DECISION AID | AT-A-GLANCE

Considering an ICD After Having Had a Dangerous Heart Rhythm



Why am I being offered an ICD?

Your doctor thinks that you might benefit from having an **implantable cardioverter defibrillator (ICD)** placed near or in your heart to help monitor for and treat a dangerous heart rhythm like the one you had and survived.

And because you had a heart rhythm that caused your heart to stop beating, you are more likely to have another one. Without immediate treatment to reset your heart rhythm, you could die within minutes (called sudden cardiac arrest). An ICD can help prevent this from happening.

An ICD is a small, battery-powered device. It can help monitor your heartbeats and correct for these dangerous heart rhythms. It is surgically placed under the skin through a small incision.





Take steps to make an informed choice

It can be scary to think about the possibility of dying early. Be sure to share your feelings and ask questions about the benefits and possible harms of having - or not having - an ICD placed, especially as you have had a dangerous heart rhythm. What matters to you might be very different from what matters to someone else. Follow these steps:





How does an ICD work?

When an ICD senses a dangerous heart rhythm, it gives the heart an electrical shock. This helps reset the heart to beat normally. Some ICDs have wires (leads) that go through the blood vessels and into the heart. Other ICDs are placed outside of the heart.

An ICD is different than a pacemaker. A pacemaker helps the heart beat at a regular pace, but it does not deliver a shock like an ICD.

An ICD's only purpose is to sense a dangerous heart rhythm and reset the heart to beat normally.

What does a shock feel like?



It's different for everyone. Patients say that getting shocked is like "being kicked in the chest" or "feeling an electrical current through their chest." It can be painful. Some people pass out due to the dangerous heart rhythm before they are shocked and, therefore, don't remember being shocked.

Will my ICD need to be replaced?



ICDs have to be replaced approximately every 10 years when the battery runs out. This requires another surgery, which is done without being admitted to the hospital. Replacing ICD wires is rare but is sometimes required.

Questions to talk with your health care team about

- How is the ICD implanted? What is the recovery like?
- What are the pros and cons of having or not having an ICD given my condition?
- What are the chances I'll have another dangerous heart rhythm?
- What type of ICD is best for me?
- Can an ICD be taken out?
- What about turning it off at some point (for example, if I have a terminal illness)?
- How often will I get shocked? What does it mean if I don't get shocked?
- How will having an ICD affect how I manage my other conditions?
- What about my lifestyle (for example, being able to exercise or be intimate, travel, use certain devices /machines, or get pregnant)?

Our longer decision aid shows pictures of different ICDs and gives basic answers to many of these questions.



Understanding what it means to have an ICD or not

There are two ways to think about what this decision might mean for you. Which option do you relate to more?

Option 1

You may choose to get an ICD.



You may be feeling as you usually do, then a dangerous heart rhythm could happen again. The ICD may help you live longer by treating this dangerous heart rhythm. You will continue to live with your heart condition, which may get worse over time.

"I'm not ready to die. I have so much to live for and many years ahead of me (for younger patients). Even if it means getting shocked, I'm willing to do anything that can help me live longer."

Option 2

You may choose NOT to get an ICD. You may be feeling like



you usually do and then another dangerous heart rhythm could happen. You may die quickly from the dangerous heart rhythm this time if your heart is not reset right away. This might be at a younger age than you had imagined.

"The idea of dying quickly sounds painless. Going through surgery and getting shocked is not something I want."

What if I already have an ICD, but I did not make the decision?

Sometimes during a cardiac arrest, you may be unable to participate in decisionmaking. Your doctors and family members may have made decisions on your behalf. Remember that you can and should have a conversation with your doctors at any time.

Understanding why decisions were made for you and getting your questions answered can be helpful in accepting your new device, knowing what to expect and getting back to living.

What are the main benefits and harms?

What are the BENEFITS of getting an ICD?

- ICDs are used to:
 - Correct for a dangerous heart rhythm.
 - Help prevent sudden cardiac arrest and dying as a result.
 - Collect important information about your heart's electrical rhythms, which can be valuable for you and your care team to know.
- Some patients feel more secure knowing that they have an ICD.

What are the HARMS of getting an ICD?

- When placing the ICD:
 - 4 out of every 100 patients will experience some bleeding after surgery.
 - 2 out of every 100 patients will have a serious problem like damage to the lung or heart.
- About 1 out of every 100 patients will develop an infection over the life of their device.
- Some patients develop anxiety or depression from worrying about or actually being shocked.

Will I live longer with an ICD?*



Without an ICD: Patients without an ICD are more likely to die suddenly from a dangerous heart rhythm. Without an ICD, 25 out of every 100 patients with heart failure will die over a 2-year period.



With an ICD: Patients with an ICD are less likely to die suddenly of a dangerous heart rhythm. With an ICD, 15 out of every 100 patients with heart failure will die over a 2-year period. This means 10 more patients would live with an ICD over this period.

* S. J. Connolly, et al. Meta-analysis of the implantable cardioverter defibrillator secondary prevention trials, *European Heart Journal*, Volume 21, Issue 24, 1 December 2000, Pages 2071-2078.

Some people say they have more peace of mind knowing that an ICD can help them if they have a dangerous heart rhythm.

Making a decision with your values and wishes in mind

How important is it to prevent sudden death?

Many people say that this is the most important question to consider when thinking about an ICD. It may be helpful for you to talk with your family and friends.

On a scale ...

No one can predict the future. But if you were able to choose, how would you like to live out the rest of your life? (Check the box that feels right for you today, knowing your needs and wishes may change over time.)



with your care team and:

- Ask questions
- Share what worries you most about living with or without an ICD
- Speak up if there is any other information that would be helpful to know

Everyone is different. Be sure to talk about your goals and values and other challenges you have. These might influence your decision to get an ICD or not.

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