



North West London Cardiac Network

Guidelines on End of Life Issues Surrounding Deactivation of Implantable Cardioverter Defibrillators (ICDs)

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Document Summary

The North West London Cardiac Network has developed this document to provide local guidance for health care professionals in the deactivation of ICD's for patients nearing the end of life.

The following points provide a summary of the contents of this document, emphasising key areas for organisations to consider during implementation.

- Appropriate discussion with patients and families regarding implications of disabling defibrillation therapies at end of life should take place as early as possible. The indicators described should be used as a trigger for such discussions and decisions with the patient.
- Information regarding the patient's device (type and model) should in all circumstances be communicated to their GP by the centre that inserted the device. It is advisable that the patient has this information also.
- The centre that the patient attends locally for device follow-up should hold the responsibility for deactivating or arranging for deactivation of the device when required. If the patient is geographically closer to another hospital it should still remain the responsibility of the follow-up centre to arrange for deactivation. For patients who have recently moved into an area the service providing their follow up are responsible for referring them onto their new local centre.
- Patients who have a preferred place of care (PPC) document should have all relevant device details clearly recorded within the document. This provides a valuable communication tool between the patient and all health care professionals involved in their care.
- A 'donut' magnet should be accessed for use on those patients whose preferred place of care is home and who experience a sudden and unexpected deterioration. However, this method is not effective for all devices. Furthermore, this temporary method is only suitable for use by 'out of hour's services' until deactivation by physiologists can be arranged within normal working hours within the patient's home. The access and availability of this service **should be restricted to emergency situations** and should not be assumed the normal pathway to deactivation.
- In all instances of deactivation the request form (see page 7) must be completed by the clinician in charge and accompany the patient in order for deactivation to be carried out.
- Communication between all health care professionals managing a patient's care should be informed of all decisions made regarding the deactivation of their ICD.
- Training and resources should be implemented to provide effective management of patients who are nearing end of life and require deactivation of their ICD.
- An appropriate resource level will need to be agreed with commissioners within each local health economy for circumstances where Cardiac Physiologists are required to attend a patient's home for deactivation.

Introduction

The World Health Organisation¹ defines palliative care as the '*control of physical, psychological, social and spiritual suffering*' and are essential in order to achieve the best possible quality of life. These elements aim to affirm life and regard dying as a normal process, clarifying that it does not '*hasten nor postpone death*'.

End of life care continues to be a priority for the Government, evidenced by commitments in the White Paper, 'Our Health, Our Care, Our Say'² and the recently published 'A Framework for Action'³ by Healthcare for London. Both aiming to increase choices for patients by further investment in palliative care services.

The North West London Cardiac Network (NWLCN) has developed various end of life tools and guidelines in line with the National end of life programme to encourage integrated end of life care across the sector. This document forms part of that care to give people greater choice in access and management around the deactivation of their implantable cardioverter defibrillator (ICD).

These guidelines should be used in conjunction with the patients Preferred Place of Care (PPC) document, which is an advanced care planning tool for recording patient's wishes and preferences about the care they would or would not like to receive when approaching the end of their life. This can take place at home, in hospital, care home or other settings. The PPC aims to give patients support and information so that they can make informed choices about their care. The document also aids communication between the health and social care professionals involved in their care, as it helps to make their wishes known.

When implementing these guidelines it will be essential to communicate and link with all key stakeholders involved in the patients care surrounding the deactivation of their ICD. These will include: GP's, cardiac physiologists, heart failure teams, A&E staff, out of hours services, London Ambulance Service, community matrons and district nurses.

When dealing with patients nearing the end of their life with an ICD in situ the beliefs outlined in this document and other end of life documentation needs to be held by all health care professionals involved in their care and addressed, as appropriate, in discussions on end of life care.

This document aims to support and provide guidance to health care professionals when dealing with the issues surrounding the withdrawal of an ICD and the decision making process that needs to be undertaken. The British Heart Foundation⁴ (BHF) have recently published a discussion document for health care professionals which provides further support of these guidelines and their importance in end of life care.

Ethical Issues

As patients with ICD's are approaching the end of their life, it is important that sensitive discussions are had with them and their family/carers around the deactivation of the device. These conversations are often best carried out by the health care professional best known to them; this may not necessarily be the GP or Cardiologist.

These discussions frequently do not occur at the time the device is implanted as this is often considered an inappropriate time when the therapy is being instituted with the goal of lengthening life. However, many clinicians currently support the need for early discussions to be had⁴. When any device is inserted the patients GP should be informed of the type and functionality of the device. The patient should also be provided with this information for future reference.

It should be remembered by all involved and explained fully to the patient and family/carers that in most instances the disabling of the device will not change the time and course of the illness or alter the ultimate outcome. The patient and carers should be informed that turning off the ICD will be painless and not result in immediate death. Do Not Attempt Resuscitation (DNAR) documentation needs to be fully completed and kept with the patient at all times to ensure no inappropriate treatment is initiated out of hours once deactivation is carried out.

With patients suffering from intrinsic cardiac disease or dying of another unrelated disease having had a device implanted, the appropriateness of continuing the device as a defibrillator may not be appropriate.

Ethically and legally if a therapy is deemed inappropriate for a patient and will not provide them with any long-term benefit it should be discontinued to enhance their quality of life. It is also a patient's right to request the withdrawal of life sustaining interventions. It is not euthanasia and should not be associated with this. The BHF document discusses these important and delicate issues in much more detail within the context of our current legal system.

Several indicators should be used as triggers for these discussions and decisions made with the patient as follows:

Indications for the deactivation of an ICD

1. DNAR order in place
2. Patient is expected to die within a number of days
3. Continued activation of ICD is futile in management of intractable ventricular arrhythmias
4. Withdrawal of anti-arrhythmic medications, (within the context of a patient nearing the 'end of life' where such treatment is now deemed inappropriate)
5. Use of ICD is inconsistent with planned patient care

Additional triggers are listed in the BHF document and can be used alongside those listed above.

It should be reasonable to suggest that the maximum time from requesting the device be deactivated to it being carried out should be *no longer than 5 days*.⁵

Local considerations for deactivation in NW London

Due to the structure of the provision of health care in NW London, patients can find their follow up care becomes the responsibility of their local hospital rather than the hospital that actually implanted the device. It should therefore be agreed that the centre that the patient attends locally, should hold the overall responsibility for deactivating the device when required. The access, operation and availability of a deactivation service needs to be negotiated at a more local level. Contractual arrangements will also need to be considered which will support hospital staff who need to attend a patient's home for deactivation.

If a patient is geographically closer to another hospital it should still remain the overall responsibility of the follow up centre to arrange for the deactivation to be carried out. For patients who have recently moved into an area, the service providing their follow up are responsible for referring them onto their new local centre. It is important that centres communicate effectively to ensure continuity of care.

Communication between all health care professionals managing a patient's care should be informed of all decisions made regarding the deactivation of their ICD. It is assumed that primary responsibility will be held with the patient's GP and measures need to be in place to ensure all parties are aware of agreed local arrangements.

Planned deactivation

Patients should be expected to have a planned deactivation procedure carried out in their centre on a day case basis. This planned pathway should be followed for the majority of patients requiring deactivation. Local agreements with the GP and London Ambulance service will require negotiation.

Emergency deactivation

Patients whose preferred place of care is hospital and who experience a sudden and unexpected deterioration should be transferred to hospital as an emergency. The GP is responsible for alerting the A&E staff to the end of life admission and of informing them of the patient's choice to have their ICD deactivated and not to be resuscitated.

A 'donut' magnet may be accessed from the local A&E department or Coronary Care Unit by the GP 'out of hours service' for patients whose preferred place of care is home and who experience a sudden and unexpected deterioration. However, as it may not always be easy to access this, it is recommended that local 'out of hours' GP services hold a magnet for emergency use at their local base.

The magnet can be taped in place over the device to disable it. However, it should be noted that this feature (magnet application) *does not* necessarily work on all devices; the function has to be programmed 'on' and this is not always routinely done. It is therefore recommended that strong consideration is given by follow-up centres to programming ICDs to enable 'magnet deactivation' at the earliest possible opportunity. Where, this function has not been enabled, more thorough planning of end of life care is needed in order to avoid these type of emergency situations arising.

For patients who have had their device temporarily disabled with a magnet, it is the responsibility of the physician in overall charge of their care, to liaise with the follow-up centre to arrange for permanent deactivation. In all cases the patients GP must be informed of the type and functions of their device at the time of insertion.

This temporary method of deactivation can be used by 'out of hour's services' until emergency deactivation by a cardiac physiologist can be arranged within normal working hours within the patient's home. In these situations it is considered inappropriate to expect a patient who is in their last few days or hours of life to attend the hospital for deactivation. This is not considered to be in their best interest. However, where this occurs, it is acknowledged that an appropriate resource level will need to be agreed by commissioners within each local health economy.

The GP will therefore need to negotiate with the follow up centre for a cardiac physiologist to attend the patients' home. The GP will need to be in attendance at the home with the physiologist at the time of deactivation. The access and availability of this service should be restricted to emergency situations and should not be assumed the normal pathway to deactivation.

In all instances of deactivation the request form (see page 6) must be completed by the clinician in charge and accompany the patient in order for deactivation to be carried out.

Training

The training/resource implications associated with sustaining end of life care in the community have a large impact on the management of patients requiring deactivation of their ICD's. It is the responsibility of each Organisation to provide sufficient education for staff and should provide: cardiac physiologists domiciliary visits, specialist input required for discussions regarding disablement of therapies, education of primary care, community heart failure nurses and hospice staff regarding device functions.

For further information, guidance and support you should consult the BHF booklet or look on their website www.bhf.org.uk.

Request for deactivation of Implantable Cardioverter Defibrillator

Patients name:

Date of birth:

Address:

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Telephone number:

GP name:

GP address:

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GP telephone:

DNAR completed:

Reason for request:

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Signature of GP or lead Consultant:

Signature of patient or legal next of kin:

Signature of health care professional deactivating the device:

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Date and time of deactivation:

Detail of settings left active on the ICD:

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Review date (48 hours after deactivation of any changes in health status):

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References

1. World Health Organisation 2007 www.who.int/en/
2. Our, Health, Our Care, Our Say. DoH (2006)
3. A Framework for Action. Healthcare For London (2007)
4. Implantable cardioverter defibrillators in patients who are reaching the end of life. British Heart Foundation (2007) www.bhf.org.uk
5. MHRA advisory (2005) www.mhra.gov.uk