# Deactivation of ICDs as part of end of life care

Michael Cooklin

#### Guy's and St Thomas' NHS Foundation Trust



South London Cardiovascular and Stroke Network

Guidelines for deactivating implantable cardioverter defibrillators (ICDs) in people nearing the end of their life NHSE South London Cardiac Operational Delivery Network Hear Failure Nurse Specialists' Forum 7<sup>th</sup> February 2019

#### More work is needed.....

...a man on home hospice care "suffered 33 shocks as he lay dying in his wife's arms. The source of those shocks, his implantable cardioverter-defibrillator (ICD) reportedly 'got so hot that it burned through his skin'. The device that had been implanted to save his life caused this man and his wife great distress in his final hours"

...device deactivation had never been discussed.

Grassman D. EOL considerations in defibrillator deactivation. *Am J Hosp Palliat Care* 2005;22(3):179-80

# Prior research suggests (not surprisingly)..

- Providers knowledge deficits about ICD functions and attitudes about device deactivation in terminally ill patients can adversely affect the timing of deactivation discussions (if any)
- Providers may feel ill prepared to initiate discussions
- Much device deactivation is performed by industry representatives, affecting continuity of care
- Many patients lack sufficient ICD knowledge to make informed decisions
- Deactivation is more likely when formal institutional policies exist
- ICD deactivation is more likely when there is a multidisciplinary approach to patient care

## Relevant National Bodies include

- The Resuscitation Council (UK)
- The British Cardiovascular Society (including the British Heart Rhythm Society and the British Society for Heart Failure)
- The National Council for Palliative Care
- The General Medical Council
- Also local guidance....

Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death

Guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care

> NATIONAL COUNCIL F

PALLIATIVE

CARE



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## Preliminary comments

- Implantable Cardioverter Defibrillators (ICDs) are one type of cardiovascular implanted electronic device (CIED)
- ICDs are usually implanted following survival from a life-threatening arrhythmia (often cardiac arrest), where no treatable reversible cause exists (secondary prevention), or, in the absence of prior events, when the risk of sudden death is felt to be sufficiently high (primary prevention)
- The ICD 'system' includes the generator ('box') and 1 to 3 leads, usually implanted transvenously; subcutaneous ICDs do not need venous access
- Cardiac resynchronisation ICDs with an LV lead may improve heart failure
- Every 6-8 years the generator needs changing due to battery depletion; the leads do not need replacing in the absence of damage or infection
- Unlike many patients with pacemakers, most patients with ICDs are not 'pacing-dependent'

## Preliminary comments contd

- ICDs treat potentially fatal arrhythmias either by brief rapid pacing which is painless or by the delivery of high energy **shocks** (~700V)
- If the patient is conscious then a shock is painful. If the patient has collapsed before shock delivery the collapse itself may be distressing
- ICDs can deliver **inappropriate shocks** either for arrhythmias that are not life-threatening, or due to device malfunction; the risk can be reduced by careful programming but not eliminated
- Depending on the condition underlying end of life, the risk of device therapy, appropriate or inappropriate may well increase
- The 'tachy' part of an ICD (ie shock delivery) can be disabled without turning off pacing function





National Audit of Cardiac Rhythm Management Devices 2015-2016



# The ICD implant rates in the UK are low compared to many European Countries

# The ICD implant rates are increasing

# The issue of device deactivation is gong to become more prevalent and important



Uni

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High energy devices total implant rate per million population

National Audit of Cardiac Rhythm Management Devices 2015-2016

## ICD patient timelines

- Before initial implant
- Routine device management (follow up/generator changes)
- Intercurrent events (illness/shocks etc)
- Towards end of life
- During/after cardiopulmonary resuscitation
- After death

# ICD patient timelines

- Before initial implant
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#### Towards end of life

During/after cardiopulmonary resuscitation

#### • After death

## Wider circle....



# Legal/ethical aspects of ICD deactivation - 1

- 1. Importance of individual assessment
- 2. Shared decision making
- 3. Deactivation is withdrawal of treatment
- 4. Informed consent at the time of implantation (or box change)
- 5. Patients who refuse information/discussion
- 6. Patients who lack capacity
- 7. Patients who regain capacity

## Legal/ethical aspects of ICD deactivation - 2

- 8. Role of a welfare attorney
- 9. Making a 'best-interests' decision for patients without capacity
- 10. Advance care planning towards end of life
- 11. ICD checks/elective box changes towards end of life
- 12. Decisions about ICD deactivation and about CPR
- 13. ICD ownership
- 14. Communicating and recording information

### Key messages

#### **Routine device management**

- End of life issues, including deactivation should be discussed with patients and clearly documented at the time of implant
- At clinic review patients should have the opportunity to discuss concerns relating to any aspect of their device, including end of life issues; any discussions should be clearly documented
- ICDs remain the property of the recipient or their estate, only surrendered in the event of removal for clinical reasons or after death

### Key messages

#### Towards end of life - 1

- Patients with ICDs approaching end of life should be given opportunities to discuss the option of deactivation
- Individual assessment and discussion of the pro's and con's of elective replacement for battery depletion is especially important when patients are approaching end of life; discussions should be documented
- Decisions about deactivation should be shared decisions, with full involvement of the patient and the healthcare team caring for them, and must be based on careful assessment of individual circumstances at the time, and understanding the specific nature and purpose of the ICD

### Key messages

#### Towards end of life - 2

- Where lack of capacity exists, decisions must be made in the patients best interests, according to the law, and must involve those with legal power to make decision on behalf of the patient. The views of those close to the patient should also be considered when making a best interests decision
- It must not be assumed that having a DNACPR decision, or identified as dying, automatically warrants deactivation (or that deactivation automatically warrants a DNACPR decision)
- Healthcare provider organisations should have comprehensive ICD policies to ensure prompt access to appropriate care and support including access to emergency deactivation if required

#### Decision chart for ICD deactivation towards the end of a person's life





 \* A DNACPR decision does not automatically warrant ICD deactivation and vice versa.
^ See "Cardiovascular Implanted Electronic Devices in people towards the End of Life, during Cardiopulmonary Resuscitation and after Death" and "Decisions relating to Cardiopulmonary Resuscitation" <u>www.resus.org.uk/</u>.

#### **Decision chart for emergency ICD deactivation**





Ensure that the patient and those close to them have all relevant multidisciplinary support and that good communication is maintained with them and among healthcare professionals.

\* A DNACPR decision does not automatically warrant ICD deactivation and vice versa.

^ See "Cardiovascular Implanted Electronic Devices in people towards the End of Life, during Cardiopulmonary Resuscitation and after Death" and "Decisions relating to Cardiopulmonary Resuscitation" <u>www.resus.org.uk</u>.

#### How to de-activate an Implantable Cardiac Defibrillator (ICD) using a ring magnet\*

Ring magnets are available from ...... Please contact a Cardiac Physiologist on ...... during office hours.

Magnets are also located in the following areas:

- ..... Hospital: Coronary Care Unit, Emergency Department, Admissions Unit and ...... Ward(s).
- Community: ..... Hospice.
  - Locate the patient's ICD. (This may be located on the left or right side of the patient's chest just below their clavicle, usually seen as a prominent protrusion; less commonly the device may be situated in the patient's abdomen and is more difficult to locate)
  - 2. Place the magnet directly on the skin over the ICD.
  - 3. Secure magnet in place with suitable tape to prevent dislodgement from device.

Note:

A 'pro-tem' solution only pending formal inactivation

Magnet does not affect pacing function (cf pacemaker)

In some devices after hours ICD function returns

Adapted from Wye Valley NHS Trust documents 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

Patient with an ICD is approaching the End of Life Stage

Discuss ICD deactivation early when approaching end of life as appropriate ideally in consultation with the cardiologist and heart failure specialist nurse/physiologist: (Recommend planned deactivation) When resuscitation issues are explored OR When a patient's condition is worsening and deactivation may be appropriate When transfer to a hospice or home for end of life care is being planned When referral to palliative care team is being considered Links with Co-ordinate Mv care\* Planned deactivation Emergency temporary deactivation Ask patient for their ICD card/leaflet with details of the ICD \* When planned deactivation was not done and the manufacturer and implant centre cardiac physiologist could not get to the patient on time Contact ICD implant centre to discuss and arrange deactivation with the specialist Cardiac Physiologist When patient is imminently dying: \* If ICD centre is not known, contact your local hospital pacing clinic. Place magnet on the patient skin over the Ref: Appendix 1 Contact List bump of the ICD (usually left side of chest below collar bone) and tape in place\* Fill in Request for Deactivation of ICD Form (signed by patient, \* Magnet is only effective when in position. Once next of kin/carer/friend and cardiac physiologist) removed, the ICD reverts to function as before \*Leave the magnet on even after death Patient goes to the hospital for the scheduled ICD deactivation Send copy of Request for Deactivation of ICD Form to GP, heart failure nurses, district nurses and palliative care nurses Patient death

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Request for Deactivation of implanted cardiovertor Demonilator (iCD)		
ICD Details (most patients will have a card/leaflet with this information)		
Manufacturer: Implant Hospital:		
Patient Name:		Deactivation Date of request:
		Reason for Request:
GP Name:		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:		
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 and time device de-activated: 	Signature of Ca	rdiac Physiologist de-activating the device:

activation of Implanted Cardiovarter Defibrillator (ICD)



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#### 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



NHS

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Guidelines for deactivating implantable cardioverter defibrillators (ICDs) in people nearing the end of their life An Advance Decision can only be made by someone if:

- They have reached the age of 18; and
- 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:

- 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?
- 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.

## Conclusions

- ICD deactivation is important towards end of life because in general the goal of patient treatment is palliative, whereas the ICD is designed to prolong life; tachycardia terminating therapy is at very best quality of life neutral, more commonly painful and potentially very distressing
- Although devices have been around a long time, detailed thoughts about ICD deactivation and national guidance are relatively recent; we still have a lot to learn
- Many issues around device inactivation appear complex, but can be simplified to principles applicable to nearly all patient care, namely timely, clear, informative, sympathetic communication involving all relevant parties and respecting patient autonomy, allied to good documentation

## Key reading

 Pitcher D, et al. Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the Reuscitation Council (UK), British Cardiovascular Society and National Council for Palliative care. Heart 2016;**102**:A1-A17