

# Questions for healthcare professionals about SCAD and treatment

Many SCAD patients have asked what questions they should be asking their cardiologist at follow-up appointments. Here are some suggested areas for discussion and questions that could be asked to cardiologists, GPs, cardiac rehab and other healthcare professionals.

There are some notes at the end with current information, as well as useful links, which may help you in discussions with healthcare professionals.

#### Your SCAD

Which artery/where in my heart did the SCAD happen? How extensive was the dissection/bruise? How/when will I know my SCAD has healed? How much damage is there to the heart muscle? What implications will heart muscle damage have on my day-to-day life?

Can ejection fraction be improved? If so, how?

Can the SCAD lead to heart failure?

I've been diagnosed with heart failure following my SCAD, what does that mean for me?

What is the recurrence risk?

Is SCAD genetic? Should I get my family tested?<sup>2</sup>

# Medication<sup>3</sup>

What medication should I take if I'm being managed conservatively (ie no stents, no bypass)? And for how long?

What medication should I take if I have stents? And for how long? What medication should I take if I've had a bypass? For how long? When can we review my medication?

I have side effects from some of the medication, can a different type/dose/time of taking be tried?

Are there any long-term implications to taking any of the medications?

My periods are worse, can anything be done in terms of reducing blood thinners?

# Ongoing chest pain4

Why do I have ongoing chest pain? What can be done about ongoing chest pain?

# If an invasive treatment is suggested<sup>5</sup>

I've read it's not safe for SCAD patients to have a follow-up angiogram unless we are clinically unstable. What other options are there?

#### Associated conditions<sup>6</sup>

I've read that it's best practice for SCAD patients to have a head-to-hip scan to rule out abnormalities in other vascular beds – please can you organise this for me?

# Exercise<sup>7</sup>

What exercise should I be doing in the first few weeks after my SCAD?

Will I be able to get back to the exercise I did before my SCAD?

#### When?

(See also Cardiac rehab section below.)

# Cardiac rehab<sup>7</sup>

When will I start cardiac rehab?

Can I talk to the cardiac rehab team before the sessions so they can tailor them for me?

# Contraception, peri-menopause & menopause<sup>8</sup>

What contraception options are there? Can I use HRT for menopause symptoms?

# Pregnancy<sup>9</sup>

Should I try for a/another pregnancy? What are the risks? How can a pregnancy be managed?

#### Migraines<sup>10</sup>

I suffer from migraines, what medication can I take?

# Emotional support<sup>11</sup>

Can I be referred to/access talking therapies to help me recover emotionally?

Does the cardiac rehab team have access to mental health services?

# References

#### 1. Recurrent SCAD

Current figures suggest approx 10% of SCAD patients may have a recurrence within five years of the first event. Recurrences usually happen in a different location to the first SCAD and, in observational studies, the authors say increased coronary tortuosity, FMD (Fibromuscular Dysplasia), migraine, uncontrolled hypertension and non-use of beta blockers have been associated with increased risk of recurrence.

#### 2. Genetics

Research has discovered common and rare genetic variants that are associated with SCAD. See Genetics links below.

# 3. Medication

The European Position Paper and the chapter on SCAD in the PCI textbook (see useful links) say some medication given to patients

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with atherosclerotic heart disease is not necessarily suitable for SCAD patients. This depends on whether or not you have stents, high blood pressure, high cholesterol numbers, had bypass surgery or are in heart failure. **NB Do not stop or change your medication without consulting a doctor.** 

# 4. Ongoing chest pain

Many SCAD patients have ongoing chest pain and the experts suggest this happens more frequently in women, those who have migraine and those who experienced previous psychological or chronic pain issues. Re-admission to hospital is common and the authors of the PCI textbook (see useful links below) provide advice for managing these patients, including non-invasive coronary imaging where there is uncertainty about diagnosis, given the increased risks of invasive angiography. It goes on to say that in most patients improvements are seen over time, but this can take up to two years after the initial SCAD.

#### 5. Further angiograms

Invasive angiograms carry an increased risk of further dissections for SCAD patients and the advice from experts is to try other options including intracoronary (OCT) imaging and CT coronary angiography unless the patient is clinically unstable.

#### 6. Associated conditions

SCAD is associated with other conditions such as Fibromuscular Dysplasia (FMD) and the advice from experts is to have a head-to-hip scan (CTA or MRA) to rule out abnormalities in other vascular beds.

#### 7. Exercise/cardiac rehab

There is no evidence that exercise after SCAD increases the risk of recurrence and cardiac rehab is safe and beneficial, both physically and mentally. Isometric exercises are not recommended and SCAD patients should avoid exercise to exhaustion point or extreme activities.

Specialist heart hospital Papworth has this useful booklet about returning to fitness after a heart attack. Although it focuses on atherosclerotic heart attacks, the information from page 7 gives a helpful summary of the types of things that are suggested once you get home after your SCAD/heart attack.

#### 8. Contraception, peri-menopause/menopause and HRT

Although no causal link has been found between hormone therapies and SCAD or recurrence, experts say if you can avoid using them, that is the simplest option, however if this isn't possible, they suggest the following:

- progesterone-based contraception is preferable where possible over oestrogen-based
- the lowest dose of HRT and for the shortest duration required for symptom relief
- in premenopausal women the use of the levonorgestrelreleasing intra-uterine system can be an effective and safe option for both contraception and mitigation of menstrual bleeding

<u>Cllick here</u> for some context from Dr Adlam. (Start watching from 36 minutes 56 seconds).

## 9. Pregnancy

Unplanned pregnancy should be avoided after SCAD and current data suggest there is a risk of recurrent SCAD associated with

pregnancy after SCAD in perhaps 10% of cases and pregnancy-related SCAD (P-SCAD) is associated with more severe SCADs and larger heart injury. However, if you wish to investigate the options, a multi-disciplinary medical team should be involved. Both Dr David Adlam and Dr Abtehale Al-Hussaini provide counselling on pregnancy after SCAD and you can request to be referred to them (see beatscad.org.uk/scad-nhs-clinic-referrals).

## 10. Migraines

Migraines happen with increased frequency in SCAD patients, and experts say management can be tried using a range of alternative approaches (including topiramate, riboflavin, magnesium, flunarizine, lamotrigine, amitriptyline and valproate).

# 11. Emotional support and mental health

Due to the younger patient population, SCAD patients are at high risk of post-traumatic and other mental health problems and the authors advise early referral to counselling or other therapies.

# **Useful links and documents**

Chapter on SCAD in the PCR-EAPCI Textbook Percutaneous Interventional Cardiovascular Medicine, written by cardiologists and SCAD experts Dr David Adlam, who is leading the SCAD research in Leicester, Fernando Alfonso from Spain, Angela Maas from The Netherlands, Alexandre Persu and Christiaan Vrints from Belgium.

#### **European Society of Cardiology**

- European Position Statement on SCAD
- ☐ European Society of Cardiology SCAD Study Group
- Chronic infarct size after SCAD
- European Society of Cardiology Clinical Practice Guidelines for non-ST segment elevation acute coronary syndromes (including section on SCAD)

#### Genetics

- ☐ Information about the PHACTR1 genetic risks for SCAD
- Dr David Adlam (lead UK SCAD researcher) talks about SCAD and genetics
- The link between patients with genetically confirmed Loeys-Dietz Syndrome and SCAD.

#### Exercise and physical activity

Physical activity & exercise in SCAD & FMD patients research paper (behind a paywall – see here for a summary)

# See the Beat SCAD website for lots more information about

- SCAD symptoms & diagnosis
- Recovery after SCAD
- Emotional impact of SCAD
- Associated conditions
- Exercise after SCAD
- Physical activity & exercise summary of research paper
- Research updates
- Useful <u>downloadable documents</u> including leaflets and information sheets for patients and healthcare professionals plus In Case of Emergency (ICE) cards.

Download pdfs from <u>beatscad.org.uk/downloads</u> or request printed leaflets from our shop (beatscad.org.uk/shop).

