

# Deactivating an Implantable Cardioverter Defibrillator (ICD) Policy/Procedure

Unique ID: NHSL. Category/Level/Type: 1 Status: Published Date of Authorisation: Sept 2013 Date added to Intranet: Key Words: Defibrillator Comments: Author (s): Lead Heart Failure Nurse Version: 2 Authorised by: CTR Quality Improvement Team Review Date: Sept 2016

Key Messages	To highlight the need to have discussions and reach decisions about deactivation of the ICD at the right time before a crisis situation occurs to reduce last minute decision making.
	To deliver high quality care to people who are approaching end of life
	To avoid the delivery of a futile "shock" therapy when the person is nearing the end of life.
	To co-ordinate care when deactivating a device
	To ensure that all staff are aware of when and how to facilitate deactivation of an ICD, in conjunction with other relevant NHS Lothian policies.
	To support staff to respond appropriately if a person with an ICD requests it to be deactivated.
	To make the deactivation decision of an ICD a transparent process.
	The policy is available at NHS Lothian> Healthcare> Clinical Guidance.
Minimum Implementation Standards	All staff who are involved in the Deactivating an Implantable Cardioverter Defibrillator (ICD) should be aware of this policy and procedure

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#### 1. Introduction

Implantable Cardiac Defibrillator (ICD) and Cardiac Resynchronisation Therapy-Defibrillator (CRT-D) are the treatments for people who are at increased risk of sudden cardiac death due to ventricular arrhythmias. This policy and associated procedural documents have been developed to support the care of people who no longer require the defibrillator function of the ICD/CRT-D to be active. Proactive anticipatory care planning, delivered in a sensitive manner, will help address patient/carer concerns and minimise any distress that they might have surrounding deactivating the defibrillator. In addition advanced care planning will support healthcare professionals to deliver high quality structured care.

The ICD/CRT-D monitors the person's heart rhythm and responds to abnormalities with a variety of programmed functions. These include anti-tachycardia pacing (painless low energy electrical impulses that can override some tachyarrhythmia's i.e. ventricular tachycardia) to restore normal rhythm as well as bradycardia pacing. However treatment of a life-threatening tachyarrhythmia often requires the defibrillator to deliver a high energy electric shock (defibrillation) in order to restore normal rhythm. This experience may be painful and can lead to psychological distress for both the person and their family/carer.

An ICD/CRT-D is commonly implanted in people who have survived a cardiac arrest or in patients who are at high risk of sudden death e.g. people with heart failure. However people with an ICD/CRT-D may develop a non-cardiac terminal illness or irreversible progression of their underlying heart disease which leads to a palliative/supportive care strategy as they approach the end of their life. A person who is dying may have sudden cardiac tachyarrhythmia's due to hypoxia, electrolyte or metabolic imbalances, which could lead to the ICD/CRT-D delivering a shock. Shocks at this time are not appropriate and if they are given an electric shock it could lead to a painful and distressing death.

It is appropriate to consider deactivation of the defibrillator/anti-tachycardia pacing functions of the device if the person's clinical status worsens or when death is near.

# This policy does not advise/recommend deactivation of any bradycardia pacing or resynchronisation function.

HRS/EHRA consensus statement (2008): "The primary aim behind the rationale for deactivation must always be to respect the patient's right to live, or at least die with dignity, while limiting any therapeutic action that increases the patient's level of stress, pain or anxiety"

# 2. AIM OF THE POLICY AND ASSOCIATED PROCEDURAL DOCUMENTS

To provide a set of principles for all NHS Lothian healthcare professionals to follow in order to ensure clarity of process in deactivating the ICD and to provide a high standard of care throughout the persons journey.

To provide a framework in which the deactivation of an ICD is performed with appropriate consent and documentation for the benefit of the person, carer and health care professional.

# 3. KEY OBJECTIVES

- ✓ To highlight the need to have discussions and reach decisions about deactivation of the ICD at the right time before a crisis situation occurs to reduce last minute decision making.
- ✓ To deliver high quality care to people who are approaching end of life
- ✓ To avoid the delivery of a futile "shock" therapy when the person is nearing the end of life.
- ✓ To co-ordinate care when deactivating a device
- ✓ To ensure that all staff are aware of when and how to facilitate deactivation of an ICD, in conjunction with other relevant NHS Lothian policies.
- ✓ To support staff to respond appropriately if a person with an ICD requests it to be deactivated.
- ✓ To make the deactivation decision of an ICD a transparent process.

\*This policy explains how to contact the cardiac physiology services during normal working hours and out of hours. Temporary deactivation by a "Donut" magnet can be carried out if urgent deactivation is required, but proper planning with the local or tertiary cardiology department will help avoid this situation. The cardiology department must ensure that there is a designated area where the deactivation magnet can be obtained in an urgent situation (appendix 2).

#### 4. Who has authority to make the decision to deactivate the ICD?

A large number of health care professionals may be involved in the person's journey. Many people with ICD/CRT-D's will be in non-cardiac wards or departments and will likely be under the care/responsibility of another speciality/GP or hospice. Primary care staff will have increasing contact with people with ICD/CRT-D's towards the end of their life. Placement of a person on the palliative care register and completion of the electronic palliative care summary should prompt discussions regarding deactivation of an ICD. This prompt will ensure that decisions are taken when the patient is well enough to participate in the decision-making and that the deactivation procedure can be planned and carried out in a timely fashion.

However people who have an ICD implanted will have a designated cardiologist and attend regular reviews at the electro-physiology department. This means that the designated Cardiologist (if available), in partnership with other health-care professionals involved in the persons care, is in the best position to make the final decision to deactivate the ICD. It will be their responsibility to liaise with the electro-physiology team, who will perform the deactivation procedure. (If the designated Cardiologist is not available then the on-call Cardiologist must be contacted).

#### 5. Indications for deactivation

- 1- Continued use of an ICD is inconsistent with the person's goals of treatment e.g. refractory and progressive heart failure symptoms despite optimal treatment.
- 2- DNACPR order is in place.
- 3- The procedure is requested by the person with the ICD and there are no ethical or capacity concerns.
- 4- The person is diagnosed as dying and consideration is being given to use an end of life pathway to document end of life care (defibrillation inappropriate in the dying phase).

Cardiology departments should ensure that all departments within their organisation know how to arrange ICD deactivation during the day, and what procedure to use outside of normal working hours (appendix 1).

#### 6. Capacity and Consent

Consent is both a legal requirement and an ethical principle and requires to be obtained by health-care professionals, prior to the start of any examination, treatment, therapy or episode of care. Prior to deactivating an ICD verbal consent should be obtained from the patient, if possible, in order to maintain best practice. (Please refer to the Lothian policy on consent). If consent is not possible due to incapacity (e.g. dementia, unconscious) then please refer to the "Adults with Incapacity (Scotland) Act 2000". Link is below:

http://intranet.lothian.scot.nhs.uk/NHSLothian/Healthcare/A-Z/LearningDisabilities/Pages/GuidelinesandLegislation.aspx

The key to consent and understanding of the procedure is through providing comprehensive information to the patient/carer. This allows shared decision-making between the multi-disciplinary team and the patient/relative. It is good practice for the Cardiologist to discuss with the person that there may be a time when switching off the device is the best option i.e. at end of life. This could be provided at the time of deciding about implantation or in a follow up review and should be documented in the medical records as part of the decision making process.

An assessment of any significant changes in the person's health should be conducted at each ICD check by the cardiac team. This may help to identify any new issues about the person's health that may prompt discussions on deactivation. Any discussions should be documented in the person's medical records.

#### 7. Ethical considerations

There may be ethical concerns about end of life deactivation of the defibrillator or if the person has requested that the defibrillator is deactivated. Before a DNACPR order is completed consideration should be given as to whether the person has an ICD/CRT-D implanted. If they have an ICD/CRT-D then this should prompt the care provider to consider deactivation, as it not best practice to have a DNACPR in place and a defibrillator function that is still active.

The person may request deactivation due to psychological distress or pain associated with the shocks that the device delivers. If the person requests deactivation the Cardiologist must ensure the request to deactivate is not due to clinical depression or coercion. Screening for an underlying mood disorder must be undertaken, ideally in conjunction with the person's GP. If an underlying mood disorder is suspected then a referral to a psychologist/psychiatrist would be recommended prior to any final decision on deactivation. This will ensure that the person has the capacity to make this decision under the Adults with Incapacity Act (2008). In this instance the Cardiologist can inform the person that their decision to deactivate the defibrillator can be reconsidered in the future and it is possible to reactivate the functions.

There may be instances where the health care professional asked to deactivate the device has ethical or moral reservations about performing the procedure. However; if the policy has been followed, appropriate consent obtained and documentation completed then another health care professional should be found to carry out the deactivation procedure.

#### 8. Communication

Effective communication is the key to implementing this policy successfully. All communications with the person with the ICD and family should be open, honest and transparent. However there are situations when this can be challenging for the health professional. These discussions require appropriate timing and sensitivity to explain to the person why deactivation is considered an appropriate option. It may take a few

discussions with the person/carer before the decision is reached. Other healthcare professionals involved in the person's care should be informed of the discussions as they may be in a position to offer support and advice.

It is recommended that the communication process about deactivation commences as early as possible, when the persons condition is stable, as opposed to in the last few days of life. This allows time for questions and time for the person to make an informed decision and to understand the implications of deactivation. All discussions should be documented in the notes. If the person cannot speak English then it is recommended that an interpreter is requested. Family members may be present but due to the nature of the discussions an independent person is preferred to ensure accurate translation, given the conversation may be about death & dying and deactivation.

#### Frequently asked questions;

Q. Does the device need to be removed?

A. No, it is a similar procedure as to when you get your regular ICD/CRT-D check.

Q. Will it hurt? A. No

Q. Will my heart stop pumping?

A. No, Your heart will continue to pump as the ICD does not make your heart pump. The CRT will still continue to help both sides of your heart pump in synchrony

Q. Will I die when it is switched off?

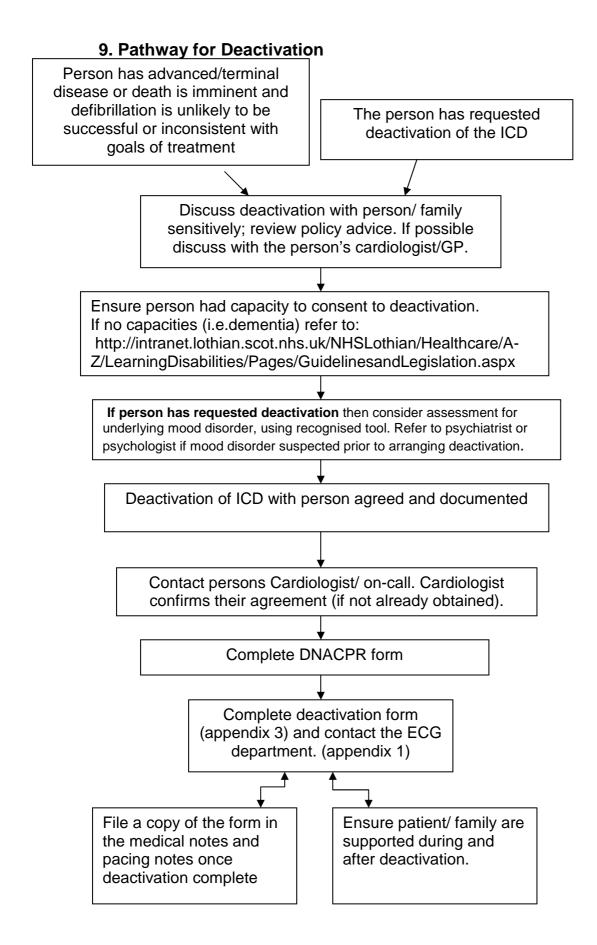
A. No, it only works when your heart rate is beating too fast in an irregular rhythm. You will not notice any difference when it is switched off. You won't collapse or faint (consider reviewing the patients understanding of deactivation if this question is asked).

Q. What if my heart goes too slow?

A. The ICD/CRT will still work to prevent your heart going too slow. Switching it off will only stop the electric shock when your heartbeat is in an abnormal rhythm.

Q. Will the anti-tachycardia pacing still work?

A. No, as this only works when the defibrillator delivers a shock. You cannot switch one off without the other.



#### **10. Pre-deactivation procedure care**

1. Ensure the policy is followed and the deactivation form is completed.

2. Ensure an appropriate time for deactivation has been agreed with staff, if an inpatient i.e. not lunch/visiting hours, so that they can provide support, if required.

3. Explain to the person with the ICD that the deactivation is the same process as a normal pacemaker check.

4. Explain to staff (if an in-patient) that they need to be available for psychological support if required. If the patient is at home give the carer the opportunity to be present to provide psychological support rather than be left alone, if possible. \*

5. Ensure the person with the ICD is informed of an approximate time of the deactivation procedure.

#### 11. Care during and after deactivation

1. The health care professional explains the procedure to the person/carer. Reassurance should be given that deactivation is painless and will not cause death or worsening symptoms, as these are common misconceptions.

2. Reassure the person throughout the procedure, as appropriate, and answer any questions.

3. It is recommended that the patient is not left alone immediately after the procedure, for psychological support.

4. The deactivation procedure and time should be documented in the person's medical notes and the completed deactivation form filed in the medical notes and pacing notes. If the person is at home a copy should be sent to the GP records.

\* It is important to achieve the right balance of psychological support to meet the individual person's needs. Many patients fear they might die when an ICD is deactivated and they may find it beneficial to have someone to support them after the procedure. For example: if the patient is in a side room when the ICD is deactivated and the person is left alone they may be fearful or anxious. However it is also important to not make it appear such a significant event that it actually makes them fearful.

## Appendix 1:- Contact Details for advice/deactivation

Electro-physiology Department Royal Infirmary of Edinburgh Hours of work: Mon-Friday 9-5pm Tel: 0131 242 1813

Electro-physiology Department Western General Hospital Hours of work: Mon-Friday 9-5pm Tel: 0131 537 2330

Electro-physiology Department St John's Hospital Hours of work: Mon- Friday 9am -5pm Tel: 01506 523851 or bleep 3031

Translator services: 0131 242 8181 (Mon-Fri 9-5) For telephone interpreting, use the Big Word – details on the intranet at <u>http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-</u> Z/EqualityAndDiversity/Translationinterpretationandcommunicationsupport/Pages/Tra nslation,%20Interpreting%20and%20Communication%20Support.aspx

#### Out of hours Contact details:

Royal Infirmary of Edinburgh: Cardiology registrar on call. Bleep 4028 until 10pm and switchboard thereafter.

Western General Hospital: Cardiology registrar on call at RIE

St John's Hospital: Cardiology registrar on call at RIE

**For Children** either contact the RIE or ECG department- Royal hospital for Sick Children (Yorkhill) 0141 201 0000

Cardiology Consultants with Special interest in Electro-physiology

Consultant, RIE, tel: 0131 242 1840 Consultant Cardiologist, RIE, tel: 0131 242 1807

## **Appendix 2:- Temporary deactivation**

Magnet application should be reserved for use in an **EMERGENCY** and only used until an electro-physiologist can program the device off (if appropriate).

"Donut" magnet storage sites (can be couriered to the community if required. The community team need to arrange the courier. Instructions are in the box and please ensure the magnet is returned to the site after use)

**RIE** – Drug cupboard in CCU & in the bottom of the resuscitation trolleys in A&E

**WGH** – On the pacemaker trolley in the ECG department and Ward 54 resuscitation trolley

SJH – A&E, CCU, ITU & ECG dep't

Please note the following:

- Inhibition of shock delivery will only be effective during magnet placement if the magnet is properly secured to the patient! Place the magnet over the device using micropore tape or equivalent. (see picture)
- Programmed bradycardia pacing will continue during magnet application to the ICD/CRTD device



#### How to apply:

Name:	Patient's Current Location:		
Date of Birth: CHI:	GP Address:		
Addressograph may used	Canaultanti		
Date Of Request:	Consultant:		
	Cardiologist:		
Reason for request:			
I confirm that (please tick):			
A Do Not Attempt CPR form is completed			
The patient/family have been informed of reasons for deactivation			
The patient has capacity and has verbally consented to deactivation			
The patient does not have capacity but NHS Lothian policy on incapacity has been implemented.			
Cardiologist has agreed to the deactivation request			
Signature of Authorising Consutant/Physician:			
Print:			
Date://			
I confirm that the ICD deactivation policy has been followed and that the patient/family understands the procedure.			
Signature of health professional deactivating the device:			
Print:			

# Appendix 3: – Deactivation of Implantable Cardioverter Defibrillator Record

Date of Deactivation: \_\_\_\_/\_\_\_/



# Appendix 4- Patient Information leaflet What does "deactivating" my Defibrillator mean'.

There may come a point in your life when you would prefer not to have a shock to correct a life threatening heart rhythm. This may be if your heart condition has deteriorated or you have another medical condition which cannot be cured. This leaflet is designed to help you when considering this option.

#### When is deactivating an Internal Cadioverting Defibrillator ICD considered?

Deactivation may be considered if receiving shocks is unlikely to prolong your life and may cause distress. This may be the case if you have been diagnosed with a terminal condition and are thought to be reaching the end of your life. For some people, their heart condition reaches a stage where it is no longer possible to maintain a good quality of life or to prevent rhythm disturbances that cause frequent shocks. It may be that you feel that dying suddenly from a heart rhythm disturbance is preferable to the prospect of a slow deterioration.

#### Who makes the decision to deactivate the ICD?

Ideally, this would be you, which is why we aim to raise the issue well before a decision is urgently needed. It is important that you are aware of this option early on so you have time to consider how you feel about deactivation and can play an active part in the decision making process. This ensures that people involved in your care know and understand your wishes.

If you have not expressed your wishes and are not able to do so, a discussion will take place between your next of kin and the doctors involved in your care. The decision may then be made to deactivate your ICD.

#### How is the ICD deactivated?

The process is carried out by a Healthcare Professional and is similar to when you have an ICD check. A programming device is placed over your ICD and the settings are altered on a computer. The ICD can be deactivated so it will no longer deliver a shock but the pacing function is left unchanged.

#### What happens when it is deactivated?

You will not feel any different. Deactivating the ICD does not cause death nor will it cause any pain or deterioration in your condition. After it is deactivated the "pacemaker" part will still continue to work if it is needed.

#### What if I change my mind?

Once it is deactivated, should you change your mind, it can be reactivated at any time.

#### Who can I talk to for further advice?

It is important you have time to think about this decision and your doctor, nurse or palliative care team will answer any questions.

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