

A discussion document for health professionals



Implantable cardioverter defibrillators in patients who are reaching the end of life

About the British Heart Foundation

The British Heart Foundation is the nation's heart charity, dedicated to saving lives through pioneering research, patient care, campaigning for change and by providing vital information. But we urgently need your help. We rely on your donations of time and money to continue our life-saving work. Because together we can beat heart disease.

Acknowledgements

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Introduction

There are five common forms of heart disease:

- coronary heart disease
- arrhythmias
- cardiomyopathy
- congenital heart disease, and
- valvular heart disease.

Congestive heart failure is a complex syndrome that can result from any of the above forms of heart disease, although it is most commonly associated with coronary heart disease.

Heart failure affects about 2% of the UK population. People with heart failure usually need to have multiple drug therapies. Increasingly, patients with heart failure are also given an implantable device to treat life-threatening arrhythmias – for example, an implantable cardioverter defibrillator (ICD), or a bi-ventricular or resynchronisation device which includes a defibrillation function. Despite such interventions, heart failure tends to be a progressive illness and remains a leading cause of death.

About this booklet

This booklet has been written for any health professional who is involved in caring for dying patients with an active defibrillator device.

The aim of the booklet is to raise awareness of the potential dilemmas that devices such as ICDs introduce in advanced disease management, and to promote discussion about the possibility of deactivating the defibrillator function of the ICD in patients who are reaching the end of their life.

The objectives of the booklet are:

- to improve care for patients with an ICD who are reaching the end of their life
- to encourage health professionals to raise and discuss – with patients and their families – issues regarding the deactivation of ICDs in patients who are dying
- to raise awareness of the need to consider ICD function when a ‘Do Not Resuscitate’ (DNR) order is in place for a patient
- to promote regular assessment of the relevance of an ICD in maintaining optimum clinical care, and of the personal goals of those patients who have progressive heart disease or another life-limiting disease
- to encourage the development of best practice guidelines for health professionals dealing with patients who may need to have their ICD deactivated.

Implantable cardioverter defibrillators (ICDs)

Most forms of heart disease will require lifelong medication and various interventions. An ICD is one form of intervention. It is used for:

- patients who have a life-threatening ventricular arrhythmia, or
- those who have been identified as being at risk of developing a life-threatening ventricular arrhythmia.

To summarise briefly, the purpose of an ICD is to monitor the heart rhythm and respond to arrhythmia. The ICD has several 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 rate VT, and
- cardioversion of VT.

Patients subjected to a defibrillation shock from their ICD tend to describe the experience as a startling, jolt-like discomfort that has been rated 6 on a 0-10 pain scale. The shock may follow a period of light-headedness or faintness related to the primary arrhythmia. The experience of having the shock is very distressing and often induces anxiety and fear. Such symptoms would certainly be intrusive in dying patients. Anti-tachycardia pacing activity may be sensed as palpitation.

Patients with left ventricular dysfunction due to coronary heart disease frequently exhibit dyssynchrony and may require complex pacing as cardiac resynchronisation therapy (CRT). These devices resynchronise activation of the cardiac chambers so that the heart beats in a more co-ordinated way (CRT-P), and they may also provide defibrillation when necessary (CRT-D).

This booklet considers the potential need to deactivate only the defibrillator function of an ICD (or a CRT-D device). The pacing functions of such devices should not be disabled, even in terminally ill patients, as withdrawing pacing support may introduce additional symptoms and accelerate the dying process.

In accordance with current treatment guidelines, ICDs are increasingly offered to people with congestive heart failure due to left ventricular systolic dysfunction that is essentially a chronic progressive syndrome. The typical trajectory of heart failure is of gradual functional decline, punctuated by crises due to episodic decompensation or arrhythmia. Death is usually due to either ventricular arrhythmia or unresponsive heart failure. Ventricular arrhythmia is the more common cause of death in the earlier stages of the disease, and hence the requirement for the ICD.

Heart failure is usually a disease of the older adult who may have several medical problems. So dilemmas may also arise when an unrelated terminal illness such as cancer occurs in a patient who has already had an ICD implanted.

Patients about to die with end-stage heart failure or another illness frequently exhibit metabolic or biochemical derangement and are at risk of developing complex agonal arrhythmias that might trigger firing of the ICD. In these circumstances, it would be inappropriate to maintain the ICD in active defibrillation mode, as such shocks would disturb the patient and cause distress. The purpose of this booklet is to raise awareness of the effects of ICD therapy in this setting.

For more information about ICDs – including what they do, and patients' experience of them – see our booklet *Implantable cardioverter defibrillators (ICDs)*, and our video/DVD *The beat goes on: Implantable cardioverter defibrillators*. See page 8 for how to order these.

Guidelines and policies, and why this booklet is needed

The British Heart Foundation (BHF) is not in a position to draw up guidelines for clinical practice. However, as an independent, national heart-related charity with a strong research and educational base and a commitment to supporting clinical services, it is fitting that the BHF should contribute to this discussion and support professionals who are facing such difficult clinical decisions.

National guidelines in this area of care have not yet been developed. However, some implant centres and local palliative care groups, as well as the Arrhythmia Alliance, have already begun to explore the complex clinical and ethical issues around deactivation of ICDs.

Ethical issues

Respect for patient autonomy

Patients have a right to make decisions about their own health care, and health professionals have a duty to help patients to make these decisions by providing impartial advice and information about treatment options, including the option of stopping or refusing treatment. Good clinical practice emphasises the importance of shared decision-making between health professionals and patients and, if appropriate, their families throughout the course of the person's illness.

Changes in circumstances – including the progression of the patient's disease, any complications, or the development of new treatments – mean that the doctor and patient will need to reappraise decisions about management of the illness. A patient who consented to having an ICD implanted when he or she was generally well but at risk of life-threatening arrhythmias, might make a different decision when dying from end-stage heart failure or another life-limiting disease, if given the opportunity to do so. It is important to allow patients to revise or reinforce previous decisions in the light of subsequent events, so that they can determine as far as possible the course that their life should take.

Clinicians caring for patients who have ICDs should, therefore, regularly review with the patient how relevant this treatment is and, when appropriate, introduce the possibility of deactivating the defibrillator function to avoid the patient experiencing distressing symptoms.

Acting in the patient's best interests

When a patient is unable to make decisions on their own behalf, health professionals caring for them have a moral and legal duty to act in the patient's best interests. An assessment of best interests includes balancing the risks and benefits associated with any given treatment. In most cases an ICD will confer greater benefit than harm to a patient. However, in some situations, the possibility that recurrent ICD activation might prevent a comfortable death could be judged to outweigh any benefit of prolonging life for a brief period of time.

If a patient with an ICD does not have the capacity to make his or her own decisions, those responsible for their care should consider whether ICD activation is still in the patient's best interests given the patient's particular condition and circumstances. This would be part of an overall consideration of what is optimal care for the patient, in discussion with the patient's family and taking into account the patient's previous wishes if known. A consensus view based on a multidisciplinary team approach would apply well in this situation and it may be particularly helpful to seek the advice of specialists in palliative care. Any such process would have to comply with the Mental Capacity Act 2005.

Withholding and withdrawing treatment

The remit of those working with cardiac patients generally lies in the prevention and treatment of heart disease, saving life and maintaining quality of life. Death and dying may be regarded as defeat, and clinical staff may feel uncomfortable about initiating discussion on these topics, or may feel inadequately prepared. Similarly, proposing to withdraw a potentially life-saving device in the face of a progressive final illness, however appropriate, may feel like abandoning the patient at a time of crisis. Therefore, clinicians, patients and their families are faced with an emotionally difficult decision about whether to withdraw an active element of therapy that was earlier perceived as being of obvious benefit.

The decision should be an informed choice made by the patient or, if the patient does not have the capacity to make a decision, the best interests principle should guide management. If a competent patient, having been informed of the risks, asks for his or her ICD to be deactivated, his or her wish should be respected. Health professionals have a responsibility to review the indications for having the ICD, and to reassess the patient's understanding of what the device does for his or her underlying condition and how it relates to their previously agreed goals of care. It is also important to examine the patient's broader concerns, and take into account any general medical, psychological and social factors that may have contributed to such a request.

'Do Not Resuscitate' orders

'Do Not Resuscitate' (DNR) orders are authorised in hospitalised patients who are in an advanced disease state, when it is felt that any resuscitation attempt would not be in their best interests. Resuscitation decisions should always be made in consultation with the patient's family and should ideally involve the patient, who may indeed raise the issue and decline resuscitation. Patients and their families sometimes have difficulty coming to terms with such decisions and frequently change their minds, particularly if they feel they have assumed responsibility for the outcome. If the patient cannot express himself or herself, or if the patient's family feels unable to make the decision, the decision on resuscitation ultimately rests with the clinical team responsible for the patient.¹

The presence of an ICD or CRT-D device can complicate a DNR order. In some cases, ICDs have been left active even though a DNR order was in place. This may have been due to an oversight by the clinical staff, or because staff were unfamiliar with the device, or simply because the equipment needed to deactivate or suspend device activity was not immediately available.

In general, maintaining an ICD in active defibrillation mode is inconsistent with an active DNR order and is rarely justified. However, it is possible that a competent patient may decline a full resuscitation attempt because of the loss of dignity inherent in this, but may decide that keeping their ICD active is an acceptable option. While this approach might seem to be at odds with conventional clinical practice, the patient's request should be respected.

While an ICD is active, the patient's family should be reminded that, if the device does discharge, it is by means of a low energy internal shock which is harmless to anyone in physical contact with the patient.

¹ British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. 2001. *Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*. London: British Medical Association.

Practical considerations

Complications, and when to consider deactivating the ICD

Generally it is difficult to give an accurate prognosis for heart failure. Some patients with heart failure and an ICD will develop progressive multiple comorbidities – sometimes linked, as in the case of heart and kidney failure – which may result in periods of rapid decline. However, short-term prognosis of these patients is not straightforward. Sometimes medical stability is fragile and an individual patient's survival or death is unpredictable. Such difficulties in prognostication at times of crisis or apparent deterioration need to be openly acknowledged, and they highlight the importance of maintaining an awareness of the presence of an active ICD and considering the possible confounding effects of this device in optimising patient care.

Raising the issue of ICD deactivation at such times can be difficult – especially if the patient suddenly becomes unable to communicate his or her wishes. In cases where a competent patient has prepared an advance decision or statement (a 'living will') to cover this eventuality, health professionals should comply with the patient's wishes, unless there are good reasons for not doing so – reasons which should take account of the patient's condition, prognosis and the potential for the pain and distress which may be caused.

Dealing with complications before they arise

Medical, nursing and technical staff are in a position to anticipate the situations described above. When addressing future possible complications with the patient, it is important to discuss ICD deactivation. Some clinicians argue that the possibility of deactivating the ICD should be discussed when the device is first inserted. It would seem sensible to raise and discuss this issue at this time, although in practice this rarely happens.

While it is difficult to advocate that early discussion about deactivation is applicable to *all* patients, in people with heart failure the following clinical features may be useful triggers to initiate such a conversation.

In advanced heart failure, a poor prognosis is likely in patients:

- of advanced age
- with refractory symptoms despite optimal therapy
- who have had at least three hospital admissions with decompensation in less than six months
- who are dependent for more than three activities of daily living
- with cardiac cachexia
- with resistant hyponatraemia
- with serum albumen of less than 25g/l
- who experience multiple shocks
- with a comorbidity with a poor prognosis, such as terminal cancer.

However, few such patients have discussed deactivation of their device beforehand. If any discussion has taken place, generally this has been put off until the very late stages of the illness – within the last few days, hours or even minutes of the patient's life. This may result in a distressing death for the patient, and also distress for their families, who have not had the opportunity to discuss these issues earlier in the course of the illness. It is important to emphasise that many of these situations, such as the one outlined on the next page, could be prevented.

Clinical example

Deactivation of this patient's ICD had not been considered until close to his death:

"Every 20 minutes, he would [get a shock and get] jolted awake. Meanwhile he was on morphine ... I saw this pattern ... he was waking up from like a really bad dream ... and he would say a word or something, and after 20 seconds he would be unconscious again."²

Clinical staff should encourage patients to discuss their general condition in relation to their planned care. Ideally, this care plan should be regularly reviewed and documented both in the patient's medical notes and in a patient-held record. When the patient is completing the record, he or she can also offer their personal perception of any gradual deterioration and be sensitively encouraged to document plans for when they may be less well. These discussions should include what the patient considers to be an acceptable quality of life, and a gentle exploration of their attitude to their potential continuing decline and possible death. It is also important to encourage patients to discuss the primary goals of management with their family, so that the family is aware of the patient's wishes and can act upon them.

Ultimately it is the health professionals' responsibility to define the treatment plan and come to a consensus with the patient and his or her family, respecting their wishes. This process should incorporate a regular review of the relevance of a functioning ICD.

Information exchange

Patients and their families should be made aware that decisions on disabling the defibrillator function of an ICD are not undertaken lightly and their involvement and agreement are paramount, as in all cases of informed consent.

They should be reassured that deactivating the device is a painless, non-invasive procedure and that death is unlikely to be immediate or even imminent. Re-programming an ICD is a simple process which involves using a programming wand linked to a desktop computer. Defibrillation function can also be temporarily suspended by placing a magnet over the device.

Those working with heart failure patients – or indeed with any patients who have an ICD – must familiarise themselves with the protocol for these interventions. This can be done through liaison with local electrophysiologists, cardiac physiologists or ICD/arrhythmia nurse specialists. Electrophysiology departments are usually based in tertiary referral centres and it is important that such units provide information and support to those peripheral units feeding into their service. Information exchange and collaboration are particularly important for those working in remote communities or at a distance from the implant centre. In the longer term, developments in telemetry may contribute to this process. As more district general hospitals develop pacing and ICD services, such technical expertise and support should become more widely available. Local arrangements will determine service provision and configuration and co-ordination of care is important across all clinical areas, including the voluntary sector where much of palliative care is based. Specific planning for out-of-hours cover is essential.

It is also important to acknowledge that safe deactivation may also be important after death, particularly as these devices must be explanted before a person is cremated.

² Goldstein NE, Lampert R, Bradley E, et al. 2004. Management of implantable cardioverter defibrillators in end-of-life care. *Annals of Internal Medicine*; 141 (11):835-8.

Recommendations

- Health professionals working with dying patients should be made aware of the increasing number of patients who have an ICD implanted, particularly for the treatment of heart failure.
- Health professionals have a responsibility to ensure that the function of the ICD is optimised in the best interests of the patient, particularly for those close to the point of death.
- Open, sensitive communication with patients and their families is essential, to ensure that their expectations are realistic and are compatible with the perceptions of the medical and nursing staff supervising their care.
- There should be close collaboration among medical staff, nursing staff and cardiac physiologists to facilitate timely device management in all care settings. Formal links with electrophysiologists and ICD/arrhythmia nurse specialists may be an advantage.

For more information

Information from the British Heart Foundation

Heart Information Line 08450 70 80 70

(A local rate number)

An information service for the public and health professionals on issues relating to heart health.

British Heart Foundation website

bhf.org.uk

Booklet

Implantable cardioverter defibrillators (ICDs) Heart Information Series number 19

DVD/video

The beat goes on: Implantable cardioverter defibrillators

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- email orderline@bhf.org.uk, or
- visit bhf.org.uk/publications.

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What you can do for us

We rely on donations to continue our vital work. If you would like to make a donation to the British Heart Foundation, please ring our **credit card hotline on 0870 606 3399** or contact us through our website at bhf.org.uk/donate or send it to us at the address on the back cover.

Other useful reading

Guidelines

British Medical Association. 2007. *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making*. London: Blackwell Publishing.

British Medical Association. 2006. *The Mental Capacity Act 2005 – Guidance for Health Professionals*. London: British Medical Association. Available at: www.bma.org.uk/ap.nsf/Content/mencapact05?OpenDocument&Highlight=2,mental,capacity

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Some journal articles

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Berger JT. 2005. The ethics of deactivating implanted cardioverter defibrillators. *Annals of Internal Medicine*; 142 (8): 631-4.

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Samanta A, Samanta J. 2006. Advance directives, best interests and clinical judgement: shifting sands at the end of life. *Clinical Medicine*; 6 (3): 274-8.

Sears SF, Vazquez Sowell L, Kuhl EA, et al. 2006. Quality of death: Implantable cardioverter defibrillators and proactive care. *Pace*; 29: 637-42.

Useful organisations

Arrhythmia Alliance

Phone: 01789 450787

Website: www.heartrhythmcharity.org.uk

Email: info@arrhythmiaalliance.org.uk

Arrhythmia Alliance - The Heart Rhythm Charity - providing better understanding, information and support leading to an improved quality of life for all those affected by cardiac arrhythmias.

The Ethox Centre

Phone: 01865 287893

Website: www.ethox.org.uk

Email: admin@ethox.ox.ac.uk

A multidisciplinary academic centre for ethics and communication skills in medical research and health care practice.

National Council for Palliative Care

Phone: 020 7697 1520

Website: www.ncpc.org.uk

Email: enquiries@ncpc.org.uk

The National Council for Palliative Care is the umbrella organisation for all those who provide, commission and use palliative care and hospice services in England, Wales and Northern Ireland. Its aim is to extend and improve palliative care services for everyone.

NHS Heart Improvement Programme

Phone: 0116 222 5184

Website: www.heart.nhs.uk

Email: info@heart.nhs.uk

The NHS Heart Improvement Programme is a national approach to support the delivery of the National Service Framework for Coronary Heart Disease by the development and spread of recognised clinical innovations and service improvement through the cardiac networks.



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