Deactivating implantable cardiac defibrillators in end of life care

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Implantable Cardiac Defibrillators (ICDs)

ICDs have 3 main actions

1. Bradycardia pacing
2. Anti-tachycardia pacing (ATP)
3. Shock delivery

And are often allied to..
1. Resynchronisation pacing (CRT-D)
STH Deactivation Protocol

The ‘ICD deactivation team’

Senior techs: Michelle Smith and Chris Drazek

Phone ECG at NGH 271 4315

Need consent of supervising consultant

If conditions met will ensure deactivation in 72 hours

Outreach service possible but patients may be asked to attend department

Urgent deactivation possible through ECG dept at NGH or the on-call ECG technician (contacted through switchboard at NGH) but patient will need to come to NGH

Magnet option remains – suggest discuss with on-call ECG technicians
The magnet

Magnet over ICD
Anti-tachycardia features disabled (only)

(Magnet over PPM  Continuous pacing with no sensing)
When a heart life-saver can become a curse:
Tiny defibrillator implants keep thousands alive but can also lead to a drawn-out and distressing death

By RACHEL ELLIS FOR THE DAILY MAIL

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When Fred Emery’s health suddenly went downhill three years ago, doctors recommended turning off the defibrillator that had been keeping him alive for the past 14 months.

The 69-year-old had had the matchbox-sized device — which fires small electric shocks into the heart if it stops beating — implanted in his chest following a 26-year battle with heart disease.

During that time he’d had two heart attacks, and had already undergone two triple heart bypass operations as well as having several stents (tiny metal tubes) inserted to prevent his arteries blocking. However Fred then developed heart failure and ventricular tachycardia — a potentially fatal heart rhythm.

Having a defibrillator would not only help with the heart failure, but also any sudden cardiac arrest triggered by the faulty heart rhythm (a cardiac arrest is where the electrical activity of the heart becomes so chaotic it stops pumping blood).

But Fred’s condition deteriorated and doctors suggested that as he was nearing the end of his life, it was time to turn off this life-line — to spare him and his family the ordeal of it repeatedly jolting his heart back to life when his body had reached the natural moment of death.
‘I was really ill. The doctors didn’t think I was going to make it because my heart was failing,’ recalls Fred, a former manual worker from Kings Langley, Herts.

‘They advised me to have the defibrillator deactivated because there was nothing more they could do and it wouldn’t be nice for my family to see it trying to keep me alive.

‘I wasn’t really with it but I didn’t want my family to see me like that, so I made the decision right then to have it deactivated. Within 24 hours it was turned off.’

Despite doctors’ predictions, Fred pulled through and has since had the defibrillator reactivated. But nearly three years later he and his family are still angry, claiming doctors had written him off before his time.
‘Having the defibrillator switched back on made all the difference to me mentally. I feel more secure having the back-up,’ says Fred.

He urges anyone considering an ICD to discuss the circumstances in which it needs to be turned off before they have it fitted.

‘For us it was a pressurised decision which made it stressful for all the family — but it doesn’t have to be that way.

‘We’ve now discussed this at length and concluded we’ll only turn it off again if my quality of life is poor and the only thing keeping me alive is the ICD.’
Implantable Cardiac Defibrillators (ICDs)

ICDs inserted for...

1. Survivors of cardiac arrest or high risk arrhythmia
2. Those at high risk of arrhythmia
   (i) e.g genetic conditions (Brugada, LQTS, HCM...)
   (ii) High risk clinical profiles 
      e.g Post MI Cardiomyopathy
MADIT II trial

Design

- Documented Prior MI
  - EF ≤ 30%
- Consent & Randomization
- ICD
- Follow-up @ 3 months
  - Monitor RX
  - Endpoints

SELECTION

ENROLLMENT

FOLLOW-UP

![Graph showing survival probabilities]

- Defibrillator Group
  - 0.78
- Conventional Group
  - 0.69

P=0.016

<table>
<thead>
<tr>
<th>Years</th>
<th>Defibrillator</th>
<th>Conventional</th>
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<tr>
<td>0</td>
<td>742</td>
<td>490</td>
</tr>
<tr>
<td>1</td>
<td>503 (0.91)</td>
<td>329 (0.90)</td>
</tr>
<tr>
<td>2</td>
<td>274 (0.94)</td>
<td>170 (0.76)</td>
</tr>
<tr>
<td>3</td>
<td>110 (0.78)</td>
<td>65 (0.69)</td>
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<tr>
<td>4</td>
<td>9</td>
<td>3</td>
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Kaplan-Meier estimates of the cumulative probability of all-cause mortality in ICD and non-ICD patients.

Figure 1. Kaplan–Meier estimates in each treatment arm.

Implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (review of TA95 and TA120)

Issued: June 2014

NICE technology appraisal guidance 314
guidance.nice.org.uk/ta314
Table 1 Treatment options with ICD or CRT for people with heart failure who have left ventricular dysfunction with an LVEF of 35% or less (according to NYHA class, QRS duration and presence of LBBB)

<table>
<thead>
<tr>
<th>NYHA class</th>
<th>QRS duration</th>
<th>LBBB, left bundle branch block; NYHA, New York Heart Association</th>
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<tbody>
<tr>
<td></td>
<td>&lt;120 ms</td>
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<td>120-150 ms</td>
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<td>≥150 ms</td>
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**NICE 2014:**
- LBBB + mod to severe or severe LVSD (of any cause)
- Consider an Implantable Cardiac Defibrillator!
- And (probably) patients with LVSD should have an ECG each year!
Patient perceptions of ICD shocks

ICD shocks are perceived as very painful (in one study graded 4.0 on a 0 to 5 scale).

After an ICD shock, patients can be immobilized, fearing that any movement or activity might trigger another shock.

Individuals who experience an ICD shock relate greater levels of psychological distress, anxiety, anger, and depression than those who do not.

ICD shocks lead to greater psychological distress for family members.

Raitt MH JACC 2008 51(14):1366-1368
Patient perceptions of ICD shocks

Electrical storms, defined as having more than 3 shocks in a 24-h period, occurs in 10% to 20% of patients during the first 2 years after ICD implantation.

‘In some ICD patients this leads to a reactive depression, helplessness, and post-traumatic stress disorder.’

Raitt MH JACC 2008  51(14):1366-1368
ICD shocks at the end of life – MADIT II analysis

Annual rate of death with ICD in situ is 11% -17%

27% of patients with an ICD in situ get shocks in the last month of life

8% - 10% of patients with an ICD in situ receive shocks in the last 24 hours of life
ICDs and hospice care

2011 survey of 50 hospices in Oregon USA.

86% had had pt with an ICD

86% reported an ‘adverse event’ relating to the ICD

Of which...
2/3rds relate to shock delivery
1/3rd relate to pt or family distress related to decision to deactivate the ICD

Fromme et al Am J Hosp Pall Care 2011:28;304-9
ICD deactivation: Cardiology perspectives

2010 Survey of 47 large European ICD implantation centres

62% physicians willing to deactivate defibrillators at the end of life

Only 4% (i.e. 2) centres provide pre-implantation advice on ICD deactivation

Marinski et al Europace 2010
ICD deactivation: Patient Perceptions

Survey of patient attitudes to their outlook and benefits of therapies in 65 ambulant HF pts with an ICD

‘Patients are very over optimistic about their outlook and prognosis’

‘Patients over-estimate the clinical benefit of their ICD by a factor of ten’

ICD deactivation: Patient Perceptions

Survey of patient attitudes to their outlook and benefits of therapies in 65 ambulant HF pts with an ICD

‘Patient preferences are hard to predict’

‘It is a common preference not to have one’s defibrillator deactivated’

The Ethics of ICD Activation

Patient autonomy and self-determination must be respected

If pt has capacity and has been appropriately informed and wishes for their ICD to remain active then this wish must be respected even if it is medically questionable

Detailed discussion must take place with the patient and must be recorded prior to deactivation

The Ethics of ICD Deactivation

If the patient lacks capacity then the provisions of the Mental Capacity Act 2005 come into force

...and consider taking ethical and legal advice?...
Conclusion

ICDs reduce the likelihood of death but, as heart failure worsens, patients are likely to receive more frequent shocks, which cause significant pain and anxiety.

Clinicians infrequently discuss ICD deactivation with patients, and most devices remain active until death.

Qualitative studies have shown that patients may not fully understand how their ICDs work and develop complex psychological relationships with their devices that may contribute to a reluctance to deactivate the ICDs.

Adler et al Circulation 2009:120;2597-2606
Conclusion

For end-stage heart failure patients, deactivation of ICDs when death is near is advisable to avoid repeated shocks in a dying patient.

Particular care should be taken to make sure that such dialogue occurs early on, while the patient is still capable of participating in the discussion, and that it is clearly documented in the medical record.

Adler et al Circulation 2009:120;2597-2606
To ‘deliver’ ICD deactivation

The patient-carer relationship is essential and a long term clinical relationship is likely to be best

Counsel patients about the possibility of a time for deactivation prior to device implantation

Patient autonomy remains paramount – do not override this!

Take the family with you

Document the details of discussions clearly

Don’t be afraid to ask for ethical or legal advice

Contact the IICD deactivation team in ECG dept NGH

The magnet is a device of last resort
STH Deactivation Protocol

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