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**CONSENSUS STATEMENT**

# EHRA Expert Consensus Statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy

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The purpose of this Consensus Statement is to focus on implantable cardioverter-defibrillator (ICD) deactivation in patients with irreversible or terminal illness. This statement summarizes the opinions of the Task Force members, convened by the European Heart Rhythm Association (EHRA) and the Heart Rhythm Society (HRS), based on ethical and legal principles, as well as their own clinical, scientific, and technical experience. It is directed to all healthcare professionals who treat patients with implanted ICDs, nearing end of life, in order to improve the patient dying process. This statement is not intended to recommend or promote device deactivation. Rather, the ultimate judgement regarding this procedure must be made by the patient (or in special conditions by his/her legal representative) after careful communication about the deactivation's consequences, respecting his/her autonomy and clarifying that he/she has a legal and ethical right to refuse it. Obviously, the physician asked to deactivate the ICD and the industry representative asked to assist can conscientiously object to and refuse to perform device deactivation.

**Keywords** CIED management • ICD deactivation • end of life patients

## Introduction

There is a large body of evidence demonstrating that the implantable cardioverter-defibrillator (ICD) is the treatment of choice for patients who are at risk of sudden cardiac death due to ventricular arrhythmias. Randomized prospective trials have established that the ICD is superior to antiarrhythmic drug therapy in both primary and secondary prevention. Eucomed data (http://www.eucomed.org/) indicate that in 2008, ICD use, alone or associated with cardiac resynchronization therapy (CRT), continued to grow in Europe (14% more than in 2007). Implantable cardioverter-defibrillator-implanted patients may later develop terminal illness due to worsening of their underlying heart disease or other chronic non-cardiac disease. Terminally ill patients are more likely to develop conditions such as hypoxia, sepsis, pain, heart failure, and electrolyte disturbances predisposing them to arrhythmias and thus increasing the frequency of shock therapy. Shocks can be physically painful and psychologically stressful, without prolonging a life of acceptable quality, a result which is inconsistent with comfort care goals. Therefore, it is appropriate to consider

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ICD deactivation when the patient's clinical status worsens and death is near.

Europe covers ~10 180 000 km$^2$, including ~50 states, with a population of 731 million people, ~11% of the world's population, and it is profoundly pluralistic in its traditions, cultures, faith communities, and legal systems.

The European health-care system is changing greatly, continuously challenged by several important factors. Improved diagnostic and therapeutic possibilities continue to develop, leading to an 'aging' society, with patients becoming increasingly older and affected by several chronic co-morbid conditions. As a result, as health-care professionals, we are faced with new important ethical questions about if and when to withhold questionably appropriate medical interventions or intensive treatments. Not every European country yet has national legislation covering advance directives or 'living wills', with some still debating the subject. Even in countries that do have such legislation, advance directives are open to very different interpretations and their application differs widely across Europe.

Improvement of the dying process for patients with ICDs presents unique challenges to both patients and health-care providers and is usually not an easy decision. Clinicians and patients rarely engage in discussions about ICD deactivation and most devices remain active until death.[1] Existing guidelines have focused on device indications, device implantation, and training standards, but recently attention has[2,3] turned to the technical, scientific, and ethical aspects of device deactivation or removal, especially in patients with incapacitating, irreversible, or terminal illness. It is now necessary to develop a medical, bioethical, and legal consensus for the ICD deactivation in such conditions, mindful that it is relevant to two different categories of patients: those cognitively intact and aware of the consequences and those cognitively incapacitated.

The HRS/EHRA Consensus on the monitoring of cardiovascular implantable electronic devices (CIEDs) stated that: 'The primary aim behind the rationale for deactivation must always be to respect the patient's right to live, or at least to die with dignity, while limiting any therapeutic action that increases the patient's level of stress, pain or anxiety'.[3] In addition to these crucial medical values, the EHRA Committee for ICD deactivation will follow key principles of liberal democratic societies, which include respect for the diversity of values and cultures, equal rights for all individuals, and preservation of fundamental human rights.

## End-of-life patients and palliative care

The manner in which a patient dies is often managed by doctors and nurses with family members as passive observers. Statistically, one out of three deaths is sudden and totally unexpected, but the remaining two-thirds are often preceded by a long illness trajectory and the delivery of end-of-life care. Some studies have shown that 4 out of 10 deaths have been preceded by a medical end-of-life decision that has potentially or certainly influenced the time of dying.[4]

The introduction into clinical practice of informed consent has helped to involve patients and families in the management of care. But, society remains uncomfortable with making any formal arrangement related to dying and is reluctant to conspire with patients in any way that might lead to premature death, since technical developments may greatly extend life. Consequently, about one-third of patients die in the intensive care unit (ICU) in the USA. In Europe, the situation is similar. Intensive care unit beds comprise 5% of all hospital beds, but they account for 20% of hospital costs. Moreover, the economic burden of the ICU will increase in the next years because of the use of aggressive and expensive treatments to improve the prognosis of patients with very severe clinical conditions.

Faced with this trend, in the last 20 years, many authors have reported a significant increase in the abstention or interruption of life support. This behaviour, known as therapeutic desistance, is applied in up to 65% of patients dying in the ICU. Four to 28% of patients in all care settings decline treatment prior to their death. This attitude, once controversial, has been accepted in clinical practice. It is a complex and difficult task to decide the right therapy for a dying patient. There are different approaches among health-care teams and there are even more striking differences in therapeutic desistance decisions. More importantly, in the majority of cases, such choices are made only by physicians without the involvement of patients and relatives. However, it is preferable that families also take part in end-of-life decisions. At the same time, documented choices related to resuscitation wishes should be obtained, since the period immediately preceding death is unsuitable for such discussions.[5–10]

Palliative care should be extended to non-oncology patients, such as those with refractory chronic heart failure and terminal cardiovascular disease. Often inappropriate or intensive treatment is given to patients who would greatly benefit from palliative care, i.e. 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual'.[4]

Palliative care should include:[4]

(i) care for the patient and family or closest friends;
(ii) a multi-professional team approach;
(iii) relief from pain and other distressing symptoms;
(iv) attention to emotional, spiritual, and psychological, as well as physical needs;
(v) maximizing the quality of remaining life.

Therefore, the strategies that should be followed by the whole health-care team in the end-of-life care are as follows.[11–15]

(i) To engage in a reflection about death and to be accustomed to the uncertainty of illness, so as to develop a personal approach to death and the process of dying.
(ii) To improve communication skills, emotional honesty, compassion, and listening ability.
(iii) To create an appropriate environment (including a dedicated room) where clinical information can be given to those concerned.

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(iv) To involve the whole health-care team in the process of care.
(v) To be able to express personal discomfort, to choose the tone of the communication which is preferred by the family, to understand the real needs of the patient and his/her family, and to understand when it is necessary to gather the relatives together to discuss the situation and the possibilities available to the patient.
(vi) To facilitate end-of-life care decisions, by relating to a specific family member and not leaving the burden of decisions on the patient and relatives. It is also important to provide information relating to the procedures that may be undertaken and to remind everyone of the patient's wishes.

# Basic principles

## Are cardiac rhythm management devices similar or different to other therapies?

Pacemakers and defibrillators are medical treatments and are subject to the same ethical and clinical considerations as any other treatment. However, their nature brings one to intuitively question their similarity to other therapies such as drugs or surgery. Indeed, cardiac rhythm management (CRM) devices all need to be implanted into the body of the patient which means that they are first, permanent, and second, inside the patient.[16] This prompts several questions with regard to the possibility of a different status for such devices and consequently the impact of such a status on dealing with them, particularly at a critical time in a patient's history, such as the end-of-life setting with all the adjustments that need to be made to provide optimal comfort.[17]

There are indeed several categories of devices which can be classified according to: (i) the way they are powered: semi-externally powered, such as ventilators, externally powered, such as external pacemakers, intermittently externally powered, such as some artificial hearts, and completely internally powered, such as pacemakers, ICDs, and CRT devices; (ii) the way they can be deactivated or withheld: some have an ON/OFF button or function (such as ICDs), some have a variable output, below or above the threshold for successful therapy (pacemakers), some can be influenced by changing or withholding medication (such as anticoagulants with artificial valves), and some are not adjustable (such as atrial septal closure devices).[18] This has a great impact on the ethics of deactivating such devices, the principle generally being that if the device has an ON/OFF button, then the physician has the power to withhold such treatment on the grounds of futility, even if the patient demands otherwise. On the other hand, the patient has the right to ask for deactivation of a device if it has an OFF button. In real life, however, both patients and physicians underuse the principles of autonomy and futility in such situations.[18]

One can wonder why CRM devices are seen as different from other therapies. Some hypotheses have been considered which are: the intuitive distinction between withholding and withdrawing, when ethically there is none; the possibility of it being a permanent, potentially life-sustaining therapy such as in pacemakers for patients with complete heart block and complete pacemaker dependency; its regulative or constitutive role, knowing that a regulative treatment restores homeostasis, whereas a constitutive one takes over a failing function and can therefore not be withheld without rapid consequences for the patient's health; and the fact that it is inside the body and therefore calls for the patient to have some degree of control over it.[16,19]

Some people have worked on trying to put CRM devices in intermediate categories called 'integral devices'.[17] The two extremes are the following: CRM as continuous medical interventions: this allows the physician to unilaterally decide to continue or withhold such a treatment on clinical grounds without the need for the patient's permission or request; and CRM as part of the body: it then forbids the physician to remove it even following the patient's request.

The concept of integral devices is governed as follows: the practitioner cannot unilaterally decide to deactivate an ICD and do it against the patient's will, and the patient can decide to have his/her ICD deactivated at any time even if his/her doctor believes it should not be done. It is based on the notion that the device is not considered a vital part of the patient's body *per se*. Integral devices are not organic, not part of the body, but internal, leaving more autonomy for the patient than with external devices. Finally, the last proposition is to see CRM as biofixtures.[17,20] In this model, each patient should decide whether his/her ICD is a chattel (i.e. impermanent) or a fixture (i.e. permanent) and at the time of implant should be asked to designate a status to his/her ICD, depending on his/her understanding of the device.[21]

## Are there differences in deactivation of implantable cardioverter-defibrillators and pacemakers?

Cardiac rhythm management devices, however similar in shape and means of implantation, do differ in functions, the best example being ICDs in comparison with pacemakers. Differences can also be noted within antibradycardia pacemakers, with regard to pacemaker dependency of the implanted patient. Thus, while general agreement exists that ICD deactivation in dying patients may be ethically permissible, especially if done to avoid uncomfortable shocks, less agreement exists for pacemaker deactivation.[22]

Pacing, depending on the device settings, can be an ongoing or intermittent therapy. It is not perceptible to the patient and is therefore painless.[3] Except in patients with complete pacemaker dependency, pacemakers are not life-support devices. A pacemaker, as opposed to an ICD, will not resuscitate a patient. But, by preventing symptomatic bradycardia and the subsequent failure of major organs, it will provide the patient with a better quality of life and prevent worsening heart failure, therefore meeting the goals of palliative care.[23,24] The same reasoning applies to resynchronization therapy by a biventricular pacemaker.

Discontinuation of pacing in a pacemaker-dependent patient has an almost immediate lethal consequence and bears a confounding analogy to physician-assisted suicide, thus needing due reflection and interactions with the patient and the team in charge before considering such an option.[3] Indeed, in assisted suicide and euthanasia, the cause of death is the intervention provided, prescribed, or administered by the clinician. In contrast, when a patient dies

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after a treatment is refused or withdrawn, as after pacemaker or ICD deactivation, the cause of death is generally deemed to be the underlying disease. Anyway the practices and attitudes associated with pacemaker deactivation have been shown to differ significantly from those associated with ICD deactivation[22,25,26] and there are countries where the deactivation of antibradycardia pacing in a pacemaker-dependent patient is prohibited by law. It is therefore crucial to be aware of the legal situation in the jurisdiction in which you are practising.

Deactivation of devices can be achieved in different ways by device programming.[19] Implantable cardioverter-defibrillator shock defibrillator function and antitachycardia pacing (ATP) may be deactivated through re-programming, but application of a magnet over the device will work just as well. A more passive approach is to choose not to replace a CRM device which has reached its elective replacement date. Surgical removal is not recommended as it is painful and carries potential complications that are not desirable in an end-of-life setting.[3]

In deactivating a CRM device, it is also important to consider the deactivation of the diagnostic, monitoring, and alert functions. The deactivation of such features is distinct from the deactivation of pacing and shock therapy and must be discussed with the patient beforehand.[3]

**Bullet points**

- In assisted suicide and euthanasia, the cause of death is the intervention provided, prescribed, or administered by the clinician. In contrast, when a patient dies after a treatment is refused or withdrawn, as after pacemaker or ICD deactivation, the cause of death may be deemed to be the underlying disease.
- General agreement exists that ICD deactivation in dying patients may be ethically permissible.
- The practices and attitudes associated with pacemaker deactivation differ significantly from those associated with ICD deactivation. It is therefore crucial to be aware of the legal situation in the jurisdiction in which you are practising.

## Logistics of cardiovascular implantable electronic device deactivation

According to the HRS/EHRA Expert consensus on the monitoring of CIEDs,[3] deactivation should be performed upon the express, written order of the attending physician. A previous consultation with the patient's cardiologist or electrophysiologist is necessary to establish the specific therapies that are to be deactivated and to assess the pharmacological treatment able to minimize symptoms of arrhythmias whatever the chosen setting of deactivation. The cardiologist, cardiac electrophysiologist, or their trained designee will program the ICDs in accordance with the order of the attending physician and it is recommended to add in the patient's medical record the report delivered by the programmer.

The specific clinical setting of the patient needs to be considered. If, at the time of ICD deactivation, the patient is remote from a centre with electrophysiology expertise (at home, in a smaller hospital, or in a hospice), two possible scenarios may be hypothesized. If the patients are well enough to travel to a clinic with programming capability, an outpatient visit for ICD deactivation will be arranged by the attending physician, after a consultation with the physician responsible for ICD programming. For patients who are unable to travel, the attending physician should arrange the recruitment of a professional expert trained to reprogram the device and for a programmer to be brought to the patient's bedside.

Physicians may also request industry representatives to provide the technical assistance necessary to deactivate the specific therapies, after confirmation that the request is within the company policy.[22,27] Upon the specific, written order of an attending physician and under his direct supervision, industry representatives can deactivate a device under such circumstances.

The physician asked to deactivate the ICD or the industry representative asked to assist in the deactivation may conscientiously object to and refuse to perform device deactivation in terminally ill patients. Individuals should not be compelled to participate in a clinical activity that they find morally objectionable.[19,22,28,29] If such a situation occurs, the attending physician must find another physician and another industry representative to carry out his/her request.

Deactivation cannot be regarded as a pure technical procedure, but it is to be considered within the context of a suffered choice of the patient, family members, and caregivers. Thus, at the moment of deactivation, the patient should not be left alone, and we encourage the presence of supportive individuals and even clergy, in the case that the patient is a believer and his/her religion supports his/her choice.

A specific problem is represented by those patients close to death who receive repetitive shocks in the last few days, hours, or minutes of their life,[1] inducing unnecessary discomfort without any clinical benefit. If deactivation cannot be arranged in a very short time, the application, by the attending physician, of a magnet over the ICD will temporarily suspend antitachycardia therapies while not disabling antibradycardia pacing. In a few devices of older generations, this procedure may be less simple.

**Bullet points**

- Deactivation, once the patient's consent is obtained, should be performed upon the express, written order of the attending physician.
- The patient's specific clinical situation should be considered.
- At the moment of deactivation, the presence of supportive individuals should be encouraged.
- The physician asked to deactivate the ICD and the industry representative asked to assist in the deactivation may conscientiously object to and refuse to perform device deactivation in terminally ill patients. In such situations, an alternative physician or industry representative must be found to carry out the patient's request.

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## Modes of deactivation

In order to prevent painful CIED therapy, it is usually sufficient to deactivate the shock function of the device. This may be achieved by completely deactivating all tachycardia functions (detection and treatment) or programming the device to 'monitoring only' or deactivating only shock therapy while maintaining ATP therapy.

In patients with terminal, untreatable heart failure as the cause of imminent death, it may be reasonable to deactivate all anti-tachycardia therapies, i.e. shocks and ATP, since any fast ventricular tachycardia (VT) or ventricular fibrillation may lead to sudden death without prolonged suffering. However, in patients who are in a stable cardiac situation, and in patients with slow VT (100–160 b.p.m.), VT may not lead to death but to severe or aggravated symptoms. In these cases, the deactivation of shock therapy alone while maintaining ATP may be preferable. Patients should be informed that the rates of VT acceleration by ATP are between 2 and 4%.[30]

It should be emphasized that the deactivation of antibradycardia pacing functions in ICDs is usually not an option at a patient's end of life since: in patients with sinus node disease or complete AV block, such low pacing rates might only add the symptoms of bradycardia without significantly affecting the duration of survival, i.e. the patient may survive as long but with a lower quality of life.

In patients with devices capable of CRT, severe heart failure is usually present at the time of terminal illness. Cardiac resynchronization therapy is primarily used as a symptomatic treatment in this situation and therefore should generally not be withdrawn. It is not evident in this situation that the deactivation of CRT has any immediate or mid-term effect on the duration of the patient's terminal illness, but there is a risk that the patient's quality of life may significantly deteriorate.

# Ethical and legal principles

Contemporary medical ethics embraces a commitment to key principles of liberal democratic societies. These principles include:

(i) respect for diversity of values and cultures;
(ii) rights for all individuals to be considered as of equal worth;
(iii) protection of fundamental human rights.

In some aspects of health care, upholding these values can prove difficult, for example, where there is an apparent conflict between protecting a patient's welfare and respecting his/her autonomy. It is incumbent on health-care professionals to ground their work in ethically defensible practices. The possible deactivation of ICDs raises particularly testing ethical problems.

Even patients who have decision-making capacity ('autonomous patients') do not have an unqualified right to demand that their physicians provide any service or treatment. When making positive demands to physicians, the concept of clinical need or appropriateness is of great importance. A patient's right to health care is based on its being good or worthwhile health care, as judged by a professional with appropriate expertise.

However, the professional judgement that an intervention is clinically mandated does not by itself provide sufficient reason to justify its instigation or continuation. Even a bona fide concern for a patient's welfare cannot support a decision to ignore an autonomous patient's competent refusal of consent. This means that a patient may refuse the replacement of an ICD or make a legitimate request for the device's deactivation.

With regard to patients' decisions concerning ICDs, there are further good reasons to be doubtful that there is a single right answer about what is the proper action in any case. Individual patients' preferences have been shown to vary widely, making 'second-guessing' a dubious exercise. This means that simply attempting to predict patients' preferences is unacceptable.

However, in terminally ill patients at the very end of life, the continued functioning of an ICD raises particular problems, as futile defibrillation is distressing both for the patient and for his/her loved ones. A doctor is in the position to decide that external defibrillation would be clinically futile, and thus ought not to be given.

For the terminally ill patient with decision-making capacity, therefore, it is crucially important that a physician responsible for the patient's care engage in a timely discussion with the patient concerning deactivation of the ICD. This will allow the patient to understand how a failure to deactivate can lead to unnecessarily distressing death. The patient must receive proper support to help guide him/her through the decision-making process. As deactivation might not have been discussed at the time of implantation, it is important that the issue be raised sensitively and at an appropriate time with a patient who is reaching the end of life.

Patients who are found to be lacking decision-making capacity are in need of a surrogate decision-making process. This need is carried out by two prevailing norms: substituted judgement (aiming at depicting what the patient would have wished for) and/or the patient's best interest (what decision best promotes the patient's overall interests in their expanded meaning, and not merely relating to physical existence). You must be aware of the relevant legal position in the jurisdiction where you are practising. Where possible, it is crucial that these treatment decisions be informed by investigation of, and reference to, the patient's own currently or previously expressed thoughts and wishes. If it is not possible to ask the patient, for example, because of unconsciousness, discussions with family, loved ones, and members of the health-care team may help establish his/her perspective.

Although deactivation may seem a purely clinical question and may hinge on purely clinical considerations, the peculiar nature of ICDs—i.e. their status as integral devices—makes their governance an ethically more complex issue. Rather, careful communication about the need to deactivate an ICD in a patient who is nearing the end of life, conducted in a timely and sensitive manner, should be the standard practice. Equally, a decision to deactivate an ICD in a patient who lacks decision-making capacity should be carefully reached, without prejudice against the patient, and with due regard to his/her loved ones and the concerns that they might have.

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**Bullet points**

- Careful communication about the need to deactivate an ICD in a patient who is nearing the end of life, conducted in a timely and sensitive manner, should be the standard practice.
- The decision to deactivate ICDs should be part of a well-deliberated and transparent process.
- Ethical and legal guidance should be readily available to counsel and support these difficult decisions.
- All patients, whether they have capacity or not, are due equal concern and respect.
- Any ICD placement should be accompanied by a detailed and documented deliberation, in which competent patients should state their preferences as to the ways to handle possible future eventualities, including end-of-life issues.
- For patients without capacity, proxies for end-of-life decisions should be sought (in jurisdictions where such procedure is legally accepted). Where this is not legally accepted, decision-making for patients without capacity must be made in accordance with legal requirements for such decision-making.

# Special populations: paediatrics

It may be presumed that children lack autonomy, and thus decision-making capacity, but it is crucial that each case be tested on its merits. A child may have such capacity, and even if not, his/her views may still bear importantly on decisions. Child patients must receive the same concern and respect that is due to adults. In the case of decision-making for minors, the best interest test is most widely used. This is partly because these individuals may not have formed a binding decision about their preferences. The best interest test is usually oriented to protect the physical well-being of such minors, but it is appropriate also to consider the patient's values and overall interests where possible. You must be aware of the law concerning decision-making by or on behalf of minors in the jurisdiction in which you are practising.

The state has a legitimate role in protecting the welfare of children, which may include placing limits on parents' freedom to make health-care decisions on behalf of their children. Where there is a risk of great harm to a child's welfare, courts have set aside parents' refusals of interventions, even where these refusals have been based on deep-seated religious or moral views. Nevertheless, in appropriate circumstances, and where the continued treatment of minors might cause severe pain and suffering, courts have accepted parental refusal of treatment or ordered its withdrawal.

Mature minors, even if they are under the legal age (a matter that you must be aware of in the jurisdiction where you are practising), are gradually granted decisional rights. This in turn may indicate the need to provide these minors a right to be heard, and a reciprocal obligation to respect their articulated wishes in appropriate circumstances. Although age may serve as an indicator of increased capacity, it is crucial to understand that a young child may have capacity, and an older child may not. Each case must be assessed on its individual merits.

**Bullet points**

- Unless medically indicated, requests for the deactivation of an ICD in minors should be subject to strict scrutiny.
- The best interest of minors should be directed primarily towards their physical well-being. As such, it will be rare to find that the deactivation of an ICD is indicated unless failure to deactivate is likely to cause pain and suffering.
- Mature terminally ill minor patients (judged individually, according to decision-making capacity) should be given due chances to articulate their own wishes, in a supportive and sincere environment.
- The process of accepting a request for the deactivation of an ICD from parents or mature minors must be supported by professionals with paediatric expertise (paediatric electrophysiologists, psychologists, social workers, palliative care physicians, etc.).
- Practitioners must be aware of the legal requirements in their local jurisdiction regarding the legal situation concerning decision-making for minors.

# Making the process work: communication

## Communicating with the patient and family

**Information provided to the patient, what and when**

Discussion with the patient and family about potential situations where consideration might be given to the deactivation of the device should begin prior to implantation. Indeed, device deactivation options should be included in the order of pre-implantation informed consent. Anyway, it is important to raise this issue early and preferably when the patient is in a stable clinical condition. The discussion should be initiated by the physician and questions from the patient and family should be encouraged. This will to some extent prepare the patient for further discussion of the topic if necessary at a later point.[25] Discussions with physicians about their experience with device deactivation indicate that patients may be reluctant to discuss this topic even when they have advanced disease.[31] A survey of next of kin has suggested that doctors rarely discuss deactivating ICDs with patients.[1] Most of the discussions which take place occur in the last few days of life. There are data, however, to suggest that in cases when physicians have knowledge of the legality of CIED deactivation, most would be willing to discuss this possibility with their patients.[26] Although it is important to discuss the topic of possible deactivation, care also needs to be taken to avoid painting too dark of a picture of this possible scenario.

At each visit to a device clinic after implant, the patient should be asked about any changes in his/her general health, cardiovascular, and otherwise.[32] New diagnoses and worsening of previously known conditions should be noted. Additionally, patients should be advised to have their cardiologist/electrophysiologist informed about significant changes in their health status. The physician

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might even, in the event of such a change, advise the patient of the right time to consider the deactivation of the device.[32]

When there is a significant deterioration of health status in a CIED patient, a decision may be made to *not resuscitate* (DNR order) or to provide palliative care only. It is imperative at this stage to discuss deactivation of the device. In such cases, it would have been beneficial if the physicians and patient have previously discussed the possibility of deactivation, e.g. at the implantation of the device. The medico-legal aspect of device deactivation needs to be considered in each case. A careful documentation of the reasons for deactivation in the patient medical records is important.

**Bullet points**

- Device deactivation options should be included in the order of pre-implantation informed consent.
- At the time of implantation of an ICD/CRT-D, the possibility that the patient's health may deteriorate to such an extent that device deactivation may be appropriate should be discussed.
- In the event of the patient having a DNR order or receiving palliative care, a discussion about device deactivation should be undertaken at the same time. At the least, the deactivation of shock therapy should be suggested.
- The physician following the patients with a CIED should ask about significant changes in the patients' health at each clinic visit and ask to be informed of significant new diagnoses.

## The conversation with the patient

### Importance of a team approach

As the number of patients with implantable devices is increasing exponentially and on account of a growing number of patients implanted prophylactically without having arrhythmias, the role of the electrophysiologist or device specialist as the patient's main caregiver is decreasing. Most device clinics are very busy with most of the routine work done by technicians and very little time for the physician to take care of issues other than device-related problems. Follow-up is therefore shifted to the general cardiologist, internist, or family physician. The electrophysiologist or the device specialist may not be aware of potentially terminal diseases until a relatively late stage; thus, the role of the other caregivers is becoming critical. Therefore, a team effort should be initiated when the patient is diagnosed as having an irreversible terminal illness.

According to the personal relationship with the patient, the team member closest to him/her should usually be the one who initiates discussion about device deactivation with the patient and his relatives.

When the physician leads a conversation with the patient about deactivating the ICD, it may be helpful for the patient to have a family member present. It has to be documented in the file if the patient is—in the opinion of the physician—able to understand the discussion and emotionally able to make a decision, and that he/she is legally competent. During the conversation, it should be evaluated whether the patient suffers from a depression that would explain an inappropriate desire to deactivate all device functions and that may distort his/her judgement. In patients with signs of suspected or overt depression, a psychiatrist should be consulted to clarify this issue. Patients should be provided the religious support they ask for and need in order to make choices based on their own religious traditions, deepest convictions, and best judgements.

Physicians should be aware that patients may have a great amount of anxiety about receiving painful shock therapy but, on the other hand, may refuse to even talk about ICD deactivation. They may even regard this as an 'act of suicide' since the goal of ICD therapy has initially been explained to them as a treatment that saves their life.[21] Therefore, it should be explained to the patient that his/her survival time is limited by the terminal disease itself and that thus withdrawal of ICD shock therapy is both legal and ethical, and not directed towards life-shortening.[19] This may be explained by analogy with the decision not to perform cardiopulmonary resuscitation in a terminally ill patient.[33]

If the patient has not yet received an ICD shock, an attempt should be made to explain how it can adversely affect quality of life. Different modes of deactivation, shock therapy alone, deactivation of all antitachycardia treatments, antibradycardia pacing, and CRT, should be explained to the patient and every effort should be made to confirm that these differences are fully understood.

The physician should not persuade the patient to reach a particular decision. He/she may express his/her professional opinion as a doctor who, in contrast to patients, is more likely to have been confronted with this situation before. The physician must be aware that the patient's decision may differ from his or her and that the patient may have a desire to maintain all ICD therapies which may seem inappropriate to the physician.[34] The refusal of the patient should be included in the patient's medical report, but the patient should be informed that he/she can always reconsider his/her decision.

The decision to have the device deactivated can be difficult for the patient, who should be provided with sufficient time to think about the issue and to discuss it with his/her relatives. Consideration should be given to offering the patient psychological counselling.

The results of the discussion should be documented. A copy of the signed consent for deactivation must be included in the patient medical report. The patient should be informed that after device deactivation, he/she can always reconsider his/her decision and that it is possible to re-activate all device functions.

**Bullet points**

- A team effort should be initiated when the patient is diagnosed as having an irreversible terminal illness.
- Different modes of deactivation should be fully understood by the patient.
- When discussing deactivation with dying patients, one should respect their autonomy and clarify that they have a legal and ethical right to refuse it.
- Patients should be informed that after device deactivation, they can always reconsider their decision and that it is possible to re-activate all device functions.
- A copy of the signed consent for deactivation must be included in the patient medical report.

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# A multilevel communication

## Importance of the family and shared decision-making

Patients at advanced stages of terminal diseases tend to lose their desire to control the situation and rely more on loved ones and on caregivers in reaching critical decisions. The family's role may be critical in helping the patients organize their thoughts and reach decisions.

Another role of the family is in situations where the patient is cognitively incapacitated, and there is no pre-existing advance directive. After having an official expert opinion on a patient's inability to make decisions, we often have to rely on the family in trying to understand a patient's previous will and attitudes towards withdrawal of life-sustaining therapies, and what constitutes appropriate treatment when approaching the end of life. However, given potential conflicts of interest and lack of agreement between family members, in such cases, a decision made only by family should be supported by an Ethics Committee's approval whenever such committees are instituted.

A potentially problematic situation may arise when disagreement exists between an incapacitated patient's will, expressed a long time prior to his/her current illness, and a different approach perceived by the family to more accurately represent the current approach of the patient. Such situations should be resolved by an Ethics Committee decision, where required, or even a court of law, according to the different jurisdictions. The patient's will always have priority over the family's request.

Whenever applicable, there should be a detailed documentation of the discussion with family, including detailed explanation of prognosis, the potential harm of the device in the dying patient, the fact that the disease rather than turning off the device will be deemed the cause of death, and their approach (as well as their perception of the patient's approach) to device deactivation.[35]

After reaching a decision to deactivate a device, family members should preferably be present during the process of device inactivation, with the patient's consent/agreement.[35]

## When to consult the Ethics Committee or even a court of law

It is clear that a cognitively competent patient who wishes to have ICD therapies turned off to prevent further suffering is entitled to have this done.

When a patient has previously given a directive in the form of DNR or DNAR, it has to be confirmed and verified with the patient that this directive includes ICD deactivation. Once this agreement has been reached, there is no obstacle to the deactivation of the device.

A problem may arise when one of the following situations exists, which may warrant the need to consult the Ethics Committee or even a court of law.

(i) An incapacitated patient without a living will referring to end-of-life situations whose family is unclear or not in agreement regarding the patient's approach to such a situation.

(ii) When a family presents an approach that seems to deviate from the original approach of the patient or his/her initial directive.

(iii) Unclear cognitive state following psychiatric consultation.

# Education

Although guidelines for the appropriate use of CIEDs are readily available, there is a lack of medical and legal knowledge among health-care professionals regarding CIED therapy in terminally ill patients. It has been shown that more than half of primary care physicians are not aware that unlike pacing the ICD shock is painful to the patients,[25] and many doctors and patients do not know that it is possible to avoid unnecessary pain in dying patients by deactivating the defibrillator function of the ICD. Furthermore, according to a recent survey, nearly 50% of the physicians who were not cardiologists or electrophysiologists were uncertain about the legality of withdrawing ICD therapy in patients who are reaching the end of their life.[26] Awareness of these issues highlights the need for multidisciplinary educational activities regarding CIED therapy in terminally ill patients and discussions should be promoted by educational activities by EHRA and national societies aimed towards general cardiologists, internists, family physicians, and palliative medicine specialists, as well as towards device specialists.

The key to any change of practice is ongoing medical, psychological, social, legal, and ethical education of all health professionals involved in the care of patients with CIEDs (e.g. various specialists, general physicians, fellows, and nurses), industry representatives, and the patients and their families. Apart from the above considerations, cultural and religious differences must also be taken into account when planning educational activities for health-care providers, and the patients and their relatives.

In the context of rapidly advancing medical technology, which may be inadequately understood by the patients and their primary care providers, the implanting physicians and the physicians in the device follow-up clinic have a key role in providing practical advice on CIED therapy. They have the responsibility to educate referring physicians and patients and their families on the effectiveness, burdens, and benefits ratios of device therapy. Other parties that have specific responsibilities include patient associations, the device manufacturers, and regulatory agencies. The responsibilities of the device manufacturers have long been debated. Communication with them must occur at some point, but they cannot be the main provider of educational information. All educational material should be made readily available, e.g. through the Internet, and it should be translated into local languages.

The decision to deactivate CIEDs, even after clear instructions from patients who are competent to decide, is known to create anguish among the therapy providers. Therefore, continuing postgraduate education opportunities focused on end-of-life care should be made available to practising physicians, regardless of their specialism. Trainees should be actively encouraged to participate in the conversations with terminally ill patients and other clinicians.

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## American perspective

The use of implantable cardiac electronic devices in the USA continues to grow. On the basis of expanding indications for ICDs and devices providing CRT,[36] over 10 000 devices per month are entered in the US ACC NCDR ICD Registry.[37] Although ICDs are effective at prevention of sudden arrhythmic death, patients will eventually develop other terminal illnesses, whether due to their underlying heart disease or other disease. As the end of life nears, painful shocks received from an ICD create an unnecessary burden in the dying patient. The US palliative care literature is ripe with editorials with titles such as 'Dying and defibrillation, a shocking experience'[32] and 'And it can go on and on and on.'[38] All describe patients receiving multiple shocks shortly before death, many in the hospice setting, to the great distress of the patient and the family. In a recent survey of next of kin of defibrillator patients who had died from a single US ICD clinic, over one-quarter had received a shock in the last month of their lives, including eight who received shocks in the last minutes.[1] Although pacemaker therapy does not induce pain, nonetheless patients may feel that pacing is an unwanted burden as the end of their life nears. Thus, an awareness of the principles underlying the concept of deactivation of CIEDs, as well as of the importance of communication between physician and patients and families of the option of deactivation, is imperative to prevent undue burden of these devices on dying patients.

Like Europe, the USA has a population of diverse cultural and religious traditions, which may have varying views of the dying process. Unlike Europe, however, the USA has a federal legal system, with laws made by a single bicameral legislative system and interpreted by a single judicial system, led by the US Supreme Court. In US law, the concept of informed consent is considered a most important legal doctrine, with its corollary right to refuse treatment. The US Supreme Court has consistently upheld the right of the patient to refuse treatment, even in cases such as a ventilator, in which death would be near-instantaneous, or of a feeding tube. Because many patients may long be mentally competent to make decisions as they become terminally ill, in every state in the USA, individuals have a right to name a health-care proxy who will make decisions for them should they become unable. Because these legal principles apply to the patient, and not to a specific therapy, patients (or their surrogates) have a right to request withdrawal of CIED therapy.[39]

Among US ethicists, the ethical concept of autonomy leads to the conclusion that device deactivation upon the request of a patient is ethical as well.[22,40] On the basis of this principle of autonomy, the American Medical Association code of ethics obligates clinicians to inform patients of all treatment options as well as the right to refuse treatment.[41] Further, the ethical concept of beneficence requires that clinicians attempt to minimize discomfort, which includes removal of treatments that a patient may find burdensome.[22,40] Burden is defined by the patient, thus pacemaker deactivation can also be requested, although a clinician may see pacing as non-burdensome. Because the deactivation of a pacemaker allows the patient to die of an underlying pathology without the introduction of new pathology, ethically, it is not considered physician-assisted suicide or euthanasia, provided that the intent of the clinician is to remove the burden. US law, as well as ethics, does also recognize the right of an individual health-care provider to refuse to perform device deactivation if this is contrary to personally held beliefs, but does mandate that a treating physician aid a patient in finding another physician to carry out his/her request.

Although most US device-physicians have been involved in device deactivations, studies show that few patients with CIEDs discuss device deactivation with their doctors.[1] It is vital that physicians be pro-active in discussing the option of deactivation for CIED patients, from briefly letting them know that this is available at the time of implant, to more detailed discussions as the clinical situation changes and the patient's overall goals for care may change as well.

In summary, in the USA, both legal doctrine and ethical consensus support the right of a patient to request the deactivation of a CIED, and the obligation of a physician to perform this (or aid in finding a physician who will). Although communication in the USA between health-care providers and patients surrounding the management of CIEDs at the end-of-life is so far suboptimal, it is the hope that documents such as this and the US counterpart will raise awareness about this important issue.

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