

Discussing deactivation of implantable cardiac defibrillators

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Abstract

Implantable cardiac defibrillators are a key component in preventing sudden cardiac death for patients with life-threatening arrhythmias. Through ageing, frailty and the progression of cardiac and non-cardiac morbidity, many will develop a 'life-limiting' condition. This raises the challenge of how to approach making decisions to deactivate the defibrillator function. This article discusses the background to deactivation of implantable cardioverter defibrillators and the practical considerations for different circumstances.

Key words: Arrhythmia; Ethics; Implantable cardiac defibrillators; Pacemaker; Sudden death

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Implantable cardiac defibrillators are a key component in preventing sudden cardiac death. Recommended for primary prevention in patients with severe systolic heart failure, certain arrhythmogenic cardiomyopathies and inherited electrophysiological disorders, they also have a secondary preventive role in individuals who have survived a ventricular arrhythmia. The implantable cardioverter defibrillator senses the occurrence of ventricular arrhythmia and can deliver anti-tachycardia pacing or, failing this, a defibrillating shock (Piori et al, 2015). In 2016–17, 179 implantable cardiac defibrillators per million population were implanted in England (British Heart Rhythm Society, 2019), making these devices increasingly common. Through ageing, frailty and the progression of cardiac and non-cardiac morbidity, many will develop a 'life-limiting' condition. This raises the challenge of how to approach making decisions to deactivate the defibrillator function. This article discusses the background to deactivation of implantable cardioverter defibrillators and the practical considerations for different circumstances.

Ethical and legal considerations

Having an implantable cardioverter defibrillator in situ carries the risk of significant side effects. Around 6% of patients per year will experience an inappropriate shock causing physical and psychological trauma (Auricchio et al, 2017). An active implantable cardiac defibrillator will also deliver (sometimes repeated) shocks to a patient experiencing ventricular arrhythmias at the end of life (Westerdahl et al, 2014). This is particularly distressing for the dying patient and their family.

Ethically, the decision to either withdraw or withhold a treatment are weighed up in the same way. The clinician must balance the risks of the treatment and decide whether continuing or withdrawing treatment is of overall benefit or harm. As far as possible, patients should be involved in this decision-making process in keeping with a patient-centred approach. However, while withdrawing a treatment might be ethically similar, it may feel more emotionally charged than a decision not to start the same treatment in the first place.

Legally, clinicians must follow the Mental Capacity Act 2005 (in England and Wales, or the equivalent law in other jurisdictions). Where a patient has capacity, they should be fully involved in the decision to stop defibrillator therapy. Where a patient lacks capacity the clinician must identify if there is a valid 'advance decision' or if the patient has appointed a legal power of attorney and that this advocate has permission to withhold life-sustaining treatment. Where these are not in place, discussion with the patient's next of kin should take place to identify what the patient would want and a decision made in their best interests. The judgement of what constitutes the patient's best interests lies with the clinician.

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The above principles, of ethics and law, do not help the clinician when conflicts of opinion arise. Fortunately, both the British Heart Foundation and the European Heart Rhythm Association have documented an approach to this (Padeletti et al, 2010; Beattie, 2013). Implantable cardiac defibrillators are relatively permanent. They can be considered ‘integral’ devices and, being internal, the autonomy of the patient is given greater weight in decision making about them than it would be for an external or more temporary device. Therefore, where a competent patient would like an implantable cardioverter defibrillator to be deactivated, their autonomy should be respected, even when the clinician feels it should remain active. A clinician should not unilaterally take a decision to deactivate an implantable cardiac defibrillator without a patient’s consent. Where not deactivating a device could lead to serious harm but there is no agreement on deactivation, measures should be taken to build consensus through multidisciplinary discussion, offering a second independent medical opinion and allowing time to further consider where this is possible. Where consensus cannot be reached, it is appropriate to obtain legal advice before continuing.

Who should deactivation of an implantable cardiac defibrillator be discussed with?

All patients should have deactivation of the implantable cardiac defibrillator discussed with them before implantation as part of routine pre-procedure counselling. As an implanted and relatively permanent device, the patient should have the opportunity to consider not only the immediate implantation procedure but the full ‘life cycle’ of the device, including the need for follow-up appointments, potential further procedures for generator replacement, possible complications over the long term (inappropriate shocks, infection) and the future need for deactivation of the implantable cardioverter defibrillator.

It should be made clear that deactivation of the implantable cardiac defibrillator function can be done independently of the pacing functions of the device and that this is performed remotely. Given that the device is likely to be in place for several years, it is good practice to involve the patient’s next of kin in this discussion, as the patient could lose capacity at some point in the future.

Situations where harm starts to outweigh the benefits include when the risks of inappropriate shocks are high while the chance of a life-saving shock is low in a patient who has developed advanced cardiac or non-cardiac disease. A further situation would be where the goal of treatment shifts from prolonging life to one based on symptom control, that is a patient receiving palliative care at the end of life.

Early identification of patients who would benefit from this discussion is important. The continued appropriateness of shocks should be considered during the routine care of patients with implantable cardiac defibrillators, including clinic appointments with their cardiologist, routine reviews by their heart failure nurse, device checks by their cardiac physiologist and when the implantable cardiac defibrillator’s generator requires replacement because of a diminished battery. Other developments can be considered triggers for further review (Table 1).

How should deactivation of an implantable cardiac defibrillator be discussed in the elective setting?

Discussing deactivation of an implantable cardiac defibrillator with a patient should be done by a clinician with experience of this. Appropriate time should be made available for the discussion and the patient should have the opportunity to involve their next of kin. Ideally, the patient and next of kin will be aware of the eventual need for deactivation of the implantable cardiac defibrillator because this has been discussed previously, for example when the device was implanted. The clinician should be aware of the patient’s indication for the implantable cardiac defibrillator and the results of any recent implantable cardiac defibrillator checks, including appropriate therapies delivered for ventricular arrhythmia. They should also have a sufficient understanding of the recent developments leading to the discussion. Where this involves a condition outside the field of practice for the clinician, this may require discussion between disciplines.

Table 1. Potential triggers for clinicians to assess the continued appropriateness of implantable cardiac defibrillator therapy

Concern raised	Frailty	Medical
By patient	An increase in care needs	Repeated hospital admissions for a chronic, progressive disease
By carer	A significant reduction in mobility	Worsening symptoms despite treatment of a chronic, progressive disease
By another professional	A significant reduction in cognitive function	A new, life-limiting diagnosis

A clear and honest approach should be taken to the discussion, allowing time for the patient and next of kin to take information in. This discussion might come as a surprise, even where it seems obvious to the clinician, and this is often because frailty and medical comorbidity have progressed gradually. There are invariably many questions which should be addressed openly. The clinician should ask about how both the patient and the next of kin feel about these issues. This demonstrates empathy with both and allows greater involvement of all parties in the discussion.

It should be emphasised that a decision does not have to be reached immediately. It is entirely reasonable for the patient or next of kin to be allowed time to consider the issues and return for a follow-up appointment. Where, despite this, there is ongoing disagreement it is reasonable to offer the patient a second opinion. Where there is ongoing disagreement and there is felt to be a clear risk of harm to the patient, the clinician should seek to formally discuss the case with colleagues to take a consensus approach to the decision. Taking legal advice might also need consideration.

In all cases it is of paramount importance to maintain a good clinical relationship with the patient. Trust is a major part of these decisions for patients and maintaining this 'leaves the door open' for patients to express their concerns and to change their minds if needed. Techniques of verbal and non-verbal communication are key, and clinicians interested in having these discussions should consider making time to observe an experienced clinician doing this.

How should deactivation of an implantable cardiac defibrillator be discussed in the urgent care setting?

Frequently the presence of an active implantable cardiac defibrillator is not realised until a patient has entered the dying process. In such a scenario, the urgency of deactivation of the implantable cardiac defibrillator is greater because of the imminent risk of inappropriate shocks, making the discussion more challenging.

The same approach and considerations apply as in the elective setting. However, discussions around deactivation of the implantable cardiac defibrillator can also be incorporated into a patient-centred conversation encompassing the goals of care for the patient and the appropriateness of a variety of treatments during palliative care. For example, for a patient who is dying of pneumonia it is reasonable for their clinician to discuss and consider the appropriateness of ongoing antibiotics therapy, parenteral fluid administration and review of their regular medications if the new focus of care is comfort and symptomatic relief. Implantable cardiac defibrillator therapy constitutes another part of this discussion.

Particular challenges include that specialist advice may be more difficult to obtain at short notice, and the patient losing capacity leads to discussions with next of kin whose involvement with the implantable cardiac defibrillator is likely to have been more limited than the patient's. It is worth taking time to check the next of kin's understanding of the device early on and supply the necessary information. The prospect of imminent mortality understandably introduces a greater emotive element to these discussions and the next of kin may need some time to process information. Clinicians must be sensitive and sympathetic but must also balance the time taken with the increasing risk of harm to the patient over time.

Key points

- Clinicians should be aware of whether their patient's cardiac device is an implantable cardioverter defibrillator.
- Clinicians must recognise the need for discussion of deactivation of the implantable cardiac defibrillator if their patient develops a new life-limiting comorbidity.
- Clinicians should know where to locate a magnet for urgent deactivation of an implantable cardiac defibrillator.

What to do if a patient with an active implantable cardiac defibrillator is imminently dying

The most acute scenario is when an active implantable cardiac defibrillator is discovered in a patient who is expected to die imminently (within minutes to hours). There is a great urgency to deactivate the device and yet this scenario frequently occurs out of routine working hours or in the community, meaning that there is limited access to a pacing clinic capable of altering the implantable cardiac defibrillator settings. In this emergency, deactivation of the defibrillator function of the device can usually be achieved by holding a magnet over the implantable cardiac defibrillator device itself (usually palpable under the left clavicle). This will temporarily alter the device's setting to deactivate the defibrillator function and will not affect any pacing functions of the device. This change will only persist while the magnet is applied, meaning that it will need to be secured in place. This is also not a long-term solution and different devices can vary in how their settings respond. Therefore, urgent deactivation via a pacing clinic is still necessary. Clinicians must be aware of where they can find magnets in their place of work and of local provision for urgent pacing advice out of hours.

Conclusions

Implantable cardiac defibrillators are increasingly common and have improved the prognosis of patients with advanced heart failure and other arrhythmogenic conditions. However, their presence can create a risk of harm to the patient through inappropriate shocks. The defibrillator function should be reviewed when the benefit no longer outweighs the risk of harm. Clinicians should be aware of whether their patient's cardiac device is an implantable cardiac defibrillator, and should consider this when their patient suffers a new or progressive life-limiting comorbidity in order to discuss this or refer to their cardiology team. Discussions with patients and next of kin should be patient, sympathetic and honest, and implantable cardiac defibrillators should generally not be deactivated against a patient's wishes. Finally, clinicians should familiarise themselves with where to find a magnet and local provision for urgent pacing advice.

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Conflicts of interest

The authors declare no conflicts of interest.

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