

# Dying with a Cardiac Device.

Pacemakers and defibrillators are designed to restore or maintain a rhythm and rate sufficient to meet metabolic needs, i.e. TO KEEP PEOPLE ALIVE.

Instead of dying from heart rhythm problems, these patients are now living long enough to be affected by other life-threatening illnesses such as cancer, lung disease and heart failure.

To provide appropriate support to their patients, all cardiac physiologists need a basic knowledge, and the ability to facilitate appropriate conversations about palliative care issues.

## Pacemaker patients:

One of the first questions many pacemaker patients often ask is “how will I die when I need to?” or they will state “I don’t want to live forever”. Fortunately, pacemakers (and the pacing component of defibrillators) are not generally a problem for the palliative care patient.

A good way to explain this is to use an analogy – here are 3 to choose from:

1. A pacemaker is really just **an alarm clock** for the heart. Its job is to make sure that the heart wakes up when it is time for it to beat. If you are extremely sick (and especially if you have stopped breathing) you won’t wake up when your alarm clock goes off. Similarly, when a patient is dying, their heart will eventually stop responding to the pacemaker. The pacemaker will keep trying to wake up the heart, but the heart will just ignore it.
2. A pacemaker **is not an engine replacement**. It is more like getting a new **starter motor** – fixing one component doesn’t mean that other bits won’t wear out. There are a whole lot of other things that can stop a car, and despite being cured of your slow heart rate there are still a whole lot of other possible problems that could do you in.
3. Imagine that the pacemaker is **a conductor**, and the heart is **the orchestra**. If the orchestra ignores the conductor (or if the orchestra is dead) then there is no music, regardless of how much he waves at them.



C3PO Conducting John William's Star Wars with the London Symphony Orchestra at the Royal Albert Hall, 1978

**In almost all scenarios the goal of a peaceful death in a medically and ethically appropriate timeframe does not require any changes to pacemaker programming.** In fact, turning off a pacemaker can actually make the quality of a patient's death considerably worse. There is no guarantee that it will hurry the process, and it may even add unnecessary suffering (such as confusion or shortness of breath).

### Defibrillator patients:

Unlike pacemakers, a defibrillator is very likely to cause harm to a palliative patient, and it is strongly recommended that they are reprogrammed to turn off shocks prior to death.

**Without reprogramming, a defibrillator can easily turn a peaceful death into a painful one.** Approximately 1 in 5 patients will experience tachyarrhythmias in the last weeks of their life, and a shock is traumatic to both the patient and their loved ones. As soon as it is not in the patient's best interests to be resuscitated it is time to discuss turning off shock therapy to increase the chances of a more peaceful death when the time comes.

If a cardiac device specialist is not immediately available, shocks can be prevented by taping a magnet to the patient's skin directly over their defibrillator.

### Patient education:

It is recommended that end-of-life issues are included in the initial education that cardiac device patients receive, *at the time of implant*, when the focus is on living. It is my experience that defibrillator patients are happy to hear that they will remain in charge of their own decision whether or not to be resuscitated, and they appreciate knowing that the device's settings are easy to adjust

(surgical removal is not required). They say “that’s good to know”. Understanding that it is a routine part of our job (and not a taboo) makes it easier for them to raise the issue down the track.

When more detailed information is required, I recommend the “End of Life and Heart Rhythm Devices” information sheet from [www.hrsonline.org/Patient-Resources/Patient-Information-Sheets](http://www.hrsonline.org/Patient-Resources/Patient-Information-Sheets))

## Ethical and legal issues:

So long as a patient is mentally competent to make legal choices regarding their own care, they are perfectly entitled to request that their pacemaker or defibrillator is turned off, even if they are not currently in palliative care. In legal terms, this is no different to a patient making the decision to stop dialysis, or to refuse surgery - even if that decision results in death.

The cardiac physiologist is legally protected in this situation if we follow protocol.

Our role is firstly to provide education, and to facilitate appropriate conversations. We cannot carry out a patient’s decision to turn off a pacemaker or to disarm a defibrillator without involving a cardiologist. It is the job of our supervising cardiologist and patient’s other physicians to be involved, to ensure that actions are appropriate, and to take clinical and legal responsibility for the outcome.

If the patient dies as a result of formally requested programming, it is technically not euthanasia because what killed them was the underlying disease. Having said that, if we are not personally comfortable with carrying out programming requested, then we are legally allowed to decline, and to pass the referral on to someone else. The guidelines state that we have the right to refuse, and we cannot be penalised.

## Each situation is unique:

I attended a nursing home to disarm an elderly patient’s defibrillator at the request of his physician (after confirming the request with my supervising cardiologist). Death was expected to occur within days. When I told him why I was there he stated that he did not want to die and started to cry. I did not perform the programming, documented the discussion, left my mobile number, and gave written instructions to the nursing staff re how to use a magnet. He passed away as expected, fortunately without incident.

Another patient facing imminent death told his cardiologist that he wanted shocks to remain on until he’d had the chance to say goodbye to family members who were gathering from interstate. He was discharged home. We arranged for the palliative care staff to provide a magnet during a home visit a few weeks later when he was actively dying.

A dependant pacemaker patient facing progressive dementia asked me about dying on her own terms before her condition worsens. I listened actively and provided the appropriate patient information sheet, plus the cover page of the full Heart Rhythm Society guideline’s document so that she and her husband would know what references to look up to be fully informed. I encouraged her to talk to her GP and to show him the references. I will deflect further discussion to my supervising cardiologist.

When attending palliative patients, I now carry 2 copies of the relevant patient information sheet with me: one for the attending staff and one for the patient and family. I insist on having a written referral, and I take time to explain. If I’m not comfortable, I don’t do it.

I have yet to turn off a pacemaker on a dependant patient, and would only do it if extensive consultation had taken place and only if I felt personally comfortable.

## Recommendations:

Take the time to read the full Heart Rhythm Society [guidelines document](#). It is a collaboration between multiple organisations and provides extremely thorough discussion of all the ethical and legal issues involved. It is extremely well written, was re-endorsed this year, and addresses the needs of the patient, and the needs of the professionals who care for them.

Be calm talking about death and be approachable. Patients should feel comfortable asking questions, and have an established relationship of trust with clinic staff.

Have education material on hand in the cardiac device clinic (I recommend the “End of Life and Heart Rhythm Devices” information sheet from [www.hrsonline.org/Patient-Resources/Patient-Information-Sheets](http://www.hrsonline.org/Patient-Resources/Patient-Information-Sheets)).

## References:

Lampert R, Hayes DL, Annas GJ, Farley MA, Goldstein NE, Hamilton RM, et al. American College of Cardiology; American Geriatrics Society; American Academy of Hospice and Palliative Medicine, American Heart Association; Hospice and Palliative Nurses Association. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm*. 2010;7(7):1008–1026.

“End of Life and Heart Rhythm Devices” information sheet from [www.hrsonline.org/Patient-Resources/Patient-Information-Sheets](http://www.hrsonline.org/Patient-Resources/Patient-Information-Sheets))