Heart Rhythm New Zealand Position Statement: Management of Implantable Cardioverter Defibrillators (ICD) and Pacemakers for patients nearing end of Life. Final version August 2014

Author: Susan Sinclair (susan@adhb.govt.nz) and Nigel Lever (nlever@adhb.govt.nz) on behalf of the Northern Region Electrophysiology Service.

End of Life Management of Implantable Defibrillators

Background:

Implantable defibrillators (ICDs) treat sustained ventricular arrhythmias by anti-tachycardia pacing or by cardioversion or defibrillation therapies. An ICD has standard pacemaker functions which are usually programmed to a back up mode unless anti-bradycardia pacing is also required (standard pacemaker treatment).

ICDs are implanted into patients who have either had a significant ventricular arrhythmia or cardiac arrest (secondary) or who are at risk of a ventricular arrhythmia (primary prevention). Often these patients have significant cardiac disease with poor LV function or heart failure, with a minority having structurally normal hearts (inherited cardiac disease eg Long QT).

Prior to initial implantation or unit replacement, discussions are held with the patient (and family) regarding the use of ICDs and end of life/quality of death issues requiring deactivation of the device.

As patients’ cardiac condition progresses (e.g. terminal heart failure) or other disease processes (e.g. malignancy, dementia) develop, ICD support may no longer be appropriate.

During the final stages of life an arrhythmic storm may occur, regardless of the underlying cardiac condition. If the ICD device is still active and gives treatment, it will be unpleasant and distressing for the patient, their family and caregivers. If it corrects the cardiac rhythm problem, it may delay the dying process. Retrospective studies have shown that 21% of patients will receive a shock in the 30 days before death.

It is essential that a management plan for deactivation of ICD therapy is implemented for patients in whom ongoing ICD support is no longer appropriate.

Deactivation of the ICD stops it from treating any further ventricular tachycardia (VT) or fibrillation (VF) events that may occur during the terminal illness. Deactivating the device is a programming change that can be undertaken at the patient’s bedside or within the clinic setting, is not painful and does not involve an invasive procedure. Deactivation does not cause death, but prevents cardiac arrest being treated automatically. If VT/VF occurs after deactivation, the ICD will not deliver treatment. The patient will not be given shock therapy and will be able to continue to receive all other appropriate cares without interference from the ICD.
Managing the ICD should be part of the overall patient care plan agreed to after discussions with the medical staff, patients and their family. This must involve the ICD clinic staff as ICD programming is a prescription.

Like prescribing or withdrawing medications, the ICD programming is a treatment. Documentation of the reasons for withdrawal of ICD support is essential. It must be agreed to by the lead clinician for the patient, the patient and family as well as the ICD clinical team. The Cardiac Physiologist will be delegated the task of deactivation only after agreement has been documented in the patient’s clinical notes.

When ICD patients are pacemaker dependent, a separate decision regarding withdrawal of pacing support is required. In cases of dependence, cessation of pacing may lead to death (see separate document). Discontinuation of ICD and pacing support is appropriate for some patients, but in most cases the pacing programming will remain unchanged when the ICD therapy is programmed off.

Note:

- Company Representatives should not be contacted directly to disable ICDs.
- If shocks occur there is no risk to anyone touching the patient.
- Disabling ICD therapy will not disable the pacemaker function of the device.
- The ICD will be explanted by funeral director if cremation is to occur.
- Cardiac Physiologists may be able to travel to a Hospice or patients home if they are unable to visit the ICD clinic.
- On call Cardiac Physiologists are available 24 hours a day to assist with any queries.
- Magnets can be used to disable therapy but these should only be used in direct consultation with the Pacing Physiologist.

**Process for Disabling an ICD**

<table>
<thead>
<tr>
<th>1. Managing Clinician</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirm progressive terminal illness</td>
<td></td>
</tr>
<tr>
<td>Initiate discussion with patient and family</td>
<td></td>
</tr>
<tr>
<td>Discuss outcome of deactivating therapy explaining that death will not occur at time of deactivation</td>
<td></td>
</tr>
<tr>
<td>Document conversation</td>
<td></td>
</tr>
<tr>
<td>Formal request to the managing Pacemaker Clinic (24 hour service) where Cardiac Physiologist will initiate discussion with appropriate Cardiologist. In Centres where there is no 24 hour on call Pacemaker service, contact the on call Cardiologist.</td>
<td></td>
</tr>
</tbody>
</table>
### 2. Pacemaker Clinic

- File will be reviewed to see if a Management Plan is already in place.

**Acute Setting:**
- If a management plan is in place a Cardiac Physiologist will be able to deactivate the device as soon as possible.
- If no plan in place the Cardiac Physiologist will discuss with the on call Electrophysiologist or Cardiologist.
- Cardiac Physiologist to sight the written order in the patient notes at time of deactivation.
- Cardiac Physiologist to document all programming changes in the patient file and send a formal report to GP and Medical records.

**Non Acute Setting:**
- File reviewed by Electrophysiologist or Managing Cardiologist.
- Patient review booked with Cardiologist.
- Management Plan made and documented in Medical Record and Patients pacing file.
- Cardiac Physiologist to sight the written order in the patient notes at time of deactivation.
- Cardiac Physiologist to document all programming changes in the patient file and send a formal report to GP and Medical records.

#### Pacemaker Clinic Contact Details:

- **24 hour service available**

**Auckland /Northland DHB:** 021 808 605  
**Counties Manukau DHB:** 021 240 7535  
**Waitemata DHB:** 021 806 985  
**Waikato DHB:** Office hours: 021 834 529 After hours 07 8398899 page the Physiologist on call  
**Capital Coast DHB:** 027 226 3295  
**Canterbury DHB:** 0272138040  
**Dunedin Hospital:** 03 4740999 pager 6436

**Other Centres:**

- **Bay of Plenty DHB:** 07 5575292  
- **Hawkes Bay DHB:** 06 8788109  
- **Mid Central DHB:** 06 356 9169  
- **Nelson Marlborough DHB:** 03 5461800  
- **Southland Hospital:** 03 2145775
Further Reading:


End of Life Management for Patients with Pacemakers

**Background:** Permanent pacemakers are implanted most commonly for bradyarrhythmias from sinus node or AV conduction disease. Approximately 2% of patients are pacing dependent. This means no intrinsic cardiac escape beats occur when the pacemaker is temporarily programmed to 30 beats per minute and is associated with significant symptoms for most patients.

Pacemaker rates are programmed according to differing clinical requirements. Most are programmed to allow intrinsic conduction to occur as much as possible. Some are programmed to a back up mode where rates can decrease to 40 beats per minute particularly in those with intermittent bradycardia. This is to prevent pacing induced problems which can occur for some patients. Other patients may be paced continuously either in the ventricle or the atrium or both depending on the rhythm requirements.

**End of life care:**

Patients and their families often assume that pacemakers will delay the dying phase and therefore prolong suffering. For those who are not pacemaker dependent, the pacemaker will not make any difference to the dying process. There is no need for any device reprogramming during the terminal illness. Following death the myocardium will not respond to the impulses generated by the pacemaker.

If the patient is being cremated the pacemaker is usually removed by the funeral director and returned to the clinic. If burial is occurring the pacemaker can remain insitu.

For patients who are pacing dependent, withdrawal of pacing will lead to death. If the intrinsic heart beat is less than 30 beats per minute, the patient will lose consciousness and other body systems will die. In some cases this happens within minutes after the pacemaker has been disabled. For this reason, withdrawal of pacing requires discussion and agreement from the patient, family and medical team involved. A clear understanding of the consequences is needed and the decision process and request for withdrawal must be documented in the patient’s medical records. The Cardiac Physiologist will program the pacemaker into a non-functioning mode once the following process has been completed.

- On call Cardiac Physiologists are available 24 hours a day to assist with any queries.
- Company Representatives should not be contacted directly to disable Pacemakers.
## Process for Withdrawal of Pacing

<table>
<thead>
<tr>
<th>1. Managing Clinician</th>
<th>2. Pacemaker Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Confirm terminal illness that patient will not recover from</td>
<td>• File reviewed by Electrophysiologist or Managing Cardiologist</td>
</tr>
<tr>
<td>• If patient or family requests withdrawal of pacing, discuss outcome of this</td>
<td>Pacing Dependent:</td>
</tr>
<tr>
<td>• Document conversation</td>
<td>• If pacing dependent and death likely to occur shortly after cessation of pacing - two consultants to agree that withdrawal of this treatment is appropriate.</td>
</tr>
<tr>
<td>• Formal request to managing Pacemaker Clinic (24 hour service) who will facilitate discussions with appropriate Cardiologist. In Regional Centres where there is not a 24 hour on call Pacemaker service, contact the on call Cardiologist.</td>
<td>• Electrophysiologist/Cardiologist to discuss with family and document conversation.</td>
</tr>
<tr>
<td></td>
<td>• Cardiologist or appropriate physician to be present where possible with Cardiac Physiologist when pacing withdrawn.</td>
</tr>
<tr>
<td></td>
<td>• Cardiac Physiologist to document all programming changes in the patient file and send a formal report to GP and Medical records.</td>
</tr>
<tr>
<td></td>
<td>Non Pacemaker Dependant:</td>
</tr>
<tr>
<td></td>
<td>• File reviewed by Cardiac Physiologist and discussed with Managing Cardiologist</td>
</tr>
<tr>
<td></td>
<td>• Patient advised this is unlikely to have any impact on the death process.</td>
</tr>
<tr>
<td></td>
<td>• Decision documented</td>
</tr>
<tr>
<td></td>
<td>• Cardiac Physiologist to disable pacing at an agreed time and place</td>
</tr>
<tr>
<td></td>
<td>• Cardiac Physiologist to document all programming changes in the patient file and send a formal report to GP and Medical records.</td>
</tr>
</tbody>
</table>

### Pacemaker Clinic Contact Details:
- Auckland / Northland DHB: 021 808 605
- Counties Manukau DHB: 021 240 7535
- Waitemata DHB: 021 806 985
- Waikato DHB: Office hours: 021 834 529 After hours 07 8398899

April 2017
Page 6 of 7
Other Centres:
Mon –Fri 0800-1630
Out of hours via on call Cardiologist

- Capital Coast DHB: 027 226 3295
- Canterbury DHB: 0272138040
- Dunedin Hospital: 03 4740999 pager 6436
- Bay of Plenty DHB: 07 5575292
- Hawkes Bay DHB: 06 8788109
- Mid Central DHB: 06 356 9169
- Nelson Marlborough DHB: 03 5461800
- Southland Hospital: 03 2145775

References and Further Reading:

