Irish Heart Foundation

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Step by Step through Spontaneous Coronary Artery Dissection (SCAD)

Produced by the Irish Heart Foundation

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Some content in the 'What just happened?', 'What is SCAD?', 'Recovery and rehabilitation' and 'Life after SCAD' sections is used with kind permission from Beat SCAD UK.

The information and advice in this book does not replace that given by your doctor or medical team.

Irish Heart Foundation

The Irish Heart Foundation is a community of people who fight to protect the cardiovascular health of everyone in Ireland.

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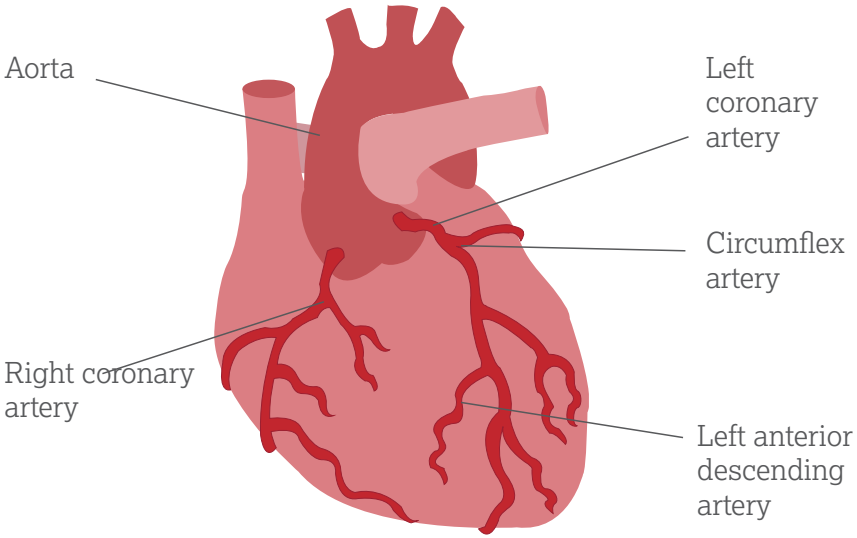
Contents

What just happened?

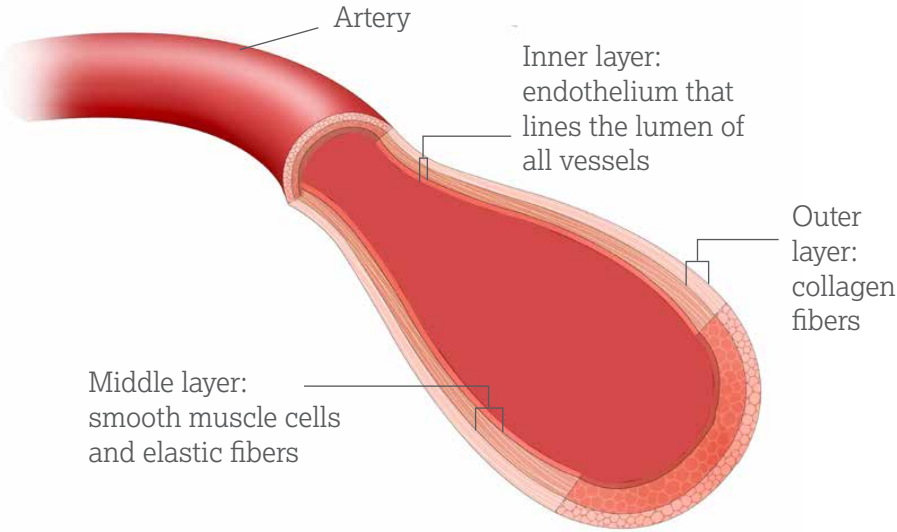
You have been diagnosed with spontaneous coronary artery dissection (SCAD), so you may feel isolated, scared and confused. You are likely to have many questions about SCAD, starting with 'Why has this happened to me?' You may have other questions about treatments, medication, exercise, rehabilitation, psychological issues and more. Some questions cannot be answered yet, which is why current research is so important. In the meantime, the Irish Heart Foundation and SCAD IRELAND are here to help you.

What is SCAD?

The coronary arteries are blood vessels that spread over the surface of your heart to supply the heart muscle with oxygen and nutrients.



The walls of the arteries are made up of an inner, middle and outer layer.



With SCAD, blood collects between the inner layer and the middle layer of the artery wall and causes the layers to separate. Blood can then get trapped within the artery wall. This collection of blood is called a haematoma. This causes a partial or complete blockage of the artery, reducing the flow of blood to the heart muscle.

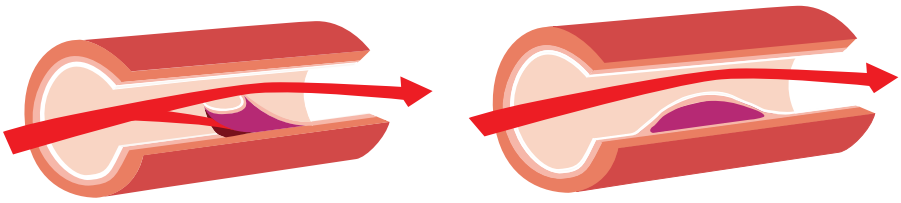
When blood flow to the heart muscle is reduced, this can lead to heart attack, an abnormal heart rhythm or even sudden death, if not treated promptly.

Why does it happen?

SCAD is a rare emergency condition, and researchers are not sure what causes it. There are currently two theories:

1. **Outside in**: tiny vessels in the artery wall haemorrhage (bleed), causing blood to leak out through the inner layer of the artery wall, causing a haematoma.

2. **Inside out:** a tear develops in the artery wall.



TEAR HAEMATOMA

Unfortunately, unlike coronary heart disease, SCAD doesn't seem to be preventable and it happens out of the blue.

- Most people with SCAD are otherwise healthy and might not have any factors that usually increase the risk of heart disease.
- Most people with SCAD are female (87% to 95%).
- The average age of people with SCAD is between 44 and 53 years. Male people with SCAD tend to be slightly younger than females.
- 10% of people with SCAD are nearing the end of a pregnancy or have recently given birth.

Factors that increase the risk of SCAD include the following:

- Conditions that can cause a weaker coronary artery wall, such as fibromuscular dysplasia, which is the abnormal development or growth of cells in the walls of the arteries. (About 60 to 70 per cent of patients with SCAD have fibromuscular dysplasia in other arteries.)
- Connective tissue disorders, such as Ehlers-Danlos syndrome and Marfan syndrome.
- Being pregnant, particularly having had multiple pregnancies.
- Hormonal therapy.
- Inflammatory diseases.

A number of 'triggers' may be linked to SCAD. These triggers include:

- Intense emotional stress.
- Extreme physical exertion (for example, through exercise or childbirth).
- Straining caused by, for example, vomiting or constipation.
- Untreated high blood pressure.
- Using drugs such as cocaine or amphetamines.

Symptoms

The symptoms of SCAD are the same as the symptoms of a heart attack (myocardial infarction). Many patients are young and fit with no risk factors for heart disease, so symptoms can often be ignored or mistaken for other causes such as gallstones, indigestion or panic attacks.

Symptoms may include some of the following:

- Chest pain, tightness or a burning or tearing sensation, or pressure spreading to the arms, neck, back or stomach
- Jaw pain
- Throat discomfort
- Back pain
- Shoulder pain in one or both shoulders
- Pain or numbness in one or both arms
- Shortness of breath (a sensation of not having enough breath to talk)
- Sweating or rapid change in body temperature
- Nausea or diarrhoea
- Feeling lightheaded or dizzy
- A rapid heartbeat or fluttering feeling in the chest
- Unusual, extreme tiredness

Diagnosis

It is difficult to diagnose SCAD because it doesn't have any warning signs. As heart attack is the most usual cause of the symptoms, this is what doctors will look for first.

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 the heart muscle.

Tests to diagnose SCAD include the following:

- **An ECG (electrocardiogram):** This is a simple, painless test which measures the rhythm and electrical activity of your heart. During an ECG, small sticky pads are placed on your body. These pads are connected by wires to the ECG machine. The machine reads and records the electrical signals from your heart.
- **Blood tests to detect the level of troponin;** a protein that is released into the bloodstream when the heart muscle has been damaged.
- **Coronary angiography:** An angiography is a test to see if blood in the coronary arteries, which supply the blood to your heart, is flowing freely. A small tube is inserted into a blood vessel and threaded up to your heart. Dye is injected through the tube and an X-ray shows the flow of blood.
- **An echocardiogram:** This test uses sound waves (ultrasound) to see how your heart muscle and valves are working.
- **A CT scan of the coronary arteries:** A CT scan uses x-ray to give a clear image of your arteries.
- **A CT scan from head to pelvis** looking for weaknesses in other blood vessels.
- **An MRI scan of the heart:** This uses magnets and radio waves to create a detailed image of your heart.

Treatment

Initially you will be treated in a coronary care unit (CCU), where you will be closely monitored for three to five days.

The aim of treatment is to restore blood flow to the heart muscle as soon as possible.

There are several treatments available, depending on the severity of the SCAD and the damage to the heart.

In many cases the artery will heal naturally over the coming weeks. For this reason, the first course of treatment includes medication that controls blood pressure, thins the blood or reduces cholesterol levels. This is always the first, and most preferred course of treatment provided.

If medication alone cannot alleviate the symptoms and increase the blood supply to the heart muscle, doctors may have to restore the blood flow by:

- Stretching the artery by inserting a balloon, inflating it and then removing it (angioplasty).
- Opening the artery by inserting a stent (a short, mesh tube) that is left in place, or
- Bypassing the damaged part of the artery with a coronary artery bypass graft (CABG) operation (where a blood vessel taken from another part of the body is attached above and below the damaged part of the artery to divert the blood around it).

The most appropriate treatment will depend on the severity of the SCAD, where it is, and your signs and symptoms.

Medicines

Your doctor may recommend one or more of the following medicines:

Aspirin

Aspirin is a blood thinner and most experts recommend its long-term use.

Blood-thinning medicines

Medicines that reduce the number of blood-clotting 'platelets' in your blood and can reduce the risk of a clot forming. You will need this medicine if you have had a stent inserted.

Beta blockers

These medicines lower blood pressure and heart rate. From the latest evidence, beta blockers may be recommended even if you do not have high blood pressure.

Angiotensin-converting enzyme inhibitors and angiotensin receptor blockers

These medicines should be used if there is any dysfunction of the heart muscle. They are also used to reduce high blood pressure.

Lipid-lowering drugs or statins

If you have high cholesterol, you may need to take this type of medicine to lower the level of cholesterol in your blood.

Medicines to relieve chest pain

These medications (nitrates and calcium channel blockers) can help treat chest pain you may experience after SCAD. You can take them as a tablet, spray, or in a patch.

Current research suggests that it is not necessarily appropriate for people with SCAD to be prescribed the same medicines as those who have had a 'traditional' heart attack. Every SCAD is different, so please talk to your cardiologist about what is right for you.

Life after SCAD

Recovery

There may be some challenges

How will I feel?

The psychological effects of SCAD can be huge, and you may experience anxiety, depression or post-traumatic stress disorder (PTSD). As mental well-being is linked with physical recovery, both should be taken into account. SCAD often happens without warning to fit and healthy people, so it can be especially difficult to accept.

Emotional stress

Recent emotional stress, such as the death of a loved one, a relationship ending, or any other significant stress has been reported in a higher than expected proportion of people with SCAD, particularly in women. Talk to your healthcare providers about how you are feeling. Many have expertise in stress management.

Physical impairment

SCAD recovery can involve a lot of tiredness and fatigue. The scale of these can vary depending on your health before SCAD, the treatment you've been given for SCAD, and your heart function after SCAD.

Chest pain after SCAD

Recurrent chest pain is very common after SCAD. Hospital admission for chest pain after SCAD is also very common. The cause of this recurrent chest pain is not fully understood. It may relate to the healing process in the artery following SCAD. Most recurrent chest pain does not seem to be a high-risk sign and usually improves over time, although this may take up to two years. However, some patients need to go to hospital for a more detailed assessment.

Deciding how to react to chest pain when you have had SCAD can be challenging. Never hesitate in returning to the emergency department if you are concerned. If you were prescribed GTN spray, you can use it in line with its instructions.

Over time, patients and their healthcare providers often learn which pains can be managed at home and which need further assessment in hospital. In some patients, the pain arises in a cycle, and may be linked to the menstrual cycle.

Post-traumatic stress disorder (PTSD)

As SCAD affects a younger, low-risk population where a life-threatening condition is unexpected, people with SCAD may be particularly at risk of PTSD and other psychological issues. Patients who have recently given birth have the added challenge of a new baby.

Counselling, cognitive behaviour therapy (CBT), stress-reducing therapies or medication for anxiety or depression may be appropriate. In the long-term, patients may also be encouraged to explore concepts like mindfulness, healing through breathing and keeping a journal.

Will it happen again?

Although the chances are low (approximately 10% within three years), SCAD can happen again. So it is important to be aware of any signs or symptoms and act quickly.

There can also be positive changes after SCAD

Although there are challenges, some people affected by SCAD report positive life changes as a result of SCAD.

After making positive lifestyle changes, some people believe they experience a better quality of life and feel physically better post SCAD.

Other people report a return to full physical health after a time, with no long-term side effects.

Many have become volunteers and supporters to other people with SCAD, which has brought a new sense of fulfilment to their lives.

Some people have gained new friendships through being part of a SCAD support network.

Cardiac Rehabilitation

Cardiac rehabilitation is a very important part of recovering from SCAD, especially if you were fit and well beforehand. Loss of confidence is very common, especially if your SCAD happened during or after exercise, so exercising in a safe, controlled environment is highly beneficial. Several studies have confirmed the safety and benefit of cardiac rehabilitation for people with SCAD, and no study has yet identified an association between moderate physical activity and SCAD happening again.

Some people with SCAD may feel out of place at 'usual' cardiac rehabilitation classes as they are likely to be much younger and fitter than most of the group. However, many aspects of the sessions, such as monitored exercise to help you regain confidence in your body, are invaluable. Some cardiac rehabilitation centres may not be familiar with SCAD, so you may need to work with them to tailor a programme for you.

Exercise

What exercise can I do?

Given the benefits of exercise, both mental and physical, current evidence suggests that it is safe to return to physical activity following SCAD. You may be concerned about the safety of physical activity and exercise after SCAD however, many patients who were previously very active may be motivated to take up physical activities again.

There are however certain physical activities that people with SCAD should avoid, so it is important to speak to your consultant, cardiac nurse, or GP before re-commencing exercise.

Exercise to avoid

Patients with SCAD are generally advised to avoid prolonged high-intensity activities, highly competitive or contact sports, activities performed to exhaustion (such as racing and boot camps), abrupt increases in physical activity without a warm-up, exercise in extreme temperature or terrain, or performing the 'valsalva manoeuvre' (holding your breath during lifting or exercise).

Recommended exercise targets

Cardiac rehabilitation guidelines when exercising are to:

- Avoid high blood pressure (no higher than 130/80).
- If you are resistance training using weights, start at a low weight and gradually increase repetitions.
- Recommendations of weight limits are:
    - Up to 9kg for women
    - Up to 22kg for men

Relationships and Family

SCAD can be difficult for your family members, so rehabilitation often include relatives in educational aspects of the programme.

Can I pass it on to my children?

SCAD does not appear to be a strongly inherited condition.

Hormone treatments and pregnancy

- Currently there is a lack of evidence on the connection between hormone replacement therapy (HRT) and SCAD recurrence. Non-hormonal treatments are recommended. However each case is different. Please discuss with your cardiologist or GP.
- It is important that you plan any future pregnancies, only after discussion with your cardiologist.
- If you are pregnant or breastfeeding, tell your cardiologist.

Cardiovascular risk factors

SCAD is frequently reported as a disorder which mainly affects people who do not have the usual risk factors for heart disease. However, conventional risk factors are not uncommon in people with SCAD. The conventional risk factors include the following:

- High blood pressure
- High cholesterol
- Smoking
- Diabetes
- Being obese or overweight
- A parent, child, brother or sister with coronary heart disease
- Inactive lifestyle (for example, having a job where you are sitting down for a large part of the day)

If you have some of these risk factors it is vital to manage them with medication or lifestyle changes.

Support

As a patient with an uncommon disease, you may find that you know more about your condition than the medical professionals treating you, so it's important to find the best support. Talking to other people with SCAD can help you get support with practical matters and give you suggestions for dealing with your feelings and emotions.

SCAD IRELAND

The SCAD IRELAND support group was launched in March 2019 by Pauline O'Shea in association with the Irish Heart Foundation. Pauline had SCAD three days after the birth of her daughter.

The group aims to support those affected by SCAD and advocates to increase awareness of the condition among the medical profession. It aims to work with experts in Ireland and world-wide to make sure that everyone diagnosed with SCAD receives prompt and evidence-based treatment.

The group has a private Facebook group,which you can find at **www.facebook.com/groups/SCADIRELAND** and a **WhatsApp group** where members can share experiences and offer each other support. The group also offers **patient to patient support on the telephone**. You can email the group directly at **scadirelandemail@gmail.com**

SCAD IRELAND holds an annual national gathering where up to date information on the condition is presented to members and people living with SCAD in Ireland can physically meet up to share experiences.

Irish Heart Foundation Nurse Support Line

For more information or support, you can contact the Irish Heart Foundation Nurse Support Line by phoning 01 6685001 or by emailing to **support@irishheart.ie**.

Sources of further information

Irish Heart Foundation: www.irishheart.ie

Beat SCAD: www.beatscad.org.uk

SCAD research: www.scadresearch.org

SCAD at Mayo Clinic: www.mayo.edu/research/scad

SCAD Alliance: scadalliance.org

SCAD IRELAND: **www.facebook.com/groups/SCADIRELAND** or email scadirelandemail@gmail.com

References

Some of the information in this guide came from the following sources:

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NOTES

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For more information visit: **www.irishheart.ie**

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