

ICD/S-ICD patient information



Promoting better understanding, diagnosis, treatment and quality of life for those affected by heart rhythm disorders (cardiac arrhythmias)

www.heartrhythmcharity.org.uk

Registered Charity No. 1107496

Glossary

Atria are the top chambers of the heart that receive blood from around the body and from the lungs. The atrium is where the heart's natural pacemaker (the sino-atrial node) can be found.

Arrhythmia is the clinical definition of an abnormal heart rhythm.

Bradycardia describes a slow heart rate, normally less than 60 beats per minute.

Cardiac arrest is when the heart suddenly stops beating because of an underlying arrhythmia. It can happen to anyone, of any age, at any time.

Cardioversion is a procedure involving the use of a synchronised (specifically timed) shock to stop fast heart rhythms.

Defibrillation is a procedure involving the use of an unsynchronised (not specifically timed) shock to stop fast heart rhythms.

Heart attack occurs when one of the coronary arteries becomes blocked by a blood clot. The blood supply to part of the heart muscle is blocked, causing part of the heart muscle to die.

Pulse generator is the part of the ICD which contains the battery and electric circuits.

Ventricles are the two lower chambers of the heart. The right ventricle pumps blood into the lungs and the left ventricle pumps blood around the body.

Contents

What is an ICD?

What can an ICD do?

Why do I need an ICD?

How is the ICD implanted?

What happens after the ICD is implanted?

Going home

Will I feel the treatment from the ICD?

What should I do if the ICD gives me a shock?

Getting back to normal

ICD clinic visits

Changing the ICD

Contacting the ICD clinic

Useful websites

Ventricular fibrillation (VF) is a fast, dangerous heart rhythm which causes the heart to stop pumping. This rhythm needs a shock to stop it and return the heart back to a normal rhythm. A cardiac arrest can soon follow if the rhythm is not treated quickly with a shock.

Ventricular tachycardia (VT) is a fast and potentially dangerous heart rhythm, which causes the heart to pump less efficiently, and may lead to dizziness, fainting and loss of consciousness. If not treated with medication, pacing or an electric shock, the rhythm may lead to ventricular fibrillation.

Important information

This booklet is intended for use by people who have, or are about to have an implantable cardioverter defibrillator (ICD), or a subcutaneous implantable cardioverter (S-ICD) implanted, and for their family/carers.

S-ICD patient information

What is an S-ICD?

S-ICD stands for subcutaneous implantable cardioverter defibrillator. If your doctor has suggested that you need an S-ICD you may have experienced or be at risk of experiencing an abnormal, fast heart rhythm. The S-ICD recognises and monitors your heart rhythm and will deliver electrical therapy to shock your heart back into normal (sinus) rhythm if required. The S-ICD is a box shaped device which contains a battery and electronic circuits. It is placed under the skin on the left side of your chest. An electrode is placed under the skin alongside the breast bone and connected to the S-ICD generator.



What is the difference between an S-ICD and an ICD?

A traditional implantable cardioverter defibrillator (ICD), has one or more leads that enter the heart allowing the device to provide pacemaker functions as well as defibrillation. Conversely, an S-ICD has no leads connected to the heart, presenting a less invasive option for patients not in need of any cardiac pacing. For example, if your doctor has told you that you have, or are at risk of, a slow heartbeat, an S-ICD would not be an appropriate option. The implanting doctor will be able to advise whether or not a traditional ICD or an S-ICD is suitable.

Function of an S-ICD

The S-ICD monitors your heart rhythm all the time. If it detects that your heart is beating faster than it should be in a dangerous rhythm, (ventricular tachycardia or ventricular fibrillation), the S-ICD will deliver a shock, or defibrillation, to bring it back to a normal rhythm. If your hear t beats too slowly after the shock, the S-ICD will continue to monitor your heart and deliver additional shocks if required.

How is an S-ICD fitted?

The procedure is performed under a general anaesthetic. The S-ICD generator is connected to an electrode which is placed under the skin. Your doctor may test the system during the procedure to ensure that it is working correctly.

The operation to implant the device should take around two hours and will leave three wounds compared to the usual one associated with implant of a conventional ICD device. Any stitches that may need to be subsequently removed will be done at your GP surgery.

What happens after an S-ICD has been fitted?

You will probably be allowed to go home the next day provided that your S-ICD has been checked and there are no complications. You will be given an S-ICD identity card, emergency information and instructions at this point. You will also be given a helpline number should you have any questions or queries later on. The S-ICD battery will normally last for around five years and the replacement procedure usually involves changing the S-ICD generator, but not the electrode.

Will I feel anything different?

Some patients have described the shock to feel like they were suddenly kicked or punched in the chest, with some pain lasting only a few seconds. Other patients feel no pain following a shock. However, if you do feel unwell after a shock, or if you have received several shocks, please dial 999 for an ambulance. Show the ambulance service your S-ICD identity card along with the emergency instructions that you were given. This way the ambulance service will know exactly which device you have fitted and the best course of action. You must always contact your S-ICD centre if you think that you have received a shock.

What about driving?

The Driving and Vehicle Licensing Agency (DVLA) has strict guidelines in relation to patients who require an ICD and whether or not they are safe to drive. There are some restrictions but these vary depending on why you have had your ICD fitted. The rules are different if you have a primary prevention ICD (that is you are at risk of dangerous arrhythmias but have not had one) or if you have a secondary prevention ICD (you have already had a dangerous heart rhythm disturbance).

After a shock there are strict rules depending on the circumstances. Please consult the driving section on page 15 for further information.

The heart and normal conduction



What is an ICD?

ICD stands for implantable cardioverter defibrillator. It is a mini-computer which contains a battery and electronic circuits. The device is connected to your heart by one or more leads. The leads are passed through a vein to your heart and the ICD box is usually implanted under the skin or muscle in your upper chest, near your collarbone.



The ICD can recognise and monitor your heart rhythm, delivering various electrical treatments if needed. It also has a memory that stores information about your heart rate and rhythm, which can be accessed when you go to the clinic for your follow up appointment. It may also have a remote monitoring facility, which can be automatically downloaded via a digital phone link.

What can an ICD do?

Most modern ICDs have three main functions; however you may not need to have all of them. Your cardiologist will select what settings are best for your condition.

- If your heart rhythm is too slow, the device can give your heart extra support by working as a normal pacemaker. This is called anti bradycardia pacing.
- If your heart beats too fast, the ICD can give you a burst of extra beats at a slightly faster rate which will normally return your heart back to a normal rhythm. This is called anti tachycardia pacing (or ATP).
- If the anti tachycardia pacing does not bring your heart back to a normal rhythm, or if the ICD senses a faster dangerous rhythm called ventricular fibrillation, the ICD can then give a shock. This is called defibrillation.

Why do I need an ICD?

If the doctor has suggested that you need an ICD, you may have experienced or may be at risk of experiencing an abnormal, fast heart rhythm. This can cause you to become unwell, unconscious, or your heart to stop beating.



How the heart works normally

The heart is a muscle and it pumps blood and oxygen around your body and to all of your vital organs. It has four chambers; two at the top (the right and left atria) and two at the bottom (the right and left ventricles). The heart also has an electrical system, which sends impulses (beats) through the heart causing it to contract and pump blood around the body. Each normal heartbeat begins in the natural pacemaker of the heart (the sino atrial or SA node) which lies at the top of the right atrium. It then travels across the atria and down through a small junction box (the atrio ventricular or AV node), which lies between the atria and the ventricles. It then spreads through the conduction pathways across the ventricles, causing the heart to contract and pump.

Sometimes the electrical system in your heart does not work as well as it should. This can cause your heart to beat too quickly. The ICD can stop fast heart rhythms that start in the ventricles. This fast heart rhythm is called ventricular tachycardia or VT. This may sometimes start after a heart attack or in people who have angina or coronary artery disease. Because the blood supply to the muscle may be impaired it does not beat in a synchronised way and this can cause VT.

There are several other reasons for having an ICD, even if you have never had an abnormal heart rhythm.

The heart and normal conduction

You could have a heart condition that puts you at risk of having an abnormal rhythm in the future, e.g. you may have a family history of sudden collapse or even death. This may be the result of muscular damage or abnormalities in the heart's natural electrical system. These conditions may put you at risk of having ventricular tachycardia or ventricular fibrillation, which can be life threatening if it is not treated quickly with an electric shock delivered to the heart. You may need to have some tests before the decision to have an ICD is made. Your cardiologist will advise you if these are needed and discuss the reasons for having an ICD implanted in full detail. You will also be offered family counselling if you have an inherited heart condition.

How is the ICD implanted?

Your cardiologist will have explained to you why you need to have an ICD and the benefits of having one implanted. You need to know how having an ICD fitted will affect you as well as what could happen if you do not have one fitted. This will all be explained to you and if you agree to go ahead, you will then be asked to sign a consent form. You will also be given a booklet explaining the consent form before you sign it.

Your ward nurse will take you to the cardiac pacing theatre or catheter lab. Once you are in the pacing theatre another nurse will check your details again and you will be asked to lie on a trolley or operating table.

The procedure will either be performed under a general anaesthetic or you will be given sedation, which will make you relaxed and sleepy.

Before the procedure starts, the doctor will inject some local anaesthetic under the skin just below your collarbone (usually the left side). This will numb the area and allow the doctor to pass a small lead or electrode through a vein into your heart. You may have one, two or three leads inserted depending on what your doctor recommends. The lead(s) are then connected to the pulse generator box, which is about the size of a matchbox. This will be placed under the skin in your chest. The doctor may test the device during the procedure to ensure it is working correctly.

Your heart may be made to beat very quickly and the ICD will give a shock to restore your heart rhythm back to normal. You will be given some sedation before this happens, so you should not feel the shock.

The incision will then be closed with dissolvable or non-dissolvable stitches. If your stitches need to be removed by your GP, practice nurse or district nurse you will be informed before you leave hospital.

What happens after the ICD has been implanted?

After the procedure and once all the checks have been made, you will be taken back to the cardiology ward. You will be asked to lie in bed for a couple of hours before you can get up, eat and drink.

As the wound can feel quite bruised and sore, especially for the first day or two, you should have regular painkillers. It is very important that you tell your nurse immediately if you have any pain. You will also be given some antibiotics to take before and after the procedure to minimise the risk of infection.

The wound should be kept clean and dry until it has fully healed, although it is fine to have a bath or shower after the first three or four days.

Ask your nurse for a protective dressing so that you can bathe without getting the wound wet. Report any problems to your nurse. You should not lift the arm on the same side as the ICD (usually the left side) above shoulder level for the first two weeks. This is because there is a small chance that the leads could move out of position. However, it is important to do gentle arm and shoulder exercises to keep the arm mobile and prevent a frozen shoulder.

You will probably be allowed to go home that day or the next provided your ICD is checked, there are no complications and your doctor/physiologist/specialist nurse assesses it is safe. Your ICD will be checked before you go home by a cardiac physiologist or the ICD nurse specialist. This check will involve the use of a special programmer that can look at the device settings and make sure the ICD is working properly. It will also be set to the best programme for your condition. The check will take about 15 minutes and can either be done on the ward or in the ICD clinic. Most patients will also have a chest x-ray to check lead positions and make sure all is well following the implant procedure. Please ask the physiologist or ICD nurse if you have any questions or worries about the device.

You will be given an ICD identity card, emergency information and instructions at this check. You will also be given a helpline number should you have any queries later on.

Going home

Although most people are pleased to be going home, it is only natural to feel a bit worried. This is very common, especially if you have been in hospital for a long time and the ICD has only just been put in.

However, we try to make sure that you get the help you need to return to as full and active a life as possible. Please feel free to ask us questions at any time. Similarly if you feel upset or down once you are at home it is very important that you talk to someone. Please contact your ICD implanting hospital if you have any concerns.

Arm movements

Extra tissue will grow around the leads after a few weeks, which will prevent them from moving out of place. Try to avoid lifting the arm above the head for the first two weeks.

Wound site

Your wound site should take about four to six weeks to fully heal. Try to avoid wearing tight clothing over the wound until it has healed completely to avoid excess rubbing over the area. If you notice any redness, soreness, swelling, any signs of bleeding/oozing or signs of infection (even if very small) from the area, report this immediately.

It is normal to experience some discomfort around the area of implant as the ICD settles down. This should gradually improve over time.

You may be able to feel the ICD box under your skin as well as other lumps close by. These are the leads that are attached to the box, curled up beside the box under the skin. It is extremely important that you don't try to move the box or leads, but let your ICD clinic know if they continue to bother you.

Will I feel the treatment from the ICD?

The device will be programmed to the best settings for your condition. Your cardiologist will do this initially when the ICD is implanted, but settings can be modified during your follow up appointments in the clinic if necessary.

The ICD can give the following treatments, but you may not have all of them programmed. Your physiologist or ICD nurse will be able to tell you what your device has been set to do.

• Anti bradycardia pacing pulses

If your heart is beating too slowly, the ICD can send small impulses to the heart generating extra heartbeats when required. These are called paced beats. As these impulses are very small they are not painful and usually go unnoticed. The heart may beat slowly for a few seconds following treatment for a fast heart rhythm. The device can tell when pacing backup is needed and will provide this for as long as necessary.

• Anti tachycardia pacing pulses (ATP)

If your heart beats too fast, the device can send out faster pacing impulses which can help to get the heart back into a normal rhythm.

This can be done so quickly by the ICD that many people do not know that this has even happened. However, it is not uncommon to experience palpitations or feel light headed/dizzy from the fast heart beat.

If the ATP does not correct your fast heart rhythm your device will be able to deliver a shock.

Cardioversion shocks

Your ICD may be programmed to give shocks to your heart during a synchronised specific part of the heartbeat. This type of shock is used to treat ventricular tachycardia. These shocks are full energy shocks like a defibrillation shock and some patients may find them uncomfortable.

• Defibrillation shocks

These are full energy shocks which the device will deliver if it senses that your heart is beating so fast that it is life-threatening.

These fast heart rhythms are called ventricular tachycardia and ventricular fibrillation. Patients have reported having shocks can feel like being suddenly kicked or punched in the chest. These shocks can be quite painful but the pain will only last for a few seconds. Others may not feel anything if their heart is beating so fast that they have become dizzy or unconscious.

If someone is with you when you have a shock, they will probably notice you jolt. No harm will come to anyone who is touching you when they receive a shock. Indeed, it can be very comforting and reassuring to have someone put their arm around you as you experience a shock.

When you come to the ICD clinic your physiologist or ICD nurse will examine your device and any treatment that you may have had will be detected.

What should I do if the ICD gives me a shock?

You may experience warning signs that your ICD is about to deliver a shock, such as palpitations, or feeling light-headed or dizzy. However, this may happen so quickly that you have no warning at all. If you do think that you are about to receive a shock, you should sit or lie down on the ground. If possible, you should also let someone know how you are feeling.

After a shock you should recover quite quickly. Even if you feel well after the shock you should still contact the implant centre as soon as you can to arrange to have your device checked. You may need to leave a message on an answering machine, but your call will be returned as soon as possible. It may not be necessary to have the device checked following each shock unless you feel unwell, but inform your implanting centre a shock has occurred at your next check-up.

If you do feel unwell after a shock or if your device has given you several shocks, please dial 999 for an ambulance to take you to your nearest hospital. Your ICD will be checked to find out why the shocks were given. If you do call for an ambulance, make sure you tell the paramedics you have an ICD implanted and show them your identity card along with any emergency instructions you have been given. This will inform them of exactly which type of device you have and what the best course of action will be.

Getting back to normal

Having an ICD implanted can be seen as a rather big event in your life. However with help and support, most people can adapt well over time.

After a fairly short recovery period you should be able to return to previous activities however some restrictions will apply for your own safety.

Driving

Current rules (2013) place a six month ban on driving following implant of secondary prevention ICD or delivery of an appropriate shock. For primary prevention ICDs the rules are a one month restriction. It is very important that you discuss this with your nurse, physiologist or doctor at your ICD centre who will explain this in more detail and let you know what is specific to your circumstances. You can access the DVLA guidelines at;

https://www.gov.uk/driving-medical-conditions

You will also need to inform your insurance company that you have had an ICD fitted.

Physical activity

Following your initial recovery, normally about four to six weeks, it is recommended that you try to increase your level of activity if possible. You may be offered cardiac rehabilitation or exercise testing to restore your confidence. Once your wound has fully healed, you will be able to go swimming if you wish. However you are advised not to swim alone in a private pool or in the sea beside a deserted beach.

Contact sports, such as rugby, are not advised as the device or leads may become dislodged. However, some people do play contact sports with appropriate protection but please talk to the doctors, nurses or physiologists at your ICD clinic before doing so. Please refer to the Arrhythmia Alliance booklet *Physical Activity & Exercise with an ICD* for further advice.

Research has shown patients with ICDs commonly avoid exercise worrying about their heart rate going too fast. However it is important for your heart health and general health to be as active as you can. This will vary depending on your age, underlying heart condition and general health. Many ICDs these days are programmed to have the ability to detect the difference between fast heart rates from exercise and fast heart rates from dangerous heart rhythms. Moderate intensity exercise does not cause dangerous heart rhythms but is beneficial for heart health. A good guide for moderate intensity exercise for many patients is that you should still be able to string a few words together whilst exercising. If you are so breathless you are unable to speak during exercise, this is too hard for the heart.

Sexual activity

It is very common to be reluctant to resume sexual activity. However the device will not cause any harm to your partner, even if a shock is delivered to you during intercourse.

DIY

You can safely use equipment (such as electric drills) as long as they are in good working order, although you should keep them away from your ICD site.

Electromagnetic interference

Electromagnetic interference will not damage your ICD but may stop it from delivering any treatment for the period of time you are in contact with it. Most electrical equipment you come into contact with in day-to-day life, such as radios, fridges, cookers, computers and microwaves, will not affect your ICD as long as they are in good working order. However, should you ever feel dizzy or experience palpitations whilst using an electrical appliance, you should move away from the appliance and telephone the physiologist, ICD nurse or doctor at the ICD clinic for advice.

When buying electrical equipment, tools or appliances the instructions often say "do not use if you have an ICD or pacemaker". This is usually to protect the manufacturer from being sued and is not normally a problem. If you do come across any of these items talk to your ICD clinic who will check it out for you.

Magnets

ICD therapies may be temporarily disabled by magnets. Sometimes this may be necessary, i.e., on a specialist cardiac area.

Do not carry magnets or place a magnet over your chest! Avoid carrying stereo or hi-fi speakers as they contain strong magnets that can interfere with your ICD.

Shop doorway security systems

There is a very small risk of interference to your ICD, so you are advised to walk through shop doorways at a normal pace and not to wait around in this area.

Electronic ignition systems

Avoid leaning over the alternator in a car while the engine is running, otherwise it is generally safe to work as a mechanic.

Medical equipment and other hospital treatments

Most equipment used by your hospital or GP surgery will not cause any problems to your ICD. However it is advised that you let medical and dental staff know you have an ICD as technical support may be required before some treatments.

Please take your ID card with you whenever you go to hospital. It may also be useful to contact your implanting centre for advice before you go into hospital for any investigations or operations that are not associated with your ICD. It is safe for you to have x-rays, CT scans and mammograms. However you must not have magnetic resonance imaging (MRI) scans. Some electrical nerve and muscle stimulators (TENS units) may cause interference with ICDs but this depends on where they are being applied. If this form of treatment is suggested to you then your ICD clinic should be contacted for advice.

Operations

If you require an operation, you must tell your surgeon and anaesthetist you have an ICD implanted. It may be necessary to temporarily switch off (deactivate) the shocks on your ICD for the duration of the operation. This can be done through a programmer, but equally using a magnet taped over your ICD. This will prevent unnecessary shocks being given during your operation, especially when diathermy is used as this can be sensed by the ICD.

Deactivating ICD shocks

As well as being able to temporarily switch off your ICD shocks during operations, there may be certain circumstances which would cause you to consider having your ICD deactivated. We know implanting the ICD is the right treatment for you at this time in your life, however it may not always be in your best interest to have the ICD active. For example, if you are diagnosed with a terminal illness and the main aim of treatment becomes to keep you comfortable, you may not wish to have the added burden of worrying if you will be shocked by your ICD when this will no longer provide life-saving treatment This will only be carried out at your request and if you have been fully informed of your choices and have signed a consent form. Should circumstances change, the ICD can be easily switched back on.

Travel

You can safely travel abroad with your ICD, but you are advised to show the security staff your identification card and ask to be searched by hand. This is because the hand held wands can temporarily interfere with your ICD.

Walk through the metal detector archway if asked to do so, but the metal casing of the device may set off the airport security alarm. The detector will not cause any harm to your ICD provided you walk briskly through the arch.

You will need to make sure that your travel insurance company is aware that you have an ICD.

Some insurance companies require written confirmation from your cardiologist that you are fit to travel.

Travel companies may also try to increase your insurance premiums to outrageous levels and it is suggested that you shop around if this happens.

Many ICD clinics carry a list of ICD friendly insurance companies. If you wish, you may be given the address of ICD clinics in the area you are visiting. Please contact the ICD clinic at least six weeks before you intend to travel or check the manufacturer's website for information. Please be aware that your doctor may advise against you visiting very isolated or remote destinations.

Arc welding

This should be avoided.

Mobile phones/iPods/MP3 players

Some studies have shown that mobile phones and MP₃ players can affect the ICD if held within six inches of the device. It is therefore recommended that you do not keep them in a coat or shirt pocket over the ICD. Keep the handset more than six inches away from the ICD; ideally hold your phone over the ear on the opposite side to the device. Avoid direct contact with the antenna whilst making or receiving a call.

ICD clinic visits

Your ICD should be checked regularly and visits may be necessary more often just after the ICD is fitted. During each clinic visit, the physiologist or ICD nurse will examine your ICD using a special programmer. This machine allows the settings and the battery life of your device to be examined. All the information is saved on a computer disc and stored in your records.

Your wound will also be checked and you may have other tests done. Please also take this opportunity to discuss any questions or concerns you have. You may also see the cardiologist or registrar at your clinic visit.

Depending on your ICD model, you may not always physically need to attend an out-patient appointment at the hospital. Some checks can be carried out remotely and your ICD centre will inform you if this is possible with your particular device. For further information please consult our *Physical Activity and Exercise with an ICD* patient information booklet.

Changing the ICD

Normally an ICD battery lasts between five and seven years. Your battery will be checked at every visit to the ICD clinic and staff at the clinic will be able to predict when you need a new ICD box. It will not be allowed to completely run down. In order to have the box changed, you will need to be admitted to hospital. The procedure is similar to having your first ICD fitted, but it will not usually involve having new leads put in. Unfortunately you will be restricted from driving for a week after the new box has been put in, unless there have been any other problems. Clinic staff will be able to advise you on your individual case.

Contacting the ICD clinic

Most ICD clinics and support services run between 9am and 5pm, Monday to Friday. Ask staff at your implant centre about arrangements to contact them outside these hours.

Useful websites

A list of useful sites can be found at:- www.heartrhythmcharity.org.uk This list is not exhaustive and it is constantly evolving. If we have excluded anyone, please accept our sincerest apologies and be assured that as soon as the matter is brought to the attention of the Arrhythmia Alliance, we will quickly act to ensure maximum inclusiveness in our endeavours.

If you wish to contact us direct please phone on +44 (0) 1789 450 787 or email: info@heartrhythmcharity.org.uk

Please help us to save lives and improve services for all affected
by cardiac arrhythmias by making a donation today.

Membership is free to individuals, however, if you would like to make a donation please complete and return to P.O Box 3697, Stratford upon Avon, CV37 8YL or visit www.heartrhythmcharity.org.uk and click on donate.

Name of taxpayer: Address: Telephone: I would like to make a donation to A-A and enclose (cash/cheque/CAF) to the amount: £
To make a donation over the phone, please call 01789 450 787.
Gift aid Please tick here if you agree to gift aid your subscription/donation Please treat as gift aid donations all qualifying gifts of money made: today in the past 4 years please tick all boxes you wish to apply. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 th April to 5 th April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 th April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 th April 2008. Name: Address:
Standing order authority
My bank: Bank address: Please pay: Arrhythmia Alliance, Account: 02685818 sort code: 30-98-26, Lloyds TSB Plc, 22 Bridge St, Stratford upon Avon, CV37 6AG The sum of $\pounds/\pounds/\$$: On (1 st date): / / 20 And after this, every:Month/Year (delete) Account No.: Sort code: Signature: Date: / /
Credit card payment Card type: Expiry date: Card number: Amount of £/€/\$: Name on card: CVS code (3 digit):





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Registered Charity No. 1107496

© A-A Published April 2005, Reviewed June 2013, Planned Review Date April 2015

endorsed by Department of Health

Acknowledgements: Arrhythmia Alliance would like to thank all those who helped in the development of this publication. In particular, thanks is given to Jean Maloney, (Arrhythmia Nurse Specialist, Sheffield Teaching Hospitals) and Helen Eftekhari, (Arrhythmia Nurse Specialist, University Hospitals Coventry and Warwickshire).

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If you would like further information or would like to provide feedback please contact Arrhythmia Alliance. Please remember that this publication provides general information only. Individuals should always discuss their own condition with a healthcare professional.