South London
Cardiovascular and Stroke Network

Guidelines for deactivating implantable cardioverter defibrillators (ICDs) in people nearing the end of their life

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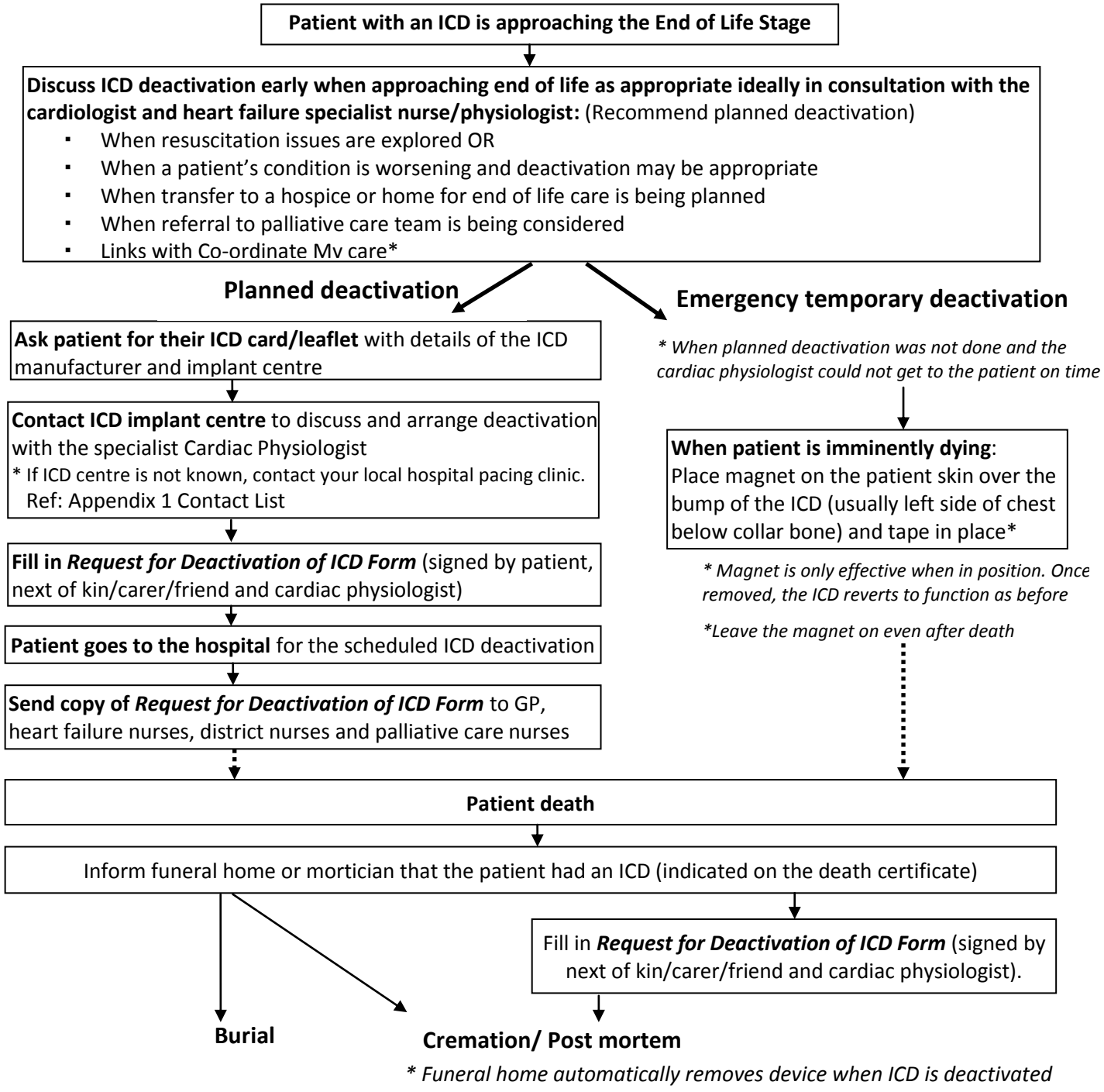
Deactivating an Implantable Cardioverter Defibrillator (ICD) means 'turning off' the shocking function of the defibrillator so that a patient is not unnecessarily 'shocked' in the last minutes of life. The ICD will continue to provide bradycardia (slow heart rhythm) support should the patient need it but will no longer provide lifesaving therapy in the event of a ventricular tachyarrhythmia. Turning off the ICD will not cause death.

ICD deactivation summary algorithm



*http://www.royalmarsden.nhs.uk/consultants-teams-wards/clinical-services/pages/coordinate-my-care.aspx

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Background

When a patient is nearing the end of their life, it is usually recommended that any implanted device is deactivated. The British Heart Foundation guidelines (2009, p. 8) recommends:

- *"Health professionals working with dying patients should be made aware of the increasing numbers of patients who have an ICD implanted, particularly for the treatment of heart failure."*

- *"Health professional have responsibility to ensure that the function of the ICD is optimised in the best interests of the patients, particularly for those close to the point of death."*

What is an ICD?

An ICD is an implanted device used to treat ventricular tachycardia and ventricular fibrillation, which are life threatening heart rhythms, by:

- monitoring the heart rhythm and delivering an electrical pacing impulse or shock when it senses an abnormal fast life-threatening rhythm thus returning it to normal and preventing sudden cardiac death;
- preventing the patient's rhythm from going too fast through its pacemaker function. This is known as fast pacing or anti-tachycardia pacing (ATP)
- providing pacing support in the event of the heart going too slowly (bradycardia).

An ICD may also have a biventricular pacemaker function to resynchronise the 2 pumping chambers of the heart (ventricles) for the management of heart failure (Cardiac Resynchronisation Therapy – CRT). CRT benefits patients in heart failure by helping to reduce breathlessness and tiredness. It may also help reduce fluid overload. This part of the pacemaker/ICD is not switched off.

Who has ICDs?

ICDs are usually implanted in people who have had or are at risk of having a life-threatening arrhythmia, often with an underlying cause such as:

- inherited cardiac conditions
- ischaemic heart disease or
- heart failure and at risk of further arrhythmias

Why should an ICD be deactivated?

At the end of life, there is a risk of the device delivering an inappropriate shock which is painful and traumatic to the patient and can be distressing for those present. One study showed 19% of ICD patients received a shock in their last month and a further 8% in the last minutes of life.

When should an ICD be deactivated?

Deactivation should be considered when:

- Continued use of an ICD is inconsistent with patient care
- Death is expected in the near future, no further interventions are planned and delivery of shock therapy from the ICD would be inappropriate as the person dies
- An active Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order is in force and the patient consents

When should deactivating the ICD be discussed?

- As early as appropriate in the patient's management to enable a planned ICD deactivation so the patient and their family are informed on what to expect and plan the end of life care. Discussing deactivation during pre-implantation counselling may be appropriate but this depends on individual circumstances and the patient involved.
- Usually with consultation with the patient's cardiologist.
- While the patient is still able to be involved in the decision making process where possible, and should include the next of kin or close family.
- With the next of kin or an Independent Medical Care Advocate (IMCA) if discussion with the patient is not possible because they are too unwell or lack capacity. See appendix 4 for guidance.
- In advance as deactivation requires scheduling an appointment with a cardiac physiologist. Last minute requests and special arrangements for a visit may therefore not be possible.

Discuss ICD deactivation with a patient and/or next of kin when:

- Resuscitation issues are explored or DNACPR is completed
- A patient's condition is worsening and deactivation may be appropriate
- Transfer to a hospice or home for end of life care is being planned

It may be appropriate to consider referral to the palliative care team at this stage and linkages with Co-ordinate My Care[1]

What needs to be discussed about ICD deactivation?

- Turning off the ICD will NOT cause death. Bradycardia (slow heart rhythm) support will still be provided if needed but not lifesaving therapy in the event of a ventricular tachyarrhythmia.
- ICD deactivation will not be painful, nor will its failure to function cause pain. The deactivation process will be similar to having a check up at the patient's ICD follow-up clinic.
- Discuss who the named health professional will be to lead the patient's care from this point onwards for questions or concerns, e.g. a team member from community heart failure or palliative care clinical nurse specialist
- Develop a care plan that ensures the named healthcare professional is clearly identified.

If there are issues not directly related to the ICD for further discussion, consultation with the cardiologist or palliative care team may be required.

Who can request deactivation of an ICD?

Ideally in consultation with the cardiologist and heart failure specialist nurse/physiologist:

- Patient and/or family
- Heart Failure or Arrhythmia Specialist Nurse/ Physiologist
- Palliative Care Nurse or Doctor
- GP
- Medical team in charge of a patient when admitted

[1] http://www.royalmarsden.nhs.uk/consultants-teams-wards/clinical-services/pages/coordinate-my-care.aspx

How is the ICD deactivated?

ICDs are deactivated in two ways, both of which are quick, non-invasive, simple and painless.

Planned ICD deactivation through reprogramming

Planned ICD deactivation is done by a specialist cardiac physiologist placing a small communicating device attached to a programmer, over the ICD implant site (commonly in the left pectoral region), which deactivates the ICD within minutes. This can be carried out at the ICD centres listed in appendix 1. This method of deactivation is fully reversible in the same way if the patient recovers sufficiently from a worsening condition.

This is the recommended method of ICD deactivation for patients as the early discussions will make the end of life experience less distressing. It does not require a further procedure after death.

Procedure for planned ICD deactivation (hospital setting, community or home). This is a simple non-invasive procedure and takes only a few minutes:

1. Discuss ICD deactivation with the patient (or next of kin) to decide appropriate timing.
2. Complete the Request for Deactivation of ICD Form (appendix 3) by the healthcare professional responsible for the patient and the patient if possible and ideally in consultation with the cardiologist and the heart failure nurse/physiologist. Verbal consent may be appropriate if documented in the patient's records.
3. Contact the appropriate ICD centre (appendix 1) to discuss the deactivation logistics with the cardiac physiologist. Fax the completed Request for Deactivation of ICD form.
4. The cardiac physiologist will then discuss deactivation with one of the cardiologists to ensure that deactivation is appropriate. Both parties will co-sign the form
5. In cases of urgency or if the patient is not known to the department, completing the form may not be practical. A written instruction by the patient's physician may be considered.
6. ICD deactivation will take place with the cardiac physiologist in the ward or the pacing clinic. A health professional involved in the patient's care should ideally be present.
7. ICD deactivation in the patient's home or community may be an option as the programmer used is portable. This will need to be discussed in advance with the pacing clinic as some clinics may not provide this service. If no arrangements were made for planned deactivation, then emergency temporary ICD deactivation can be done until death, after which deactivation using a programmer will be required

Emergency temporary ICD deactivation using a magnet

Emergency ICD deactivation can be done by any healthcare professional by placing a special magnet directly over the implant site. This stops the ICD delivering any shock or ATP therapy but does not disable bradycardia pacing delivery. This is a temporary solution as the ICD will return to normal function as soon as the magnet is removed. The ICD will still require deactivation by a cardiac physiologist using a programmer after death. This deactivation method may be considered if a planned ICD deactivation was not arranged and a cardiac physiologist cannot get to the patient in time. Special magnets are available at your local ICD follow up centre / all pacing clinics. Centres may have specific criteria for providing magnets. Contact details for local ICD centres are listed in appendix 1

Procedure for emergency deactivation (primary care, secondary care out-of-hours)
Refer to appendix 2 for the procedure for emergency deactivation.

Following ICD deactivation

A copy of the deactivation form should be sent to the GP and other members of the healthcare team such as the heart failure nurses, district nurses and palliative care team, informing them that deactivation has occurred and the rationale for the decision.

Appendix 1

Contact details of ICD centres to arrange deactivation

All patients should have card/leaflet with details of their ICD, including the manufacturer and the hospital at which it was implanted. ICD deactivation should be scheduled at the hospital where the ICD was implanted in the first instance. Have this information available before you call.

Where implant details are not known, contact the hospital most conveniently located listed below:

South East London		
Guy's & St Thomas' Hospital Monday – Friday	9.00am - 5.00pm	**Pacing/ICD clinic** Tel: 0207 401 9249 (diverts to the senior physiologist's mobile if not answered in 15 seconds) Out of hours: cardiology registrar
King's College Hospital Monday – Friday	9.00am - 5.00pm	**Pacing/ICD clinic** Tel: 0203 299 8167 Out of hours: cardiology registrar
Queen Elizabeth Hospital Monday – Friday	9.00am - 5.00pm	**Cardiac department** Tel: 0208 836 4343
South West London		
St. Georges Hospital Monday – Friday	8.30am - 5.00pm	**Pacing ICD Clinic** Tel: 020 8725 1372/3597 Out of hours: Cardiac Physiologist on call
Croydon University Hospital Monday – Friday	9.00am - 5.00pm	**Cardiology department** Tel: 020 8401 3046
Epsom Hospital Monday – Friday	9.00am - 5.00pm	**ECG department** Tel: 01372 735735 ext: 6054 Out of hours: CCU
Kingston Hospital Monday – Friday	9.00am - 5.00pm	**Cardiology** Tel: 020 8934 3854
St Helier Hospital Monday – Friday	8.30am - 5.00pm	**ECG department** Tel: 020 8296 2575

Appendix 2

Emergency temporary deactivation (primary care/ secondary care out-of-hours)

A magnet temporarily stops the ICD delivering shock therapies whilst in position over the ICD. Normal function is restored as soon as it is removed. Applying a magnet does NOT cause death it just stops shocks occurring if the patient has an arrhythmia. Ensure a magnet is obtained from your nearest ICD centre (ideally ahead of time). These are available upon request where appropriate. Centres may have specific criteria for providing these.

1. **Consent:** Obtain verbal consent to use the magnet from the patient if possible and record this in the notes. This is not essential in an emergency situation, when clinical staff will make a 'best interests' judgement for the patient.
2. **Explain** briefly to the patients and any relatives what is happening
3. **Use the magnet to deactivate the ICD:**
    i. Place the magnet directly on the patient's skin over the bump of the ICD (usually on the left side of the chest just below the clavicle/collar bone.)
    ii. Tape the magnet in place with some appropriate strapping and do not remove even after death. The magnet is only effective whilst in position and the ICD will revert to normal function when the magnet is removed.
4. **Safety:**
    i. The magnet is safe for all staff to use. It does not affect staff or relatives who may have active pacemakers.
    ii. It is safe to touch a patient whilst the ICD is delivering shocks – no shock will be transmitted to the person touching the patient. You will just feel a twitch but try to avoid touching their chest close to the ICD just in case.

After death

All ICDs deactivated using a magnet will require subsequent deactivation by a cardiac physiologist using a programmer prior to post mortem and burial or cremation. The ICD will also need to be removed prior to cremation (automatically done by the funeral home / undertaker).

1. Do not remove the magnet.
2. Contact the ICD pacing clinic to arrange for a cardiac physiologist to turn off the ICD. Let them know where the body will be. Complete and fax the Request for Deactivation of ICD Form [appendix 3] to enable the cardiac physiologist to identify which equipment is needed to deactivate the device and for the patient's hospital notes to identify that the device has been deactivated and is safe to be removed. This should be completed as soon as possible after the patient has died.
3. Inform the funeral home or mortician of the ICD status (whether or not it has been turned off). This will be noted in the death certificate. Send them a copy of the Request for Deactivation of ICD Form [appendix 3]. Early notice will also minimise delays in the funeral arrangements as post mortem and burial cannot be arranged until the ICD has been turned off. If the deceased person is to be cremated, the funeral home will remove the ICD beforehand as standard practice.
4. Either the deceased person's next of kin or the funeral home can complete the request for deactivation of an ICD form. However, it may be more appropriate and less distressing for the funeral home to complete it, provided that they have access to the appropriate information contained on the patient's ICD ID card.

Contact your local ICD Centre (appendix 1) should you need further guidance or have questions.

Appendix 3

Request for Deactivation of Implanted Cardiovertor Defibrillator (ICD)

ICD Details (most patients will have a card/leaflet with this information)

Manufacturer: Implant Hospital:

Patient Name: ……

Hospital number: ……

Date of Birth: ……

Normal Address

……

……

……

Address patient is currently located (if different to above):

……

……

GP Name: ……

Address: ……

……

Deactivation

Date of request: …… (dd/mm/yyyy)

Time of request: ……(hh:mm)

Reason for Request:

……

……

……

Signature of authorising Consultant/Physician (delete):

……

Authorisation

I understand the reasons for deactivating my ICD and that the decision to de-activate can be reviewed if necessary. I agree to the de-activation of my ICD.

Signature of patient: …… Date: ……

or if not the patient please complete the box below.

I understand the reasons for the deactivating the ICD of the patient named above and that the decision to de-activate can be reviewed if necessary.

I agree to the de-activation of their ICD.

Signature of next of kin/ relative/carer (circle as appropriate): ……

Print name: …… Date: ……

Date and time device de-activated:

…… (dd/mm/yyyy)

…… (hh:mm)

Any Other Comments:

Signature of Cardiac Physiologist de-activating the device:

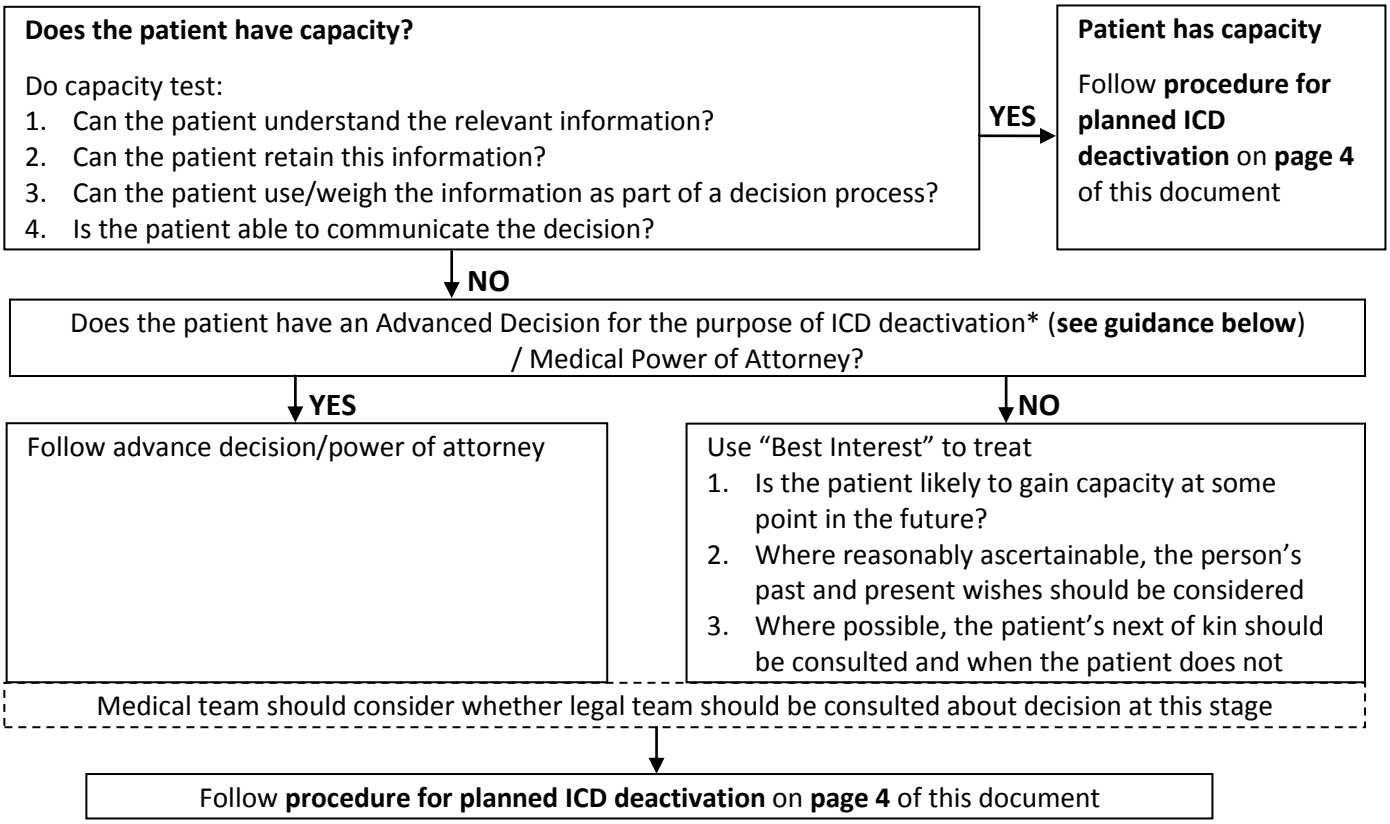
……

Print name: ……

Appendix 4

Guidance on patients lacking capacity to make a decision about ICD deactivation

An assessment of patient's capacity to make decision about deactivation should be made in line with the trust's policy on mental capacity



*Guidance for Advance Decisions and ICD deactivation

An Advance Decision can only be made by someone if:

1. They have reached the age of 18; and
2. They have capacity to make decisions at the time the Advance Decision is being made.

If a patient has made an Advance Decision for the purpose of ICD deactivation, the following, whilst not an exhaustive list, should be considered:

1. Does the Advance Decision refer specifically to the ICD deactivation? It need not use medical or technical terminology, but it must be obvious the person making the Advance Decision is intending it to be relevant to ICD deactivation.
2. Has the Advance Decision been verified by a statement made by the person making the Advance Decision to the effect that: the decision within the document is to be followed even if life is at risk?
3. Is the Advance Decision in writing? Each trust should have a policy which should be consulted for clarification on where the advance decision is recorded. It should be made prominent, usually at the front of the notes and a 'flag' entered onto computer system if possible. The patient's relatives may also have a copy.
4. Is the Advance Decision signed by the person making the decision or by another person on their behalf?
5. Has it been signed in the presence of a witness?

The medical team should consider the internal guidance on Advance Decisions within their Trust and they may wish to seek legal advice from the Legal Department. If the answer to any of the above questions is no, legal advice should be considered before deactivating the ICD.

Adapted from the ICD De-activation Policy developed by Surrey Cardiac Physiologists' Network, Western Sussex Hospitals NHS Trust, and the Arrhythmia & Sudden Cardiac Death Working Group, and the Arrhythmia Alliance ICD deactivation leaflet www.arrhythmiaalliance.org.uk