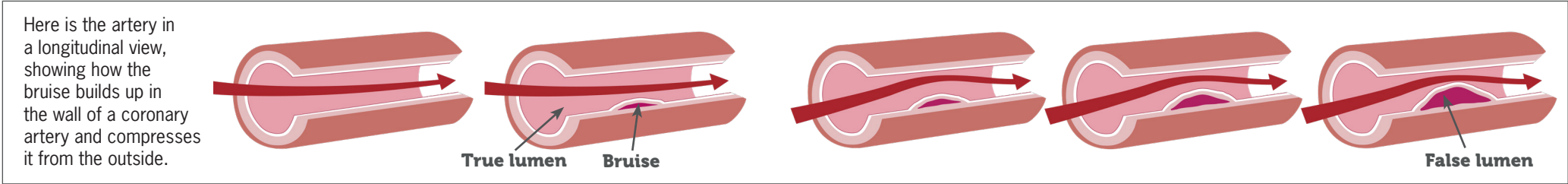
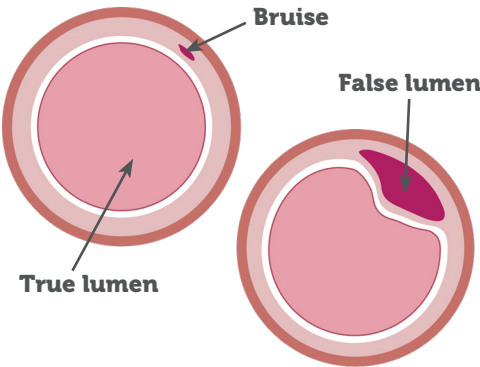


# What we think happens during a SCAD

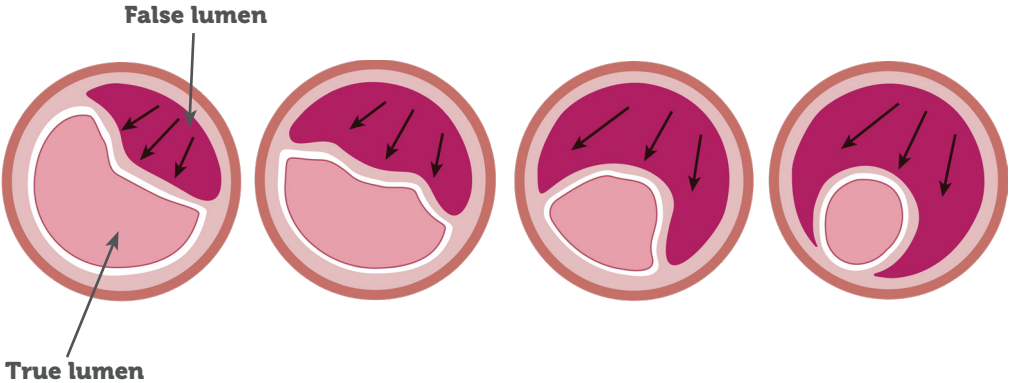


Blood normally flows through the true lumen in your coronary (heart) artery. During a SCAD, microvessels in the wall of the artery rupture and patients get a bruise or a bleed that builds up in the wall of a coronary artery and compresses the artery from the outside so the blood can't flow as normal to the heart muscle and this causes a heart attack.

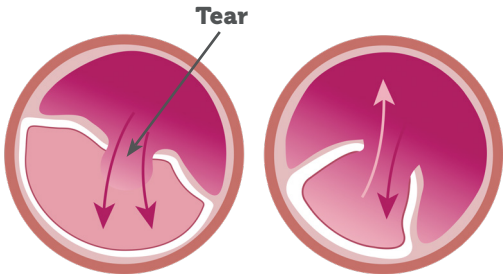
This is a coronary artery in cross-section showing how a SCAD begins with a bleed between the layers of the artery wall, creating a false lumen.



Sometimes as the pressure builds up the bruise tracks along the artery wall.



The pressure in the false lumen can lead to a fenestration or tear between the false lumen and the true lumen. While this depressurises the false lumen and can be a first step towards healing, the flap of arterial wall at the site of the fenestration can sometimes block or reduce blood flow in the true lumen.



SCAD explained



Scan the QR code to download an information sheet explaining what we think happens during a SCAD.

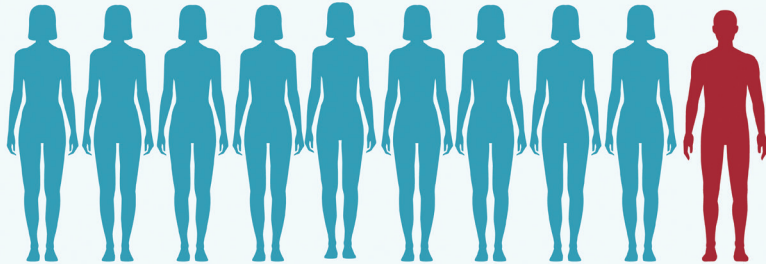
Awareness of SCAD is not universal among healthcare professionals, so it's important for SCAD patients to get well informed and learn to advocate for themselves.

Self-advocate

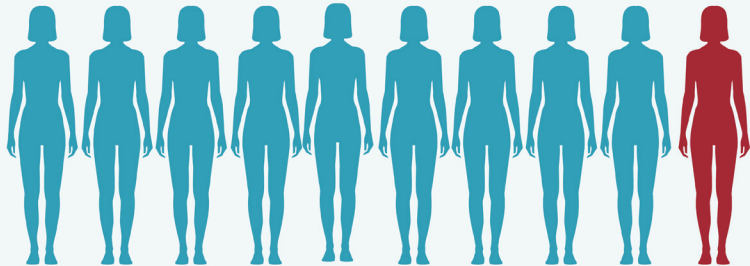


## Who gets SCAD?

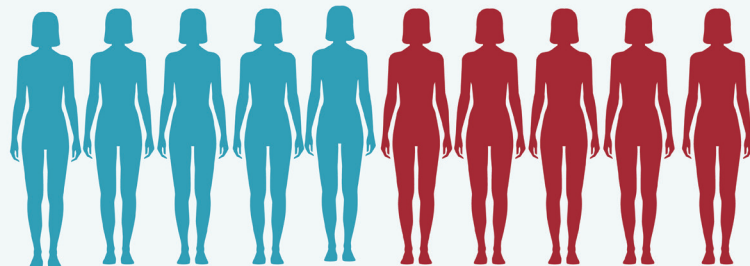
90% of SCAD patients are female and 10% are male



10% of female SCAD patients are pregnant or have recently delivered a baby (post-partum)



Approx 50% of pregnancy-related (mostly post-partum) heart attacks are caused by SCAD



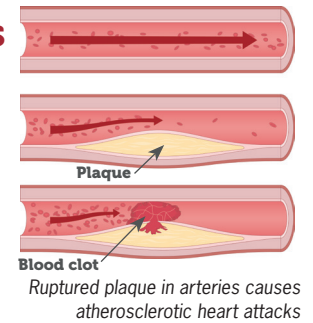
## SCAD & 'normal' heart attacks

SCAD is different to heart disease caused by atherosclerosis, where fatty deposits (plaque) build up in the arteries reducing blood flow. Sometimes this plaque can rupture and blood clots can form. Risk factors for atherosclerosis include being over 65, smoking, having high cholesterol, high blood pressure and close relatives who have cardiovascular disease.

There are some things that can reduce the risk of atherosclerosis getting worse, such as not smoking, eating less saturated fat and sugar, exercising regularly and maintaining a healthy weight.

Many SCAD patients are told their arteries are 'clean as whistles' with no sign of atherosclerosis. On rare occasions, SCAD patients will be told there is also evidence of fatty deposits in their coronary arteries.

Research has identified a genetic risk factor for higher blood pressure in many SCAD patients, so controlling blood pressure is important. And having a healthy lifestyle is recommended. But as the mechanism for SCAD is different to atherosclerosis, more research is needed to understand if there are any treatments that may help prevent the first or recurrent SCADs.



## Symptoms of SCAD

SCAD patients often have symptoms commonly seen in patients with conventional atherosclerotic heart attacks, including chest pain.

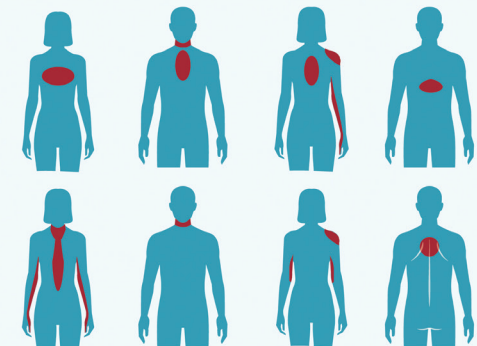
However, they may also report pain in other locations and some may not have chest pain at all. The most common symptoms are:

- Central chest pain
- Pain or numbness in one or both arms
- Jaw pain
- Back pain
- Shoulder pain
- Nausea
- Sweating/clamminess
- Difficulty breathing

Symptoms



Female and male SCAD patients have reported pain in some or all of these locations





## How is SCAD diagnosed and treated?

Chest pain and other cardiac symptoms in young, fit people with no history of or few risk factors for heart disease, is often dismissed as anxiety, panic attacks, indigestion, gall stones and other conditions.

It's important that a diagnosis of SCAD is not delayed. The sooner a diagnosis is made, the better the outcome is likely to be. The longer blood flow is reduced, the higher the chance of permanent damage to heart muscle.

Tests to diagnose heart attacks and SCAD include:

- ECG (electrocardiogram) – although ECGs can look normal in some SCAD patients
- Blood tests to assess Troponin levels (Troponin is a protein that is released into the blood during a heart attack)
- Angiogram
- CT scan

You may also be given an Echocardiogram which shows how well the heart is functioning and what your Ejection Fraction is (the amount of blood a heart pumps with each beat). A normal Ejection Fraction is 55% and above.

Ejection Fraction



Current best practice is that patients should be monitored in hospital for at least five days because the majority of recurrent SCADs occur during early follow-up. Treatments and medication will vary depending on the severity of the SCAD event and how much heart damage there is.

Conservative management (using just medication) is preferred where possible, but sometimes intervention is required. This may include inserting stents or, rarely, performing coronary artery bypass.

As the current NICE guideline for Acute Coronary Syndrome (ACS) doesn't include SCAD, many SCAD patients are given the medication normally prescribed to patients with heart disease caused by atherosclerosis, including aspirin, statins, blood pressure pills and beta blockers. SCAD researchers are investigating if this is the best approach for SCAD patients.

Scan the QR codes for more about Ejection Fraction and best practice treatment guidance from UK lead SCAD researcher, Dr David Adlam.

Treatment



## Can SCAD happen again?

Yes, but it's not that common. Current data suggests around 10% of patients will have a recurrent SCAD within a 5-10-year follow-up. Which means 9 out of 10 are NOT getting a recurrence in that timeframe.

Despite the recurrence risk, it's important to say that the prognosis for SCAD patients is very, very good, partly because SCAD tends to cause small injuries to the heart in most patients, and that's why patients, even those who are unfortunate enough to have recurrent SCAD, do very well with the support of their medical teams.

Recurrence



## SCAD & genetics

Recent research has identified genetic variants that confer a higher risk of having a SCAD, but it is not usually caused by a single gene in the same way genetic diseases that run in families are.

Children of SCAD patients will have a different combination of genetic variants, which means the risk of them having a SCAD is very low. It is not currently recommended that other family members have genetic screening unless the SCAD patient has clinical or imaging findings of hereditary conditions.

Some of the genetic variants are related to the integrity of tissues within

the arterial wall and to blood clotting.

And there seems to be a genetic risk factor for higher blood pressure in many SCAD patients, so controlling blood pressure is important.

Genetics



## Recovery after SCAD

The first few weeks and months after a SCAD may feel like a rollercoaster and, for many SCAD patients, recovery isn't a linear process and includes many elements. You can feel fine one day and exhausted the next. You may be asking questions such as Why me?, Why now?, What did I do wrong?

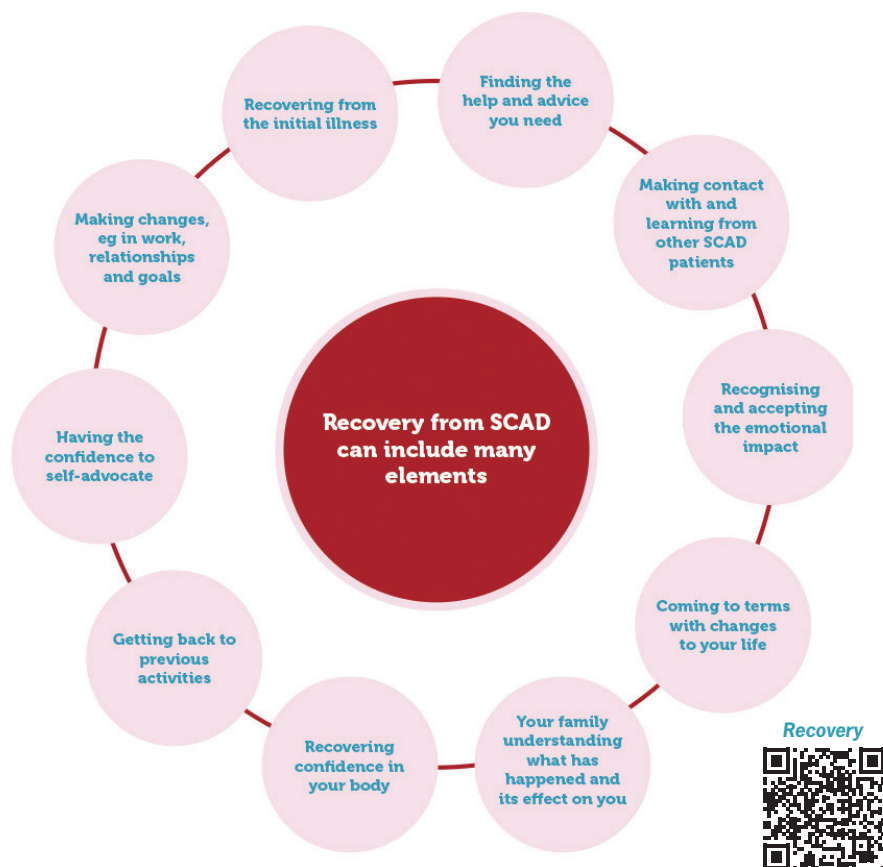
Firstly, make sure you get lots and lots of rest to give your heart a chance to start healing.

You may go through lots of different emotions during your recovery, from shock and denial to anger and depression, but the majority of SCAD patients eventually reach

a stage of acceptance and hope for the future. As mental well-being is linked with physical recovery, taking a holistic approach can be invaluable.

Having quick and easy access to support to manage stress, grief and other emotional issues, is vital. Some patients may need counselling or specialist psychological support. We also encourage patients to explore concepts like mindfulness, healing through breathing and journal-keeping.

Please reach out to healthcare professionals if you feel you need help to deal with the emotional impact of SCAD.



## Post-SCAD chest pain

Recurrent chest pain is very common after SCAD as are repeat visits to hospital. The cause of these symptoms is not fully understood.

Most recurrent chest pains do not seem to be a high-risk sign and in most patients these symptoms will improve over time, although this may take 18 months to two years after the SCAD event. However, sometimes admission is necessary for a more detailed assessment.

Determining how to react to an episode of chest pain post-SCAD can be difficult. Given the risk of recurrence (current figures suggest 10% in the first five years), it is recommended that ECG and Troponin tests should be considered where symptoms are suggestive of a heart attack. However, chest pains are often very different from the initial presentation, are self-limiting and 'atypical' in that there is no clear provocation with, for example, exercise. Over time patients and their clinicians can often 'learn' which pains can be managed



conservatively and which require further assessment or admission.

In some female patients the pain is cyclical, usually pre-menstrual. Anecdotally, cyclical symptoms may respond to progesterone-based contraception (eg progesterone hormonal coil). For those who get non-cyclical spasm-like pain, vasodilator (antianginal) treatments can sometimes be tried.

You may have other pain as you recover, such as aching shoulders or extreme tiredness. If you are concerned, do get checked out.

Chest pain



## Cardiac rehab & exercise

All SCAD patients should be referred to, and encouraged to participate in, a cardiac

rehabilitation programme to aid recovery.

A paper published in the European Heart Journal, recommends moderate aerobic exercise, interval training, resistance training using lower resistance and higher repetitions. Patients are advised to be cautious when doing high-endurance aerobic training, muscle-building exercises or Yoga poses that involve extreme head and neck positions. They should avoid abrupt high-intensity exercise, contact sports, extreme head positions and exercises involving the Valsalva manoeuvre.



Cardiac rehab



Exercise





## Contraception, menopause & HRT

Concerns about the use of contraception and hormone replacement therapy by SCAD patients are based on the assumption that there is an association between SCAD and female sex hormones, however it is still unclear what this association is. At present there is no definitive evidence that hormonal contraception or HRT increase the risk of SCAD recurrence.

SCAD experts advise that it is important to ensure secure contraception in SCAD patients of childbearing age to avoid unplanned pregnancy. Where hormonal contraception is required, this should be progesterone-based (coil, mini-pill or implant).

Systemic HRT is a balance of risks in all women. For SCAD patients, if the menopause can be managed without HRT, this is the best and easiest option. If menopausal issues are mainly local, topically applied oestrogen (eg vaginally) may assist. For women with intrusive systemic menopausal symptoms, low-dose HRT options may be appropriate and this is not contraindicated in SCAD. SCAD experts prefer the body-identical forms of HRT (patches and gels) rather than synthetic ones because they have a lower cardiovascular risk profile.

Hormones



## Pregnancy after SCAD



Many women in the SCAD community are given blanket advice that pregnancy after SCAD is too dangerous to consider. However, you do have a choice to investigate the options.

All SCAD patients considering pregnancy should seek pre-conception counselling so they can be fully assessed, their individualised risk discussed and medications reviewed to ensure they are safe in pregnancy.

Pregnancy



## Associated conditions

Many SCAD patients are also diagnosed with extra-coronary abnormalities including Fibromuscular Dysplasia (FMD). It is recommended that patients are scanned from head to hip to investigate if they have other abnormal arteries which may require follow-up. Most of the findings made are benign and require no intervention or follow-up. Occasionally findings are made that require further surveillance imaging and/or changes to medication. Interventions are very rarely needed.

Other rarely associated conditions (fewer than 5% of all SCADs) include hereditary connective tissue disorders such as Ehlers-Danlos, Loays-Dietz, Marfan Syndromes, or adult polycystic kidney disease, so further testing may be required in selected patients with a family history of clinical or imaging findings suggestive of these conditions.

Associated conditions



## Referral to a SCAD specialist

Beat SCAD has found patients benefit from referral to a SCAD specialist and strongly encourage GPs to refer patients to one of the NHS Clinics.

If referral is not possible, SCAD specialists are happy to be contacted by healthcare professionals to discuss care of a SCAD patient.

SCAD clinics



## How can you get support?

A SCAD diagnosis can be scary and isolating, but it can be very helpful to talk to someone who has had a similar experience. Someone who 'gets it', and who may have experienced the same concerns and emotions you have and can help you cope with your diagnosis and find ways to move forward.

It's unlikely that any SCAD patient will be glad they had a SCAD, but most long-term SCAD patients will tell you about something positive that has come out of their diagnosis. Many re-evaluate their life – work and relationships – and, with time and healing, come to know what really matters to them so they can try to put most of their energy and focus into those things.



Images: iStock

In the SCAD UK and Ireland Survivors Facebook group there are many fellow SCAD patients ready to support, advise and inspire you as you recover.

Facebook group



You can also meet other SCAD patients in person – there are often local get-togethers and Beat SCAD organises walks and conferences, so keep an eye on our Events page, social media and newsletters.

Beat SCAD's Buddy Service offers one-to-one support for patients to help you navigate your post-SCAD journey. Our Buddies are people just like you who have a personal experience of SCAD. They are not trained medical experts or counsellors so cannot offer any medical advice or mental health support, but they can identify with what you are going through, will have great empathy and be able to point you in the right direction to get more information and help. All our Buddies are trained volunteers who will do their best to support you.

Support



## About Beat SCAD

Beat SCAD is a charity created by SCAD survivors who met on social media while trying to find support and information about the condition. Before Beat SCAD was created, the patient group helped initiate the UK research led by Dr David Adlam at the Leicester Cardiovascular Biomedical Research Centre ([scad.lcbru.le.ac.uk](http://scad.lcbru.le.ac.uk)) and the charity now works closely with the research team.

Our vision is a world that understands SCAD, where those affected are quickly and accurately diagnosed and never feel alone.

Beat SCAD's mission is to:

- raise awareness of SCAD among healthcare professionals, SCAD patients, family and friends
- provide support for those affected by SCAD
- raise funds for research into SCAD

Beat SCAD believes it's important that first responders, paramedics, midwives, cardiac rehab nurses, GPs, cardiologists and other medical professionals are aware of SCAD diagnosis and treatment, so fit, healthy people with cardiac symptoms receive the best treatment without delay.

SCAD for medics



## Please help us beat SCAD!

Beat SCAD is run entirely by volunteers and is funded by the kind donations and fundraising of our supporters.

If you have found this booklet, our website and the services and support we offer useful, please help us continue to fund research, raise awareness and support those affected by SCAD by donating. Thank you!

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