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Planning ahead: End-of-life decisions for patients with defibrillators

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1 INTRODUCTION

Implantable cardioverter defibrillators (ICDs) and cardiac resynchronization therapy devices with defibrillators (CRT-D) are two types of cardiovascular implantable electronic devices. ICDs check your heart rhythm. CRT-Ds are like ICDs, but also help the heart to pump blood more effectively. These devices provide a shock to help the heart return to a normal rhythm if an abnormal rhythm is found. Defibrillators also have pacing functions that may stop dangerous rhythms. Defibrillators are lifesaving devices that can lower your risk of dying from a sudden cardiac arrest.¹ Yet, they will not prevent you from dying due to illnesses such as cancer or advanced heart failure. Even with a defibrillator, heart problems can worsen over time. Discussing your health care goals (eg, your wishes for your health care) with your loved ones, caregivers, and health care providers is important. You will also want to discuss whether you want the shocking functions of your device turned off as you near the end of life.² These conversations are important to have even if you are feeling healthy.

Many patients and their families may have questions about what it means to “turn off” the defibrillator. This PACE patient page provides information to patients and family members

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about end-of-life care with a defibrillator. Patients may also learn how to have these conversations with others.

2 KNOWING YOUR OPTIONS WITH A DEFIBRILLATOR

2.1 Why would I turn off my defibrillator?

As some serious illnesses progress, you may decide to turn off your defibrillator. Table 1 lists reasons why you may want to turn off your defibrillator and why you may want to keep your defibrillator turned on.

Since shocks can be painful, you may decide that you do not want to receive shocks near the end of your life. Nearly 30% of patients with defibrillators receive shocks at the end-of-life. These shocks do not meaningfully prolong life but can cause stress for patients and families.³ Patients and family members can experience distress, anxiety, depression, and grief.^{3,4} Turning off the shocking function of a defibrillator will not affect how you feel day to day. However, when it is turned off, you will no longer receive shocks, which means that you can die from an abnormal heart rhythm. Pacing can remain turned on even if the shocking function is turned off.

2.2 The process of turning off a defibrillator

Patients in the United States and Canada have the legal right to turn off their defibrillator if they choose.^{5,6} Turning off a defibrillator is also considered ethical. Table 2 provides an overview of the process for turning off your defibrillator in the clinic.

Other ways to turn off a defibrillator include using a specialized medical magnet that is placed over the device. This medical magnet is typically only used in urgent situations or in situations in which a patient may not be able to go to his or her healthcare provider's office.

3 RECOGNIZING THE SIGNS AND PLANNING AHEAD

3.1 When it might be time to discuss turning off my defibrillator

You and your family may want to consider turning off your defibrillator if your health care goals change. For example, if you experience a decrease in your quality of life and you no longer wish to receive treatments to keep you alive you may want to consider turning off your defibrillator. Signs that your quality of life is decreasing may include worsening symptoms. Examples of these symptoms are shortness of breath, inability to do the activities that are important to you, and being in the hospital many times over a short period. You may decide to focus on your quality of life instead of trying other more advanced medications or treatment options. The shocking function does not need to be turned off if you are no longer trying other advanced treatments. However, for some patients at this time, turning off the shocking function may fit with their goals.

3.2 Planning ahead

As your health declines, it may become more difficult for you to make decisions. For example, some patients with defibrillators may develop other health conditions, such as

depression, anxiety, memory problems, or severe illnesses that make decision-making hard. Planning ahead allows you to make decisions before your health declines. There are several steps that you and your family can take that will help you plan ahead for managing your defibrillator.

- Talk with your healthcare provider to learn the options available to you. Talking can also help to answer your questions. This is a discussion you can have at any appointment.
- Talk to your loved ones and caregivers so that they understand your wishes.
- Consider joining a support group. Sharing your experiences with other patients can be helpful. You may also learn from other's experiences.
- Create an advance care plan, including an Advance Directive.
 - Advance directives are legal documents. These documents explain the type of medical treatment that you want to receive. These documents also identify a person to make medical decisions for you if are unable to make decisions.

4 DISCUSSING TURNING OFF MY DEFIBRILLATOR

You may feel uncomfortable discussing turning off your defibrillator. Discussing your goals and wishes is still important, because it gives you control over your life. It also helps your family and healthcare providers know your wishes.

4.1 Discussing turning off my defibrillator with my loved ones and caregivers

It might be helpful for your loved ones and caregivers to be involved in discussions about turning off your defibrillator. By having your loved ones and caregivers involved in these discussions, they will understand your wishes and healthcare goals. They may also be able to assist you in choosing therapies that match your wishes and goals.

Talking about turning off your defibrillator with caregivers and loved ones may not be easy. Figure 1 gives a few examples of how to start the conversation with your caregivers and loved ones.

4.2 Discussing turning off my defibrillator with my healthcare provider

You and your loved ones and caregivers may be hesitant to discuss turning off your defibrillator with your healthcare provider. Your healthcare provider may also feel uncomfortable discussing this. Yet, this is an important discussion to have. It will be helpful to let your healthcare provider know in advance that you would like to talk about turning off your defibrillator. It also might be helpful to write down any questions or concerns you have. This will allow you to bring these up with your healthcare provider. The following list includes some common questions you may want to consider asking your healthcare provider:

- If I keep my defibrillator on what will happen?

- If I turn my defibrillator off what will happen?
- What are the different functions of my device?
- How will turning off the different functions affect me?
- How might my quality of life be affected?
- What can I expect from my heart condition?
- How do the different options fit with my health care goals?

Figure 2 lists a few examples of ways to start the conversation with your healthcare provider.

5 SUMMARY AND CONCLUSIONS

Deciding to turn off the shocking function of a defibrillator is an important choice. You will need to discuss it with your loved ones and caregivers, and your healthcare providers. You will also want to discuss your healthcare goals with your loved ones and caregivers and healthcare providers. You will want to take the time to learn all the facts. You will also want to discuss how turning off your defibrillator would fit with these goals (see Figure 3 for additional resources). This may be a difficult conversation to have with your loved ones, caregivers, and healthcare providers. Having these conversations can help you learn the facts, understand what options you have, and may help to ease your worries or concerns.

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Talking with Loved Ones and Caregivers

1. Set the goals for your conversation.
 - **Example:** I would like to talk with the doctor about my defibrillator and how it fits in with my future health care goals at my next appointment.
2. Discuss how you want your loved ones involved in this discussion.
 - **Example:** Your support could be helpful during the conversation and I think it will be important for both of us to know this information.
3. Prepare for your appointment.
 - **Example:** Let's prepare a list of questions that both of us have for the doctor.
4. Summarize the discussion.
 - **Example:** It's important to me to learn more about the options for how my defibrillator is managed. I want to talk with the doctor about these options at my next appointment and I would like you to be with me. We both have the following questions for the doctor.

Image: Baer, 2005⁷

FIGURE 1.

Tips for discussing turning off your defibrillator with your loved ones and caregivers⁷

Talking with Healthcare Providers

1. Set your goals for your appointment.
 - **Example:** I want to learn more about how my defibrillator may be managed if my health gets worse.
2. Explore the options for how your defibrillator is managed and the effects on your health.
 - **Example:** I want to know what might happen if I keep my defibrillator on and what might happen if I turn it off.
 - **Example:** I want to learn more about how my health and quality of life may change in the next few months and over the next couple of years.
3. Discuss your healthcare goals.
 - **Example:** My healthcare goals are to make it to my granddaughter's wedding.
 - **Example:** My healthcare goals are to be comfortable.
4. State your wishes.
 - **Example:** My wish is for the shocking function of my defibrillator to be turned off if my health gets worse to the point where shocking me may not be helpful anymore.
 - **Example:** My wish is for the shocking function of my defibrillator to be kept on even in my health gets worse so I can be treated for life-threatening rhythms.
5. Summarize your understanding of the discussion.
 - **Example:** I understand that I have the option to turn off my defibrillator or keep it on. I also understand that _____ may happen to my health in the future. Since my healthcare goals are _____ right now, I want my defibrillator to be _____.

Image: Baer, 2008⁸

FIGURE 2.

Tips for discussing turning off your defibrillator with your healthcare provider⁸

Test Your Knowledge!

☐ **Fear**

☐ Turning off my defibrillator will be painful.

☐ I worry that I will die immediately if the shocking function is turned off.

☐ Once I turn off the shocking function it cannot be turned back on.

☐ It is illegal to turn off my shocking function.

☐ My doctor will not agree with my wishes to turn off the shocking function.

☐ My device needs to be removed after I die.

☐ **Fact**

☐ It is a painless procedure.

☐ I will stop receiving shocks, but will not die immediately when the shocking function is turned off.

☐ It can be turned back on after it has been turned off if I change my mind.

☐ In the United States and Canada it is legal to turn off the shocking function.

☐ Most, but not all, doctors will be comfortable turning off the shocking function of my defibrillator. If my doctor is hesitant or does not agree, I can be referred to another doctor.

☐ In some countries my defibrillator may need to be removed if I wish to be buried or cremated. In other countries it may only be necessary to remove my defibrillator if I wish to be cremated.

Resource	Topic	Web Site
Heart Failure Society of America	Advance Care Planning	www.hfsa.org/patient/patient-tools/educational-modules/module-9/
American Heart Association	Planning with Advanced Heart Failure	https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure
ABIM Foundation	Defibrillators at the End of Life	www.choosingwisely.org/patient-resources/implanted-heart-devices-at-the-end-of-life/
Mended Hearts	Patient and Caregiver Support and Education	https://mendedhearts.org/

FIGURE 3.

Common fears and facts and additional resources about deactivation of defibrillators

TABLE 1

Reasons for turning off a defibrillator vs. reasons for keeping a defibrillator turned on

Why would you want to turn it off?	Why would you want to keep it on?
<ul style="list-style-type: none">• You may have a serious illness, in which case your defibrillator may not improve your life expectancy in a meaningful way.• Your quality of life may have declined.• You may not want to receive painful shocks as your life is ending.	<ul style="list-style-type: none">• You will continue to be treated for life-threatening rhythms.• Treatment for life threatening arrhythmias may prolong your life.• It is worth it to you to receive a painful shock to stay alive at this time.

TABLE 2

Process of turning off a defibrillator

Process of turning off a defibrillator

- Doctor uses a programmer device, which allows communication with your device.
- Programmer device is used to make adjustments to the device, including turning off the shocking functions.
- Often performed as an outpatient in your clinic’s office
- A painless procedure that does not require surgery.
- Turning it off will not cause you to die immediately.
- Can be turned back on at any time.

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