

End of Life and Heart Rhythm Devices

How do I handle death and dying issues with my implantable cardioverter defibrillator (ICD) or cardiac pacemaker?

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Implantable cardiac defibrillators (ICDs) and pacemakers improve quality of life and may prevent premature death for people with certain irregular heart rhythms. There are times, such as when life is nearing its end, when patients may no longer desire these heart therapies. Patients and families may wish to have their cardiac devices turned off.

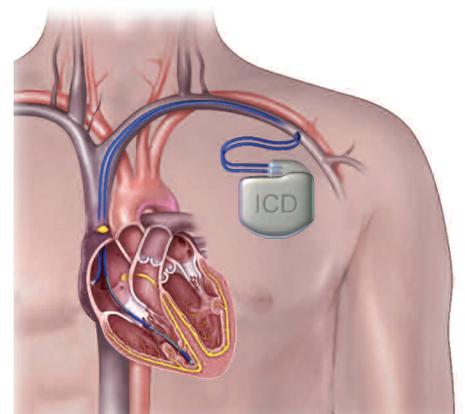
The purpose of this document is to provide you with some information about the pros and cons of turning off your ICD or pacemaker if you have been informed by your doctor that you, or your loved one, have a terminal illness or are nearing the end of life. The value of thinking about this issue is to seek a more peaceful death for you or your

family member. It is often easier to have thought about the issue in advance, so that when the time comes, patients know it is an option, and families know the wishes of their loved ones.

How do ICDs and pacemakers work?

The pattern of heartbeats is known as the heart rhythm. ICDs and pacemakers are medical devices that treat irregular heart rhythms (also known as arrhythmias). ICDs and pacemakers consist of a battery connected to wires, which are threaded through blood vessels and attached to the heart.

ICDs are used to treat dangerously fast heart rhythms. This type of arrhythmia can cause a severe decrease in the heart's ability to



pump blood and can cause “sudden death”. ICDs have the ability to check the heart rhythm, detect these dangerous heart rhythms, and deliver a shock to stop them. Although some people who have an ICD never experience a shock, patients who are shocked commonly describe the sensation as a painful “kick in the chest” or spasm of the body. While these

shocks are lifesaving, they can cause physical and emotional pain to a patient and his loved ones.

Pacemakers are used to treat slow heart rhythms. Slow heart rhythms can make it difficult to lead an active life. By using a small amount of energy, pacemakers stimulate the heart to beat at a normal rate. They improve quality of life and may increase longevity as well. For some patients, pacing both ventricles can also decrease symptoms of heart failure, such as shortness of breath. Pacing both ventricles is called “cardiac resynchronization therapy or biventricular pacing”.



ICDs and pacemakers have helped people live longer. Instead of dying from heart rhythm problems, these patients are now dying from other

illnesses such as cancer, lung disease, or heart failure. Heart failure is a condition in which the heart muscle becomes weak, and the heart is no longer able to pump blood well. This is the most common reason to get an ICD. While the ICD will prevent you from dying from a dangerously fast heart rhythm, it will not stop you from dying from your terminal illness, including heart failure.

Why would I want to turn off my ICD or pacemaker?

Patients may reach a point in their lives when their goal of care is to be comfortable during their remaining time. Terminally ill patients often have discussions with their primary care doctors regarding end of life issues. Sometimes, this discussion simply results in changing your care plan to “allow nature to take its course.” Managing your ICD and/or pacemaker during these times is important to ensure you don’t receive treatment that is not in accordance with your wishes. It is also important that your family know your wishes so they know what you would want if you reach a point that you cannot make decisions for yourself.

When would I consider turning off my ICD?

The ICD is programmed to prevent death from dangerously fast heart rhythms and will correct these

rhythms using shocks. Unlike a pacemaker which causes no pain, an ICD may cause significant pain when it shocks the heart back to a normal rhythm. Studies have shown that about 1 in 5 people with an ICD experience painful shocks, which they or their family find troublesome in the last weeks of their lives. It is for this reason that patients nearing the end of their lives may request that their ICD be turned off. It is important to understand some facts about turning off your ICD:

- Although every ICD has a built-in pacemaker, the shocking action of the ICD can be turned off and pacemaker function can remain on.
- “Biventricular pacing”, a treatment to improve heart failure symptoms, can be left on even if the shocking action is turned off.
- Turning off the ICD will not cause immediate death.
- Turning off the ICD will not be painful, nor will a patient’s death be more painful if it is turned off.
- Turning off the ICD will mean that the device will not prevent sudden death in the event of a dangerously rapid heart rhythm.
- It is not legally or morally wrong to stop any medical treatment if it

no longer serves you or your loved ones' purposes. Turning off an ICD is not suicide or killing someone. It simply means that when the symptoms of heart failure or other terminal illnesses can no longer be managed, you will allow nature to take its course.

- Although it is legal for physicians to turn off devices, some physicians may be reluctant or simply refuse to do so, on the basis of their personal beliefs. If that is the case, and turning off the ICD is what you desire, you may request a referral to another physician who will comply with this request.

When would I consider turning off my cardiac pacemaker?

Turning off a pacemaker is also possible, although the issues are somewhat different than turning off an ICD, as a pacemaker does not cause pain and may actually make the patient more comfortable. When a pacemaker is turned off, the blood supply to the body is reduced, which can make a patient feel considerably worse. Even if the goal is to avoid unwanted prolongation of life, turning off a pacemaker may not accomplish this. In addition, the consequences of turning off a pacemaker are different for each person. It is very important to discuss with your doctor whether turning off a pacemaker

goes along with your health care goals and how your daily quality of life could be affected.

Will the pacemaker keep my heart beating forever?

This is a common misunderstanding. A pacemaker does not actually beat for the heart, but delivers energy to stimulate the heart muscle to beat. Once someone stops breathing, his body can no longer get oxygen and the heart muscle will die and stop beating, even with a pacemaker. Therefore, the pacemaker will not prevent death and a patient will die from his terminal illness without turning off the pacemaker.

What are the key facts for me and my family about death and dying with a cardiac device?

You as the patient or the health care proxy have the right to decide whether to stop treatment with an ICD or pacemaker. Every person and situation is different. Your electrophysiologist and primary care physician who have treated you or your loved one should know your situation well, answer any questions you have, and help you in your decision-making.

There is a difference between stopping an ICD's shock and pacing functions. You have the option to turn off the ICD's ability to shock

You Should Know

Turning off an ICD is not difficult or time consuming. It is not a surgical operation and does not cause any discomfort. The ICD is turned off using the same programmer that your doctors use to talk to your ICD. Your cardiologist or electrophysiologist may do this themselves. Sometimes your doctor may request that a clinic nurse or representative from the device company perform this function.

your heart but keep the pacing function on. In this case, if you have a life-threatening arrhythmia, your heart will not be shocked back to a normal rhythm. The continued pacing of the ICD should help your blood flow to your body, which may positively affect how you feel. If you decide to turn off the pacing function, your health and quality of life may be affected by a slow heart rhythm.

You can request that an ICD be deactivated at any time. However, there are certain times when many patients begin to seriously consider this option:

- Has your doctor indicated that you are not likely to live more than 6 months in your current condition?

- Has your quality of life changed in a way that you no longer need or want the ICD to deliver a shock in the event of a dangerously fast heart rhythm?
- Have you or your family expressed fear or distress over the type of care that you would receive at the end of life?
- Have you reached a point in your life where dying suddenly from a lethal heart rhythm would be as good a way for your life to end as any other?
- If you are in the dying process, would it be better to avoid the risk of being shocked repeatedly without significantly prolonging your life?

If you answered “yes” to any of these questions, it is reasonable for you to talk with your health care providers about making changes to your care plan to respect your wishes. You should always feel free to talk to your doctors about your health goals and any concerns or questions you have about your ICD.



Summary and Conclusions

Achieving a more peaceful death is a valuable goal for you, your family, and your health care team. The question of whether to have your (or your loved one’s) ICD or pacemaker turned off is not a simple one. The answer depends on whether or not having the ICD or pacemaker turned off meet your needs (or your loved one’s wishes, if you are the health care proxy).

Your medical providers want to help you make the decision that suits you or your loved one best. Whatever you decide, they will do everything possible to keep you or your loved one feeling as comfortable as possible, and protect you or them from suffering. Please consider this infor-

mation, and feel free to ask your medical providers any additional questions that you might have.

One way to remember the important steps involved in any significant medical decision is the following memory device:

- N**otify your loved ones of your wishes and document them
- E**ducate yourself about treatment options
- E**valuate all of your treatment options
- D**iscuss your preferences and consider palliative care
- S**eek mental and spiritual health care to aid you in this difficult time.