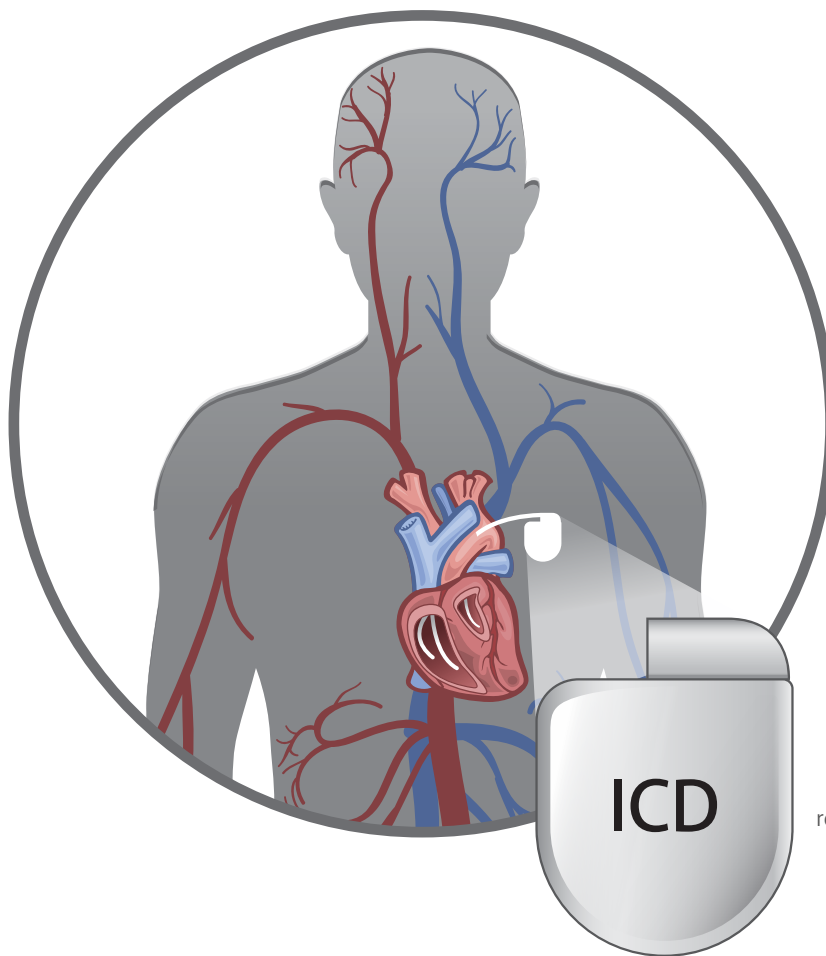


A decision aid for

## Implantable Cardioverter-Defibrillators (ICD)

For patients with heart failure considering an ICD who are at risk for sudden cardiac death (primary prevention).



See the back page for real-life sizes of the device

You are being offered an ICD.

This booklet will

- Explain how ICD works and why your doctor is recommending it.
- Help you make your decision based on your values and wishes

## What is an ICD?

An ICD is a small device that is placed under the skin of the chest. Wires (called “leads”) connect the ICD to the heart. An ICD is designed to prevent an at-risk person from dying suddenly from a dangerous heart rhythm. When it senses a dangerous heart rhythm, an ICD gives the heart an electrical shock. It does this in order to get the heart to beat normally. An ICD is different than a pacemaker. A pacemaker helps the heart beat but does not give a shock like an ICD.

## Is an ICD right for me?

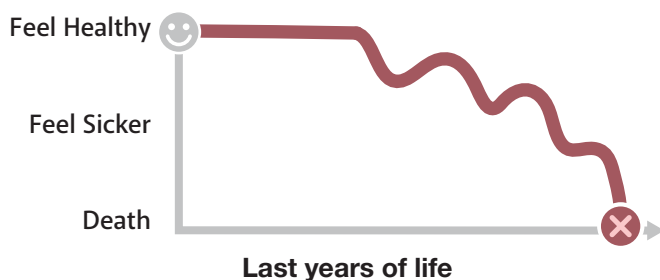
Your doctor has suggested that you might benefit from having an ICD. This is a big decision. Understanding what to expect after getting an ICD might help you to feel better about your decision. The ICD may not be right for some people. Although this may be hard to think about, other patients like you have wanted to know this information.

While the future is always unpredictable, there is an important trade-off to consider when deciding whether to get an ICD.

Consider two possible paths:

### Path 1

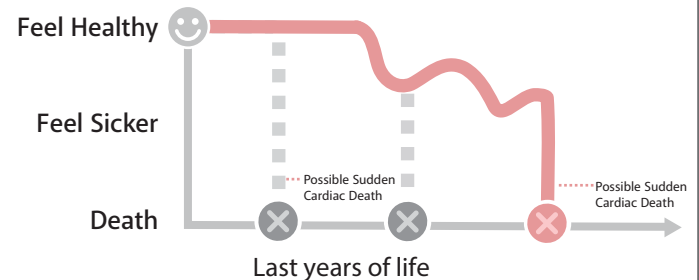
You may choose to get an ICD. You may be feeling like you usually do, then a dangerous heart rhythm could happen. The ICD may help you live longer by treating a dangerous heart rhythm. You will continue to live with heart failure that may get worse over time.



"I'm not ready to die. I have so much I'm trying to stay alive for. Even if it means getting shocked, I'm willing to do anything that can help me live longer."

### Path 2

You may choose to NOT get an ICD. You may be feeling like you usually do, and then a dangerous heart rhythm could happen. You may die quickly from the dangerous heart rhythm. This can happen at any time.



"I've lived a good life. The idea of dying quickly sounds like a painless way to go. I've always said I hope to die in my sleep. Going through surgery and getting shocked is not the kind of thing I want."

## How do I make a decision? Isn't it just up to my doctor?

You have a choice to get an ICD or not. You should talk with your doctor and your care team about whether or not you want to get an ICD. Many people find it helpful to think about:

- Your goals and preferences for treatment
- Your heart condition and the chance of having a dangerous heart rhythm that could lead to sudden cardiac arrest
- The possible harms and benefits of an ICD

# Considering an ICD

## My doctor has asked me to consider an ICD. Why?

Due to heart failure, you are at higher risk for developing a dangerous heart rhythm. A dangerous heart rhythm can cause you to die within minutes if not treated.



Heart failure is when a heart is too weak to pump enough blood for the body. People with heart failure sometimes have breathing problems, leg swelling, and feel tired. Some people with heart failure may have no symptoms.

## Does getting an ICD require surgery?

Yes. The ICD is put under the skin and one or more wires (called "leads") are put into the heart. The surgery takes a few hours. Some people need to stay in the hospital overnight.



There will be a bump the size of a small bar of soap under your skin and a visible scar. See the back page for a life-size image of an ICD.

## Will an ICD make me feel better?

ICDs do not make you feel better. They help prevent sudden cardiac death. Some patients might get an ICD that also helps pace the heart that can make them feel better. You should talk with your doctor about the differences between these devices.

### What are the risks of getting an ICD?

Problems do occur:

**CURED?**

- 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.
- Some patients develop anxiety or depression from being shocked.

## Lifestyle Considerations



In general, people with an ICD may need to avoid strong electromagnetic fields. That's because they can affect how the ICD works. You may not be able to use some heavy equipment like chainsaws and arc welders. Normal appliances like a microwave are okay. It's always best to check with your doctor or the maker of your device to get a list of what is safe and what might not be based on your specific ICD.



You should be careful about metal detectors at the airport. Some metal detectors do not work with an ICD. You should talk with airport security and your doctor. It is okay to walk through security systems at department stores.



Many doctors recommend that a patient not drive for up to 6 months after getting a shock from their ICD. Some states and countries have even stricter laws. Talk to your doctor about the driving laws in your area.



It is possible to exercise with an ICD. Talk to your doctor to learn which exercises are safe for you, and when you can start exercising again.



It is okay to have sex when you have an ICD.



Having an ICD does not prevent you from getting pregnant, although you may want to talk to your doctor about how your underlying health condition may affect your pregnancy.




You may use a cell phone, but you should keep the phone at least 6 inches away from the ICD.


# Survival

## Would I survive a dangerous heart rhythm without the an ICD?

You may survive a dangerous heart rhythm only if you are treated within a few minutes with an external shock by an AED or by a paramedic. However, many patients die before emergency help can reach them.

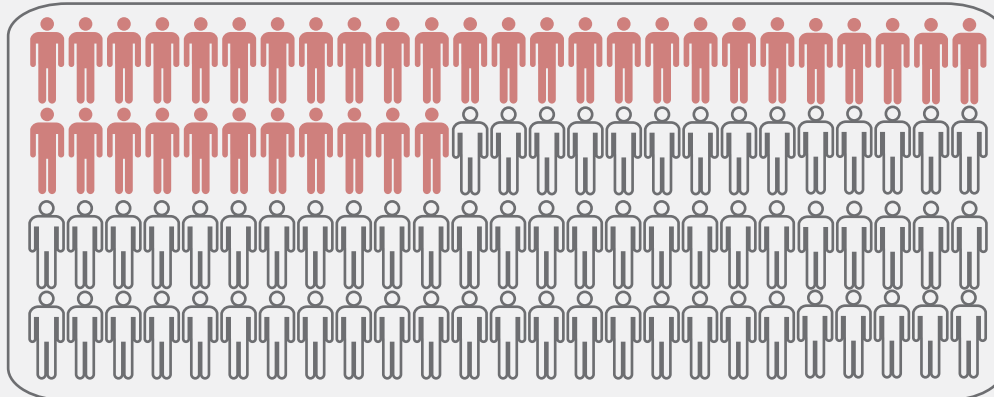
## Will I live longer with an ICD?\*

 **Without an ICD:** Patients without an ICD are more likely to die suddenly from a dangerous heart rhythm. Without an ICD, over 5 years, 36 out of every 100 patients with heart failure will die over a 5-year period.

 **With an ICD:** Patients with an ICD are less likely to die suddenly of a dangerous heart rhythm. With an ICD, 29 out of every 100 patients with heart failure will die over a 5-year period. This means 7 more patients would live with a CRT-D over a 5-year period.

The number below are from recent medical studies. However, no one can know what will happen to any one person.

### What are the benefits of getting an ICD? Results from a 5-year study\*



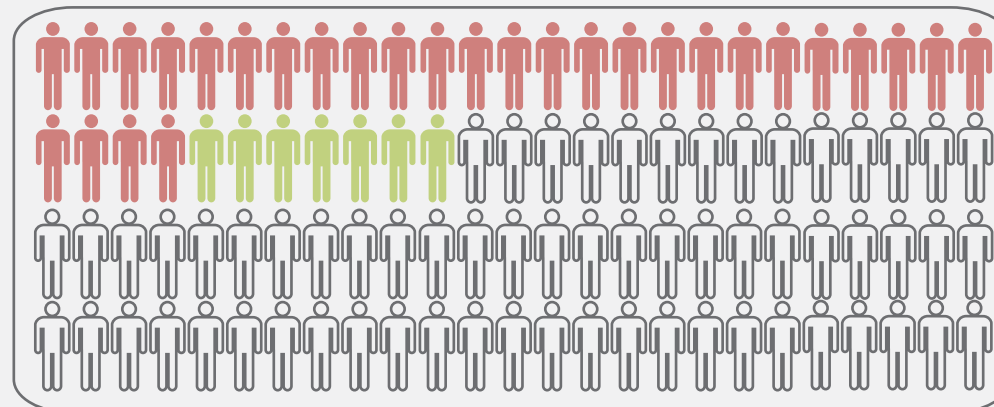
No ICD



36 die



64 live



Yes ICD



29 die



71 live



7 saved



Number of people who live because of the CRT-D



Number of people who die for any reason



Number of people not affected

lives saved over 5 years by having an ICD

\*SCD-HeFT. Bardy, GH, et al. NEJM

# Consider your values and wishes

## Can the ICD be taken out?

It is best not to remove the ICD unless you have an infection or are having the ICD replaced.



ICDs have to be replaced every 5 to 10 years when the battery wears down. This requires another surgery. Replacing ICD wires is rare but is sometimes required.

## Can the ICD be turned off?

Yes. It is possible to turn off the ICD without surgery. This is even recommended when a person is close to dying of another cause. It is possible to keep the pacemaker turned on. Talk about this with your doctor.

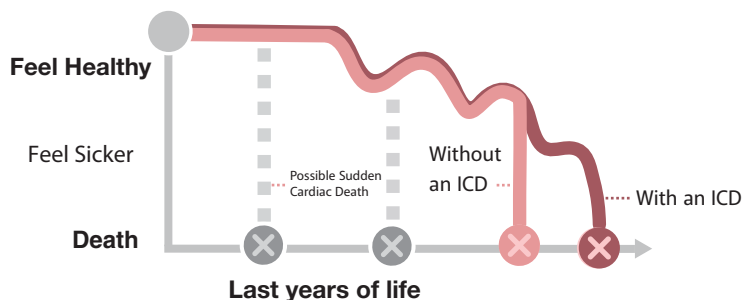


## Why would I want to turn off the ICD?

In the future, people may reach a point where living as long as possible is not what they want anymore. This could be because of worsening heart failure or another illness. When this happens, the ICD can be turned off to avoid shocks.



The ICD does not stop an advancing illness like heart failure. The only purpose of the ICD is to try to get a dangerous heart rhythm to beat normally.



## On a Scale...

While no-one can predict the future, if you were able to choose, how would you like to live out the rest of your life? (check one box)

Die quickly (for example, dying suddenly in your sleep) and not live as long.

▶            ◀

Live as long as possible even with an illness like heart failure that may get worse over time.

## Reflection...

What benefits do you think you might experience:

What losses do you think you might experience:

How might your life change:

What frightens you about living with or without an ICD:

with an ICD?	without an ICD?

## In Summary

FAQ	Implant an ICD	Do not implant an ICD
What does an ICD do?	An ICD may stop a dangerous heart rhythm that could cause sudden death by giving an electrical shock to the heart.	Without an ICD, you will have a higher risk of dying suddenly if a dangerous heart rhythm happens.
What is involved?	An ICD is put under the skin on your chest and wires ("leads") go into your heart. You will probably stay one night in the hospital. In about 5-10 years, when the battery runs out, and the ICD will need to be replaced.	You can continue to use medicine to treat your heart problem.
Will I live longer with an ICD?	Patients with an ICD are less likely to die suddenly of a dangerous heart rhythm. With an ICD, 29 out of 100 patients with heart failure will die over a 5-year period. This is 7 fewer deaths than if they did not have an ICD.	Patients without an ICD are more likely to die suddenly from a dangerous heart rhythm. Without an ICD, 36 out of 100 patients with heart failure will die over a 5-year period.
Will I get shocked by the ICD? What will that feel like?	Over 5 years, 20 out of every 100 patients who have an ICD will get a shock. 80 out of 100 patients will not get shocked. Patients say that getting shocked is like "being kicked in the chest."	You will not get a shock from an ICD if you don't get an ICD.
What are the risks of getting an ICD?	4 out of every 100 patients will have some bleeding. 2 out of every 100 patients will have a serious problem, such as damage to the lung, a heart attack, or a stroke. 1 out of every 100 patients will get an infection, which may require removing the ICD.	You will not have the risks of placing an ICD.
Will an ICD improve my symptoms?	Having an ICD will not improve your symptoms or cure your heart problem.	Your symptoms will be influenced by your heart problem.
Are there things I cannot do?	This depends on your heart problem. Talk to your doctor about driving limitations and other activities.	Even without an ICD, talk with your doctor about driving limitations and other activities.
Can the ICD be taken out?	It is best not to remove the ICD unless it gets infected or it is time to have it replaced when the battery runs out.	Does not apply.
Can the ICD be turned off?	Yes, the ICD can be turned off without surgery. This is recommended if a person is likely to die from another illness.	Does not apply.

You are the expert on what is important for you.

What else do you need to help you make your decision?

## Questions...

It may be helpful for you to talk with your family and friends. You may want to share the information in this decision aid with them. You should also share with your doctor your questions and concerns before making a final decision. It is important that you have all of the information you need to make a decision that is right for you. You have the right to make your own choices!

## Concerns...



You know what is important to you better than anyone else. Any decision about your treatment should be based on your goals and values!

### Patients' thoughts:

**Jim:** "The whole thing is just getting all the information from any source that you can. And take it all in and the final decision is up to you. You have to make that decision, not your doctor. And too many patients think the doctor is God, but the doctor doesn't know your body the way you do. So the final decision is yours."

**Caroline:** "First of all, I think it's a very personal choice. I think everybody needs to make their own decision. But, I think it needs to be an informed decision."

### Life-size ICD images



