

HEART SERIES H10

LIVING WITH AN ICD



Chest
Heart &
Stroke
Scotland



**Chest
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Stroke
Scotland**



**Chest Heart &
Stroke Scotland
improves the
quality of life for
people in Scotland
affected by chest,
heart and stroke
illness, through
medical research,
influencing public
policy, advice and
information and
support in the
community.**

FUNDRAISING

Chest Heart & Stroke Scotland is a wholly independent Scottish charity. We receive no core funding from Government or any public body or private agency and rely entirely on the Scottish public to raise the £7 million a year we need to help people with chest, heart and stroke illness throughout Scotland.

RESEARCH

We are one of Scotland's largest charitable funders of medical research, with a programme worth over £600,000 a year. We fund research projects throughout Scotland into all aspects of the prevention, diagnosis, treatment and social impact of chest, heart and stroke illness.

PERSONAL SUPPORT GRANTS

We provide small grants to people in financial difficulty, because of chest, heart or stroke illness, for items ranging from disability equipment and household goods to respite care and holidays.

VOLUNTEER SERVICES

We give support to people whose communication skills are impaired after a stroke and those living with heart failure. The Volunteer Stroke Service (VSS) provides weekly group meetings and home visits for patients. The Heart Failure Support Service (HFSS) provides volunteer befrienders to reduce social isolation.

CHSS NURSES

Our nurses provide independent practical advice and support to those who have chest, heart and stroke illnesses, their families, carers and health professionals. There are dedicated nursing services in Fife, Forth Valley, Grampian, Highland, Lanarkshire, Lothian and Dumfries and Galloway. There is also a Scotland wide nurse led Advice Line (0845) 077 6000. Calls are charged at a local call rate (out of hours answerphone). We have a wide range of booklets, factsheets and videos on chest, heart and stroke illnesses.

COMMUNITY SUPPORT NETWORK

CHSS provides support to affiliated chest, heart and stroke clubs through the Community Support Network. The clubs are independent and are run by local volunteers. The groups provide a range of activities and offer people support, stimulation and companionship in a friendly and relaxed environment. Please ask for more information.

**FOR FURTHER INFORMATION ABOUT ANY OF
THE SERVICES ABOVE PLEASE CONTACT HEAD
OFFICE BY PHONING 0131 225 6963 OR VISIT
www.chss.org.uk**

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LIVING WITH AN ICD - Implantable Cardioverter Defibrillator

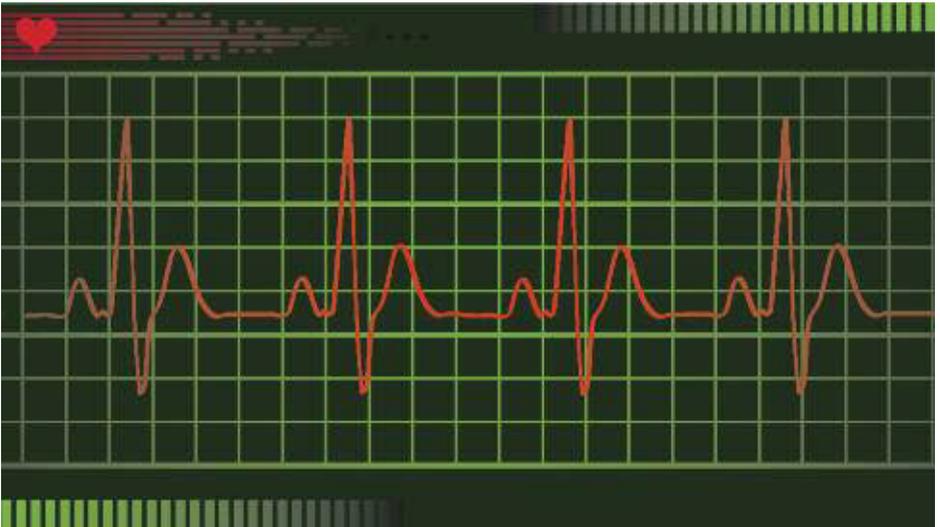
INTRODUCTION

This booklet looks at what an Implantable Cardioverter Defibrillator (ICD) is and what it is used for. It also provides information to help you decide if an ICD is right for you and how to adapt to living with your device.

WHAT IS AN ICD?

ICDs are life-saving devices, similar to pacemakers. They are programmed to pick up and stop specific life-threatening arrhythmias (abnormal heart rhythms) and restore your heart to its normal rhythm.

See the CHSS booklet 'Understanding heart disease' for more information about how the heart works.



WHY DO I NEED AN ICD?

ICDs are recommended:

- if you are at risk of specific life-threatening arrhythmias (known as ‘primary prevention’)
- if you have survived a specific life-threatening arrhythmia (known as ‘secondary prevention’)

There are two types of arrhythmia that are treated with ICDs:

- **Ventricular tachycardia (VT):** this is when the ventricles (bottom chambers of your heart) produce abnormal electrical signals which cause your heart to beat very quickly. This can interfere with the pumping action of your heart and may cause your heart to stop beating.
- **Ventricular fibrillation (VF):** this happens when irregular electrical signals are rapidly produced throughout the ventricles. In VF your heart is unable to contract and pump blood. It will stop beating unless an electrical shock is given to restore your heart rhythm.

Heart Failure

If you have heart failure you may need a special type of device which incorporates an ICD. This is called a CRT-D (cardiac resynchronisation therapy defibrillator) device.

In heart failure the heart muscle has become weakened and is unable to pump blood around the body as efficiently as before.

As well as treating heart arrhythmias, a CRT-D device synchronises your heart's chambers to contract and relax in a regular way, thus improving the pumping action of your heart.

See the CHSS booklet 'Living with heart failure' for more information.



HOW DOES AN ICD WORK?

What does an ICD do?

An ICD can work like a basic pacemaker to stabilise your heart's rhythm and / or can cardiovert your heart (i.e. correct abnormal heart rhythm) through the delivery (or 'firing') of a controlled electrical 'shock'. This process, called 'defibrillation', stops a dangerous arrhythmia and allows the normal rhythm of your heart to start again. Sometimes this is simply referred to as your ICD 'firing'.

Depending on the continual monitoring of your heart rate, an ICD can:

- Deliver pacing pulses to increase your heart rate if it is too slow. You are usually unaware of this.
- Deliver fast pulses to help to restore a normal rhythm when your heart rate is too fast. You may be unaware of this or you may notice palpitations and / or dizziness.
- Perform cardioversion: an electric shock is delivered to your heart to stop a dangerous heart rhythm (such as ventricular tachycardia or ventricular fibrillation). This can be quite painful. However, if your heart rhythm is so fast that it causes loss of consciousness then you may be unaware of this happening.
- Record the electrical activity so that your heart's rhythm and any treatments delivered can be examined.

What happens when my ICD fires / shocks?

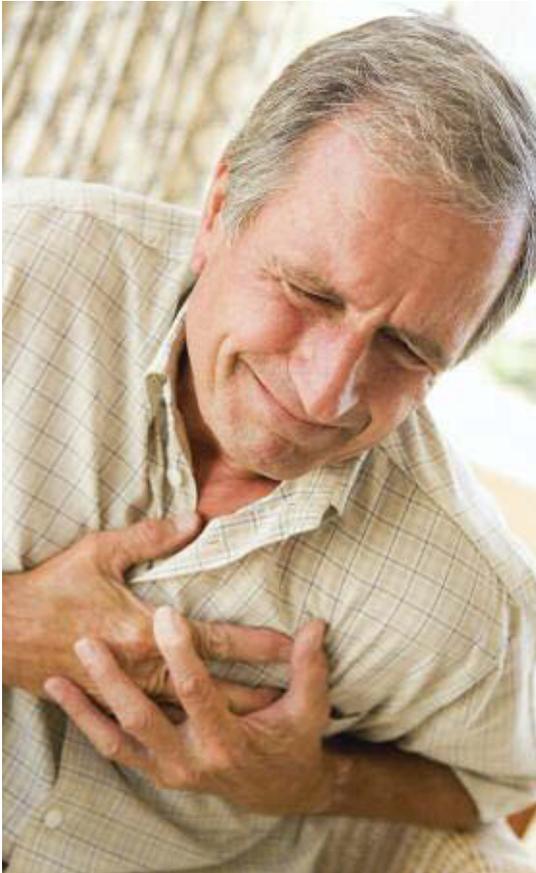
Before:

- You may get warnings such as palpitations, feeling light headed or dizzy. If this happens then you should sit or lie down immediately. Let someone know how you are feeling. Try not to panic.
- You may not get any warning as some arrhythmias make you become unconscious quite quickly.

During:

- Most people describe the shock as a jolt, like a kick or punch to the chest, the pain of which passes very quickly.
- Some people describe a tremor that goes through their whole body.

Remember that your ICD is a life-saving device. Although a firing can be painful, and it may take some time to recover afterwards, it is returning your heart to a safe rhythm.



After your ICD fires / shocks

- You should recover from the shock and jolt fairly quickly. However, it is advisable to take a little time to rest before recommencing activities as you may feel dizzy.
- Although, after a short time, you are likely to feel OK, you should contact your doctor / clinic to arrange to have your ICD checked.
- Any treatments delivered are recorded in your device; this information can be retrieved by the clinic and they will be able to see why it fired.

Occasionally your ICD might deliver more than one shock in quick succession. If this happens you need to go to hospital unless your doctor tells you otherwise. Your ICD will be checked to establish what was happening when the shocks were delivered.

If you feel unwell after one shock or your device delivers several shocks one after another, phone 999 so that you can be taken to hospital as soon as possible.

Inappropriate shocks

Very rarely an ICD can fire inappropriately. This will be picked up at the clinic when you have your device checked. The function will be carefully monitored at your follow-up appointments. Talk to your doctor / nurse if you have any concerns about this.

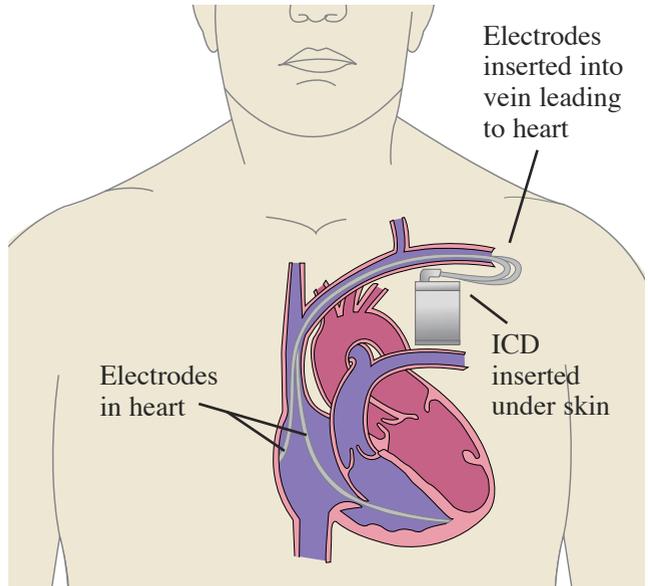
HOW IS AN ICD FITTED?

An ICD consists of a small 'box' with pacing wires which are situated within the chambers of your heart and provide information about your heart's rhythm.

A small incision is made and the ICD is inserted under the skin in your chest. The wires are inserted into a vein that leads to your heart. They are positioned with the help of an x-ray.

The ICD 'box' is attached to the other end of the wires and placed flat in a pocket under your skin. Stitches are then used to close the wound. The procedure is usually done under local anaesthetic.

Each device is programmed, specifically, to respond to your individual needs. The programme can be modified at clinic visits if necessary.



Taking care after surgery

Immediately following surgery the positioning of the wires can be vulnerable. For the first few days it is important that you take care by avoiding extreme movement of your arm on the affected side or by using it too much. Also avoid any sport or activity where you could get hit or kicked on the area where your ICD has been fitted.

It is important to keep an eye on the wound for about 10 days. If there is any sign of infection (such as redness, tenderness, soreness or swelling) you should notify your GP immediately, so that antibiotics can be started straight away.

Most stitches will dissolve on their own. If not they will be removed 7 - 10 days later, usually by the nurse at your doctor's surgery.

Identification card

You will be given an identification card to carry with you at all times. This will have details about you, your ICD, your doctor and the hospital you go to.

Remember to tell medical, nursing and dental staff about your ICD before any test or procedure using medical / electronic devices.

Routine check-ups

You will need regular check-ups, usually at a special pacemaker / ICD clinic, to ensure your ICD is working properly and to monitor your device's battery life.

At first your doctor may want to see you every month; once things are stable your check-ups will be every 3 - 12 months.



MAKING THE DECISION TO HAVE AN ICD

Tests and investigations

You will need some tests and investigations to help your cardiologist (heart doctor) to decide if an ICD will help you. These may include:

Electrocardiogram (ECG)

An ECG is a recording of the electrical activity of your heart. Electrodes, attached to sticky patches, are positioned on your chest, wrists and ankles and a recording is made.

The ECG reflects what is happening in different areas of your heart and helps to show up any abnormality in electrical activity.

An ECG is painless and the procedure usually takes about 5-10 minutes.

24 hour ECG

ECG electrodes are connected to a small box attached to a belt which you wear for 24 hours, as you go about your normal daily activities.

A 24hr ECG records the information on a tape, which can then be analysed by the hospital physiologist (technician) / doctor. This is very helpful in looking at irregular heart rhythms that come and go. It can also be used to confirm whether or not your symptoms are heart-related.

Echocardiogram

Also referred to as an ‘echo’ this is an ultrasound scan of your heart. Special conductive jelly is applied to your bare chest to make good contact. An operator lays a probe on your chest and moves it around to get different views. Sound waves bounce information about the structure of your heart back to a computer to make a picture of your heart.

This tells the doctor about:

- the size of your heart
- how well your heart muscle is working
- how well your heart valves are working

Other tests

More advanced tests such as an Adenosine Test and Electrophysiology (EP) studies may be carried out under special circumstances to provide important information to your cardiologist.

Issues to talk about with your doctor

If your cardiologist feels that an ICD would be helpful to you then he / she will explain to you about your arrhythmia and why you need to have an ICD. You may want to talk about:

- the benefits of having an ICD fitted
- how having an ICD fitted will affect your everyday life
- what would happen to you if you choose not to have one fitted

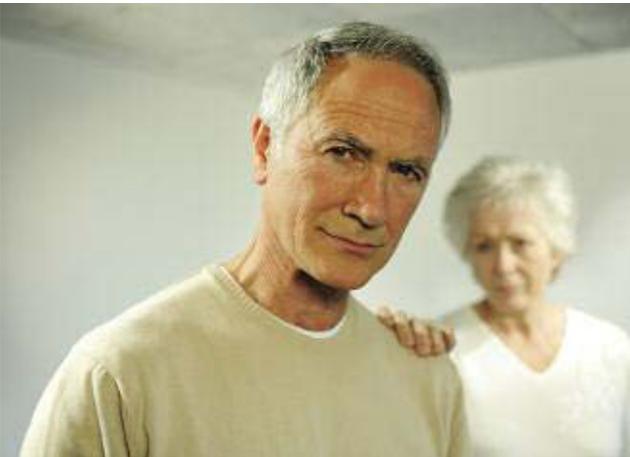
HOW AN ICD CAN AFFECT YOU AND YOUR FAMILY

Your family and close friends may feel more anxious about your ICD than you do. For example, they may feel overprotective towards you and constantly be checking you are OK. Or perhaps they may not want you to be alone or go anywhere unaccompanied.

You may find this frustrating and stifling or it may make you feel you should be worrying more about yourself than you do.

Everybody copes differently so try to remember that other people may:

- lack understanding of how you are feeling
- benefit from sharing your thoughts and feelings
- have been affected by your condition too
- be too scared to talk about fears and worries they might have



Children and family issues

If you have young children to look after, either your own or those of your wider family and friends, you may find that having an ICD changes the way people perceive your ability to care for children. Some people may even think that children in your care may be in some danger because of your ICD. This is not the case.

It may help to explain the facts to those around you. Though it is possible for someone to feel a vibration or distant ‘thump’ if they are close to you, when your ICD fires, they will not be ‘electrocuted’, ‘zapped’ or affected in any other way.

Explain to children what might happen to you should your ICD fire and reassure them that you are just the same as before and that they don’t need to worry about you.

Remember that they may have witnessed you being ill and that they may be frightened this might happen again.

If your ICD fires then it may help, once you have fully recovered, to talk it through with your children and explain what has happened.

Sex and pregnancy

There are two common worries about an ICD in a sexual relationship: that increasing your heart rate during sex will cause your ICD to fire and what it would do to your partner if it did fire during intercourse.

It is normal for your heart rate to increase when you are physically active; this provides the blood supply and nutrients your body needs. This is very different to a fast arrhythmia that will need to be corrected.

If your ICD happens to fire during intercourse it will not cause any harm to your partner.

A misconception about having an ICD is not being able to conceive and give birth naturally. This is not necessarily the case; women have had children and cared for them successfully with an ICD. If you are planning to get pregnant you must talk to your doctor as you will need to be carefully monitored throughout your pregnancy.

COMMON ISSUES OF CONCERN

Physical activity / exercise

Some people are afraid to be physically active after having an ICD fitted. After your wound has healed (usually 10 - 14 days), any limitation on your activity levels will only be determined by your underlying condition. You should always seek individual advice from your doctor before attempting any new physical activity.

Driving

Restrictions on driving, and whether you need to tell the DVLA, vary depending on the reason you have an ICD and if it has ever fired. You must ask your doctor, or contact the DVLA, for guidance about your situation.



If you are a Group 2 driver (i.e. lorries and buses) you are permanently barred from driving and you must notify the DVLA.

Full information is contained in the Medical Standards of Fitness to Drive available from the DVLA (see useful addresses and websites).

Work

Most ICDs are designed with built-in features to protect them from common types of electrical interference that you might encounter. You should talk to your doctor, or cardiac physiologist at the clinic, about what equipment is dangerous to use at work e.g. electric welding equipment, operating machinery etc.

What can and can't interfere with my ICD?

If you suspect electrical interference with your ICD, simply move away or turn off the electrical equipment. Sit down if you feel dizzy and contact your doctor if you continue to feel unwell.

- Mobile phones, MP3 players, headphones and palm / pocket PCs can be used safely as long as they are not placed directly over your ICD (e.g. in a breast pocket).
- Airport security systems: bring your ICD identification card with you and tell security staff that you have an ICD.
- You cannot have a Magnetic Resonance Imaging scan (MRI) when you have an ICD.

Having your ICD turned off

At the end of life, your ICD could keep your heart beating artificially. This can be the case for both heart and non-heart related conditions or when your quality of life has become very poor.

For some people there comes a point when the decision needs to be made as to whether an ICD is still appropriate. The decision to turn off an ICD can be very difficult and should involve discussions with close family and your doctor / specialist nurse.

Turning off an ICD is a simple, non-invasive procedure, which can be performed by a cardiac physiologist (technician).

It is important to know that specialised care will be provided to support you if the decision to switch off your ICD is made. Specialised care, referred to as palliative care, ensures that all your needs will be met and that you and your family are well supported.

EMOTIONAL IMPACT OF HAVING AN ICD

Being told you have a life-threatening condition is scary. You may have already experienced an emergency situation. How you deal with this varies from person to person. Having an ICD should be seen as a positive and potentially life-saving step. Ideally it should give you reassurance that if anything should happen your device will take care of it. However, not everyone feels like that straightaway, especially if you had a cardiac arrest before getting your ICD.

You may feel:

- like you are a walking time bomb: e.g. when is my ICD going to fire?
- scared of dying
- scared of being ill
- scared it doesn't work
- like you are living on borrowed time

Grief-related emotions

Sometimes coming to terms with a major life event, or illness, involves similar emotions to those felt as part of a grief reaction. For example:

- Shock: feeling that what is happening is not real.
- Denial: this initially protects you from being overwhelmed by your situation.
- Anger: this is often directed at those closest to you.
- Guilt: perhaps you feel guilty about the cause of your condition, or the disruption and worry brought to those around you. Feelings of guilt can be powerful and destructive and can be completely irrational.
- Fear: can cause anxiety and depression.

See the CHSS factsheet 'Living with stress and anxiety' for more information.



How you may feel about yourself

Having an ICD can affect how you feel about yourself in many ways, including:

- having an altered sense of self (feeling different about yourself)
- having a sudden dependence on other people and change of role within your family
- having a sense of loss e.g. loss of control, loss of confidence, loss of work / social life
- feeling low in mood or depressed
- having an altered sexual identity or sexual relationship
- waiting to get back to 'normal', to take up your life where you left off

Try to remember that all of these feelings are perfectly normal as you learn to adjust to life with your ICD. It can often help to talk about them to someone close to you and seek some support for how you feel.

In time you will hopefully:

- feel that your ICD is there to help you
- accept that it is going to keep you well if you should become ill

Letting go – adjustment and acceptance

Letting go happens when you can see yourself as you are now and not as you used to be – accepting the loss of your ‘old self’. You will be able to reflect on what has happened, accept how things have changed and be able to look at the future.

“People who have had ICDs fitted because their heart has developed abnormal rhythms often find life a bit frightening and uncertain. It is easy to become scared to do anything and become more disabled than necessary. Anxiety and depression are normal reactions to such problems. One may become very angry about one’s situation and about the device. Remember that the ICD is not the cause of the problem – that is caused by the condition that led to your heart misbehaving. True, it can restrict you a bit but remember...

**The box is there to save your life
...as many of us can testify, it does this very well.”**

(Quote from a member of the public who has an ICD fitted.)

There are some support groups around the country; please ask your nurse or clinic if there is one near you.

Arrhythmia Alliance

PO Box 3697

Stratford-Upon-Avon

Warwickshire CV37 8YL

24-hour helpline: 01789 450787

Email: info@arrhythmiaalliance.org.uk

Website: www.arrhythmiaalliance.org.uk

DVLA

Tel: 0300 790 6807 - coach or lorry

0300 790 6806 - car and motorbike

(Monday to Friday 8.00am to 5.30pm,

Saturday 8.00am to 1.00pm)

Website: www.direct.gov.uk/driverhealth

www.direct.gov.uk/DrivingAnd

MedicalConditions

ICD Patient and Family Heart**Support Group**

National ICD helpline: 01782 852509

Email: icdnorthstaffs@yahoo.co.uk

Website: www.icdsupport.org.uk

**USEFUL
ADDRESSES AND
WEBSITES**

Contact the Chest Heart & Stroke Scotland Advice Line nurses for confidential, independent advice.



**The line is open
Monday – Friday
9.30 – 4.00**

**0845 077 6000 or
0131 225 6963**

Out of hours answering machine.

Email: adviceline@chss.org.uk

The information contained in this booklet is based on current guidelines and is correct at time of printing. The content is also put out to peer, patient and expert review. If you have any comments about this booklet please contact Lorna McTernan, Health Information Manager, at the address on the facing page.

HEART PUBLICATIONS

Booklets		Factsheets - Free	
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Tel: 01463 713 433

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5 Mealmarket Close
Inverness IV1 1HT
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Chest Heart & Stroke Scotland is a wholly independent Scottish charity. We receive no core funding from Government or any public body or private agency.

We need your help to achieve our aim of improving the lives of those in Scotland with chest, heart and stroke illness. You can help by volunteering your time with our services, by supporting your local Regional office or as a fundraiser. You can help by giving now and in the future, by making a donation, organising a local fundraising event, leaving us a gift in your will or by setting up a regular Direct Debit.

**If you would like to speak to one of our Advice
Line nurses in confidence, phone
Chest Heart & Stroke Scotland Advice Line.**

**Monday – Friday
9.30am – 4.00pm**

**0845 077 6000 or
0131 225 6963**

**Email us: adviceline@chss.org.uk
There is a text relay service for the hearing-impaired.**

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