

GUIDELINE TITLE: Deactivation of Implantable Cardioverter Defibrillators (ICD / CRT-D) at the end of life

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People Authorised To Use This Guideline:	Healthcare professionals involved in the process of arranging the deactivation of an Implantable Cardioverter Defibrillator / Cardiac Resynchronisation Therapy Defibrillator.	Training Requirement To Use This Guideline:	No specific training required, however, if involved with the discussions about deactivation, then communication skills training should have been undertaken.
GUIDELINE CHECKED FOR:			Yes/No
Corporate Issues:			Yes
Clinical Governance Issues:			Yes
People Governance Issues:			Yes

GUIDELINE REVIEW HISTORY

Version No:	Review Date:	Reviewer:	Changes Made:
1.0	Sept 2017	Helen Livingston, Pauline Park, Ian Livingston	Original guideline produced
2.0	Nov 2020	Haqeel Jamil	Updated to include information about CRT-D
2.1	Dec 2020	Michelle Hinchliffe	Glossary updated and information regarding location of magnets reviewed and updated

If printed, this Guideline is valid on the day of printing only. Please ensure that you check AireShare to ensure you are using the current version

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1. INTRODUCTION

Airedale NHS Foundation Trust fully recognises that the obligation to implement guidance should not override any individual clinician to practice in a particular way if that variation can be fully justified in accordance with Bolam Principles. Such variation in clinical practice might be both reasonable and justified at an individual patient level in line with best professional judgement. In this context, clinical guidelines do not have the force of law. However, the Trust will expect clear documentation of the reasons for such a decision and for this variation. In addition, any decision by an individual patient to refuse treatment in line with best practice must be respected, escalated to the consultant and fully documented in the appropriate records of care/treatment

An Implantable Cardioverter Defibrillator (ICD) is implanted into patients who have either had or are at risk of a life threatening ventricular arrhythmia:

An ICD has a number of key functions:

- automatic administration of defibrillation shocks to terminate ventricular fibrillation (VF) or fast ventricular tachycardia (VT)
- anti-bradycardia pacing often used after a defibrillation shock as the heart returns to normal sinus rhythm
- anti-tachycardia pacing to terminate slower VT

A CRT-D is a special kind of pacemaker which includes a built-in implantable cardioverter defibrillator. This type is called a cardiac resynchronization therapy defibrillator (CRT-D).

A CRT-D device is a special device for heart failure patients who are also at high risk for sudden cardiac death. While functioning like a normal pacemaker to treat slow heart rhythms, a CRT-D device also delivers small electrical impulses to the left and right ventricles to help them contract at the same time. This will help your heart pump more efficiently.

A CRT-D device also treats dangerously fast heart rhythms (arrhythmias) that can lead to sudden cardiac arrest. If the device senses heartbeats that are dangerously fast, it delivers a shock to the heart. This shock (defibrillation) stops the abnormal rhythm. Without this life-saving therapy, the dangerously rapid rhythm could lead to death in just minutes.

The benefit of these defibrillators in the prevention of sudden cardiac death in those with inherited and acquired cardiac conditions is well documented.

Due to guideline recommendations, there has been an increase in defibrillator implantation rates, particularly to prevent sudden cardiac death in those with heart failure due to left ventricular systolic dysfunction. Devices inserted into these individuals are either stand-alone ICDs, (which are occasionally placed subcutaneously), or combined with cardiac resynchronisation therapy (CRT-D). This is a more sophisticated form of pacemaker with three leads used to improve the coordination of cardiac contractility.

2. MANAGEMENT

ICDs and CRT-Ds are now encountered in routine clinical practice across all care settings.

While considered beneficial on insertion, the presence of an ICD/CRT-D in an individual over time will need review as the patient's condition may change due to progressive heart failure, or the development of other life limiting conditions such as cancer or dementia. Such developments raise questions on the continuing benefit of ICD therapy. Defibrillation can cause physical discomfort and emotional distress to the patient and their families / carers and in the context of a person known to be dying this can be particularly distressing.

Healthcare professionals have a duty of care to consider withdrawal of non-contributory therapies and the potential distress caused by any continuation of resuscitation measures (such as ICD/CRT-D triggering) in those patients near the end of life¹.

Consideration of deactivation should be part of the process of advance care planning with individuals, and should be reviewed when a patient's condition or wishes change.

If a patient with an ICD/CRT-D is placed on the Gold Standard Framework it should prompt discussions about future management of the ICD therapies as part of advance care planning discussions.

Deactivation of the defibrillator mode of an ICD/CRT-D does not deactivate the pacing mode, and therefore will not end a patient's life. However it will allow for a natural death without the risk of unnecessary shocks.

Indications for Considering Deactivation (as used by the Arrhythmia Alliance)

- Patient preference in advanced disease
- Imminent death (activation inappropriate in the dying phase)
- If a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) order is in place
- Withdrawal of anti-arrhythmic medications

2.1 The Decision

A senior clinician (usually the GP, Cardiologist, or Palliative Care Consultant) should lead a multidisciplinary team (MDT) approach to defibrillator therapy deactivation in order to fully explore prognosis, treatment options and choices. Composition of the MDT will depend on a patient's comorbidities. If heart failure is the principal diagnosis, the heart failure specialist should lead the MDT. Specialist palliative care involvement is also often useful. Consideration should also be given to whether it is appropriate for the patient or their representative to attend any MDT.

¹ Arrhythmia Alliance

http://www.heartrhythmcharity.org.uk/www/media/files/For_Patients/100413-FINAL-ICD_in_Dying_Patients.pdf

If the patient has the capacity to make a decision regarding their own treatment the doctor in charge of the care has a responsibility to discuss defibrillator therapy with them. The doctor should outline the prognosis of the patient's condition, including the disadvantages and advantages of withdrawing defibrillator therapy and/or continuing with defibrillator therapy. Family members and relevant others should also be involved in these discussions providing the patient consents to their involvement.

Rationale for decisions should be documented in the patient's notes, along with any relevant clinical findings and discussions. They should include sufficient detail to ensure that they describe a clear rationale for the decision.

The MDT lead clinician must record the reasons for the decision to deactivate on the "[request for deactivation form](#)" (Appendix I).

It is advisable that at the time of the decision a review date is agreed where the patient's condition, clinical findings and wishes can be reviewed. The ICD therapies can be reactivated if indicated. If the senior clinician making the decision to reactivate the ICD/CRT-D is not the same as the one who made the original decision it is also advisable to liaise with the original senior clinician before embarking on reactivation.

The decision must be communicated to the health care parties involved e.g. GP, Specialist Nurses, Hospital Consultants.

2.2 The Discussion

The patient should be aware that therapy deactivation is possible before a device is implanted².

However, this can be a difficult and often unexpected conversation for many patients. More than one meeting may be required before a patient understands the consequences of this proposed revised treatment plan on the remainder of their lives, and has all the information and support they need to participate in the decision making process.

The discussion should include reassurance that defibrillator deactivation:

- **is painless**
- **only discontinues the shock component of the ICD / CRT-D**
- **does not cause or hasten death or any change in their general condition.**

Patients should be reassured that they will continue to receive all the care and support they need from their established team, and that consideration may be given to reactivation of defibrillator therapy should their condition indicate that it may be beneficial.

With this information, the competent patient has the right to make an informed decision about whether or not to and when to withdraw defibrillator therapy, and should sign the request form.

² ICD deactivation at the end of life: Principles and practice: A discussion document for health care professionals. Dr James Beatie, British Heart Foundation 2013

2.3 Patients who may Lack Capacity

If there is concern that a patient may lack mental capacity to understand the issues of defibrillator therapy deactivation, a formal capacity assessment should be made and the findings documented. Follow the principles of the Mental Capacity Act 2005.

Detail on assessing capacity can be found in the Mental Capacity Act Code of Practice³.

The Mental Capacity Act is covered in the WYCSU palliative care coordination system EPaCCS template on System One in the Advance Care Planning section. The capacity assessment outcome can be recorded there.

Decision making with regard to deactivation of defibrillator therapy in a patient who lacks capacity must take into account any valid and applicable advance decisions to refuse treatment, or the decision of an appointed LPA (Lasting Power of Attorney), or Court Appointed Deputy where this decision is covered within the LPA.

In the absence of either of the above the decision to deactivate an ICD represents a best interest decision; see [Mental Capacity Act Code Of Practice](#)

Staff must follow any local procedures for assessment of mental capacity and best interest decision making^{4 5}.

2.4 The Process (see flow chart appendix II)

Deactivation requests will be accepted for patients in hospital, hospice or at home. Once completed, the request for deactivation of ICD / CRT-D form must be sent to either the Cardio Respiratory Department at Airedale General Hospital or Bradford Royal Infirmary as appropriate. From here it will be acted upon by the Cardiac Physiologists.

A copy of the form must also be filed in the patients notes.

For patients in outlying hospitals it may be appropriate to arrange for the patient to attend the Cardio Respiratory department for the deactivation. Alternatively staff from Cardio Respiratory Department will make arrangements to visit the patient in the outlying hospital.

For patients at home or in a hospice it may be appropriate to arrange for the patient to attend the Cardio Respiratory department for the deactivation. If the patient is unable to attend the department for whatever reason, a home visit may be arranged by liaising directly with the Cardio Respiratory department.

When a deactivation occurs out of the hospital an additional health care professional must be present to provide support to patient/ family/ carers pre and post procedure.

³ Mental Capacity Act - <https://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

⁴ Airedale Hospital Capacity assessment tool – AMCABID [Mental Capacity Assessment](#)

⁵ Policy and Procedures for Working with the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards (2009) Bradford Teaching Hospitals NHS Foundation Trust.

For useful telephone numbers see Appendix III

2.5 Out of hours and emergency temporary ICD / CRT-D Deactivation

Emergency defibrillator therapy deactivation can be done by any appropriately trained healthcare professional by placing a doughnut magnet directly over the implant site and taping this in place securely (see photo).

This stops the ICD/CRT-D delivering any shock or ATP therapy but does not disable bradycardia pacing delivery. This may be particularly important when the defibrillator is repeatedly shocking someone close to death which is distressing for both the patient and their family.

This is a temporary solution as the ICD/CRT-D will return to normal function as soon as the magnet is removed. The device will still require deactivation by a cardiac physiologist using a programmer as soon as is convenient or after death.

It is advised to leave the magnet in place until the death has been verified.

Doughnut shaped magnets are available in hospital and the community base - Appendix II.

The person placing the magnet is responsible for returning it to base once death verified



2.6 Post mortem device handling

If the ICD/CRT-D has not been deactivated by a cardiac physiologist before death then the device will need to be fully deactivated after death by the local cardiac physiologist, to avoid the risk of electric shock to clinicians and mortuary workers.

ICDs/CRT-Ds must be removed prior to cremation of the body due to the risk of lithium battery explosion. This is done in the hospital mortuary. If a patient dies in the community the undertakers will take the body into the hospital mortuary where the device will be made safe and removed.

Department of Health guidance implies that implanted electronic devices should be accorded a legal status as intrinsic to the deceased's estate. Explanation and disposal of the device may therefore need to be discussed and agreed with next of kin or the appointed executor.

3. IMPLEMENTATION & AUDIT

Development of this guideline was by the following clinicians:

Pauline Park	Specialist Nurse
Tracey Hellowell	Specialist Nurse
Sharon Grimsdale	
John Smyllie	Consultant Cardiologist
Helen Livingstone	Consultant, Palliative Care

The dissemination of this document will be via Airesshare and the Palliative Care Managed Clinical Network website.

4. DEVELOPMENT

4.1 Consultation

Consultation was via the ICD steering group and clinicians

Pauline Park
Tracey Hellowell
Sharon Grimsdale
John Smyllie
Haqeel Jamil
Helen Livingstone
Andrew Daley
Paul Smith
Chris Morley
Youssef Beaini

4.2 Peer review

Version 2.2 (current version) was reviewed by both the cardiology and palliative care teams across Airedale and Bradford to ensure a breadth of input for peer review.

5. GLOSSARY OF TERMS

5.1 Advance Care Planning - Advance Care Planning (ACP) is a process of discussion between an individual and their care provider irrespective of discipline. The process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration of the individual's condition. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.

A patient may wish to discuss and document their wishes around deactivation of defibrillator therapy during an ACP discussion

Wishes expressed during ACP are not legally binding but should be taken into account when professionals are required to make a decision on a person's behalf.

5.2 Advance Decision (to Refuse Treatment) - In some circumstances the patient may have made an advance decision. The advance decision should specify the treatment which is to be refused and may specify the circumstances in which the refusal applies. In this particular instance there should be written documentation of the wish to withdraw defibrillator therapy.

Should an advance decision have been made that is relevant and applicable to the current circumstances the doctor in charge of care should consider these wishes.

5.3 Lasting Power of Attorney (LPA) - It is possible for a patient to have appointed an attorney(s) under the Lasting Power of Attorney for health and welfare document. This must have been completed and registered with the Office of the Public Guardian while the patient still had capacity. A registered Lasting Power of Attorney (LPA) form for Health and Welfare would usually consist of 12 pages (unless there are more than one attorney or replacement attorneys). It would bear the Office of the Public Guardian stamp on the front page, and would display the text 'Validated - OPG'.

Should the patient have appointed an attorney for health and welfare, and the patient is deemed to lack capacity the decision regarding withdrawal of defibrillator therapy may be covered in the LPA.

In this situation the doctor in charge of patient care must discuss the treatment options with the attorney, prognosis of the patient's condition and both the disadvantages and advantages of withdrawing ICD/CRT-D therapy and also those of continuing ICD/CRT-D therapy.

5.4 Best Interests - If a patient lacks capacity and has not made an advance decision or appointed a Lasting Power of Attorney with regard to defibrillator deactivation a senior clinician will be required to make a decision based on the best interests of

the patient, using the code of practice set out in section 1.4 of the Mental Capacity Act.

6. REFERENCES

Arrhythmia Alliance

[http://www.heartrhythmcharity.org.uk/www/media/files/For_Patients/100413-FINAL-ICD in Dying Patients.pdf](http://www.heartrhythmcharity.org.uk/www/media/files/For_Patients/100413-FINAL-ICD_in_Dying_Patients.pdf)

ICD deactivation at the end of life: Principles and practice: A discussion document for health care professionals. Dr James Beatie, British Heart Foundation 2013

Mental Capacity Act - <https://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

Airedale Hospital Capacity assessment tool – AMCABID [Mental Capacity Assessment](#)

Policy and Procedures for Working with the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards (2009) Bradford Teaching Hospitals NHS Foundation Trust.

7. APPENDICES

7.1 Appendix I -Request for Deactivation of Implantable Cardioverter Defibrillator (ICD or CRT-D)

Request for Deactivation of Implantable Cardioverter Defibrillator– ICD or CRT-D	
ICD details – patients will usually have this on a card / leaflet	
Manufacturer..... Implant Hospital.....	
Patients Name..... NHS No..... Date of Birth..... Address..... Telephone..... Current Location..... GP Name..... Address..... Telephone.....	Deactivation Date of request-..... Time of request-..... Reasons for request :
Authorisation/ Consent Does the patient have capacity to make this decision – YES/NO (please refer to local procedures if you think the patient may not have capacity to make this decision)) Signature of authorising professionalPrint Name.....	
FOR PATIENTS WITH CAPACITY ONLY I understand the reasons for deactivating my device and that the decision to deactivate can be reviewed if necessary. I agree to the deactivation of my ICD / CRT-D. Signature of Patient..... Date.....	
Date and time device deactivated: Date.....Time..... Comments.....	Signature of Cardiac Physiologist deactivating the device Print.....

7.2 Appendix II - Guidelines for deactivation of implantable cardioverter defibrillators (ICD and CRT-D) in people nearing the end of their life

Patient with an ICD/CRT-D approaching the End of life

Discuss defibrillator therapy deactivation early when approaching end of life – ideally consultation with Cardiologist / GP / Heart Failure Nurse Specialist / Palliative Care Consultant

- When a patient is considered eligible for GSF register
- When resuscitation issues are being explored
- When transfer to a hospice or home for end of life care is being planned
- When referral to palliative care is being considered.
- Patient no longer wishes for defibrillator to remain active.

Obtain details about ICD/CRT-D from patient card i.e. manufacturer / implant centre.

Contact AGH /BRI or hospice to discuss with Cardiologist /HFNS/ Cardio Respiratory Physiologist/Palliative Care Consultant.

Complete the request for deactivation form

PLANNED DEACTIVATION

Patient goes to hospital for planned deactivation arrangements are made for deactivation at home/hospice if patient is unable to attend hospital due to clinical deterioration.

Ensure Health care professional is present in addition to technician to provide support.

EMERGENCY DEACTIVATION

When planned deactivation is not possible and Cardiac Physiologist is unable to get to patient in time.

Deactivation is achieved by placing magnet on the patient's skin over the ICD/CRT-D and taped in place. ***magnet only effective when left in place – leave on patient even after death until death has been verified.**

Magnets are available from

Community use: Manorlands Hospice (Keighley), Marie Curie Hospice (Bradford), Craven Collaborative Care Team (Skipton General Hospital), Airedale Collaborative Care Team (Airedale General Hospital), Airedale Palliative Care Support Team (Canalside Health Centre), Bradford Palliative Care Support Team (ShIPLEY Health Centre), Meridian House (Keighley), Single Point of Access Team (Lynfield Mount), Castleberg hospital (Giggleswick) - Contact details in appendix III

Hospital use: AGH - Cardiorespiratory Department, CCU, A&E
BRI – Cardiorespiratory Department, CCU

7.3 Appendix III - Useful Telephone Numbers

Airedale General Hospital - 01535 652511

Cardio Respiratory Department - 01535 293401 8.30 am - 4.30 pm

Bradford Royal Infirmary - 01274 542200

Contact Cardio Respiratory Department Via Switch board 8.30 am – 4.00 pm

Available to bleep out of hours

Manorlands Hospice - 01535 642308

Skipton Hospital CCCT – 01756 793206

Marie Curie Hospice /Hospice at Home – 01274 337000.

Airedale Palliative Care Support Team – 01274 322007

Single Point of Access – 01274 256131 (use for Bradford Palliative Care Support Team as well)

Castleberg Hospital – 01729 823515

Patient Advocacy Contacts

Bradford and Airedale Area Bradford IMCA – 01274 770118

CHOICE (learning disability) 01274 391691

Craven /North Yorkshire IMCA Service 019244 54875

8. PROCEDURAL DOCUMENT DEVELOPMENT CHECKLIST

Prior to submitting any document for initial ratification or following a review, the following checklist must be completed and appended by the author to the document. Please remember when writing a procedural document you need to be as specific as possible and not leave any area open for misinterpretation.

TITLE OF DOCUMENT:	✓ or X	Comments
Front page – title, document reference table		
Is the title clear and unambiguous?	✓	
Is it clear whether the document is a guideline, policy, or SOP?	✓	
Has the correct document template been used?	✓	
Is the document reference table completed?	✓	
Is the review date identified?	✓	
Is the frequency of review identified? If so, is it acceptable?	✓	
Contents page and associated trust documents		
Are the contents page and page numbers accurate?	✓	
Are all associated trust documents hyperlinked?	N/A	
Introduction		
Are the intention, purpose and scope of the document made clear?	✓	
Are all relevant, supporting policies, local and national guidelines and SOPs listed?	✓	
Has an equality impact assessment been completed?	N/A	
Definitions		
Are all terms clearly defined?	✓	
Duties		
Are all roles and responsibilities made clear?	N/A	
Developing a new procedural document		
Have any training needs been identified?	N/A	
If so, have Education & Training / practice development been consulted?	N/A	

TITLE OF DOCUMENT:	✓ or X	Comments
Consultation, approval and ratification process		
Is the consultation / peer review process explicit?	✓	
Has the patient and carer panel been consulted?	N/A	
Does the document identify which committee/group has approved it?	✓	
Are there any fraud implications with this policy? If yes has the Local Counter Fraud Specialist been consulted?	N/A	
Is this document used to evidence CQC or NHSLA standards (if yes has the Assistant Director Healthcare Governance been consulted)	N/A	
Dissemination & Implementation		
Is there an outline/plan to identify how this will be done?	✓	
Does the plan include the necessary training/support to ensure compliance?	N/A	
Have resources implications (including financial) been considered and documented?	N/A	
References		
Are all references properly listed?	✓	
Is there a clear evidence base?	✓	
Version control		
Does the document have a clear version number?	✓	
Are minor amendments clearly documented on the version control page?	✓	Outline of amendments listed
Process for Monitoring compliance		
Are there measurable standards, KPIs or a defined audit tool to support monitoring compliance of the document?	N/A	
Is it clear which committee or group is responsible for monitoring compliance with the policy?	✓	
Overall Responsibility for the Document		
Is it clear who will be responsible for coordinating the dissemination, implementation and review of the documentation?	✓	MCN
Are there any other issues to be considered?	N/A	