

A decision aid for Implantable Cardioverter-Defibrillators (ICD)

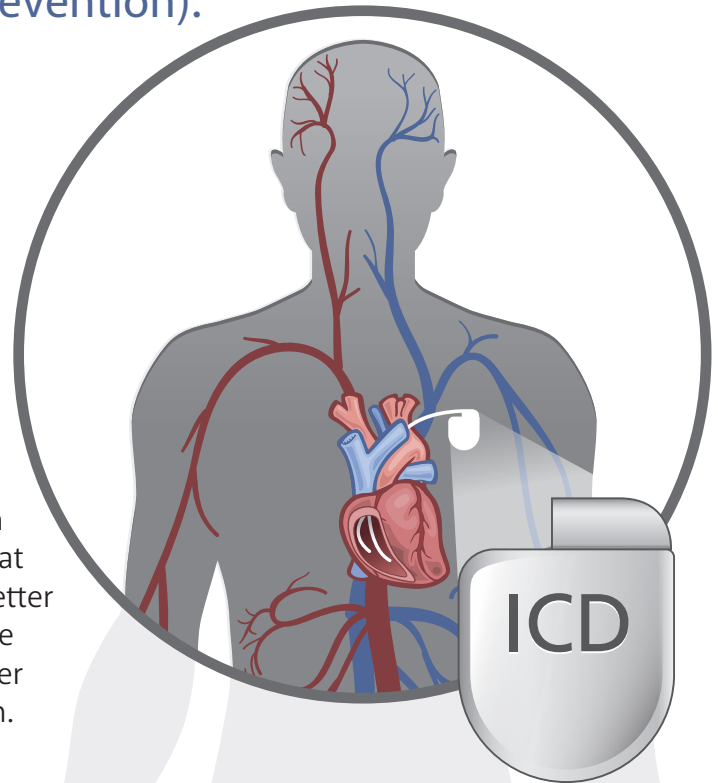
For patients with heart failure considering an ICD who are at risk of sudden cardiac death (primary prevention).

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.

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.



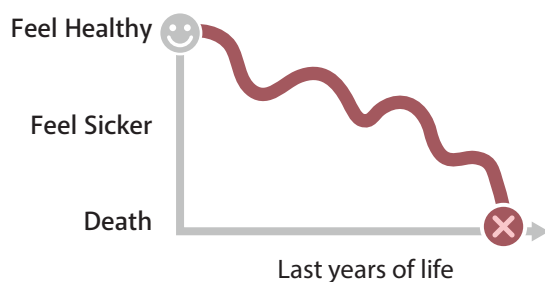
See the back page for real-life sizes of the device

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

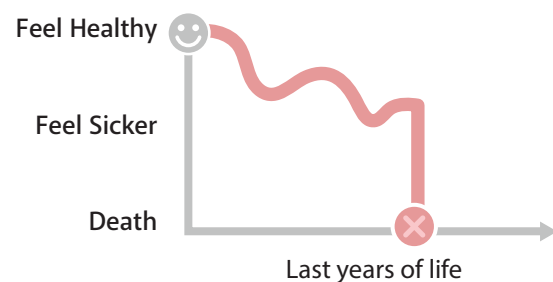
You may choose to get an ICD. You may be feeling like you usually do, then a dangerous heart rhythm could happen. The ICD may help you live longer by treating a dangerous heart rhythm. You will continue to live with heart failure that may get worse over time.



"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.



"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."

Considering an ICD

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

Due to your heart failure, you are at higher risk of 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 with local anaesthetic and sometimes sedation. The procedure takes 60-90 minutes. You may 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. Some patients might get devices with other features that can make them feel better. You should talk with your doctor about these devices.

CURED?

What are the risks of getting an ICD?

During the first year after ICD Implantation:

- 6 out of every 100 patients will require a second procedure to reposition a lead.
- 1 out of every 100 patients will have air around their lung which delays them going home.
- Less than 1 in 100 will have bleeding or heart damage.
- Less than 1 in 100 will have an infection which may require the removal of the ICD.
- Some patients develop anxiety or depression from being shocked.

Lifestyle Considerations



People with an ICD should avoid strong magnetic fields and some industrial equipment. If you work with industrial equipment, discuss this with your doctor. Normal appliances like a microwave are okay.



You should not walk through the metal detector at the airport. Instead, you should ask to be hand searched. It is okay to walk through security systems at department stores.



There will be a period of at least 4 weeks after the device is implanted where you cannot drive. Your local cardiology team will advise you about driving when you get an ICD put in and if you get any shocks.



It is possible to exercise with an ICD. Talk to your doctor to learn which exercises are safe for you.



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



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



Over 5 years, about 20 out of every 100 patients get shocked by their ICDs. About 80 out of every 100 will not get shocked. Most shocks happen because of dangerous heart rhythms but some happen when they are not needed.

How does it feel to receive a shock?

Patients say that getting shocked is like "being kicked in the chest." Some patients pass out before they are shocked and do not remember being shocked. Before a shock is delivered, the ICD will try to correct your dangerous heart rhythm by using its pacemaker function to get the heart to beat faster and try and stop the fast heart rhythm. You may or may not feel your heart racing while this happening.


Survival




Would I survive a dangerous heart rhythm without an ICD?

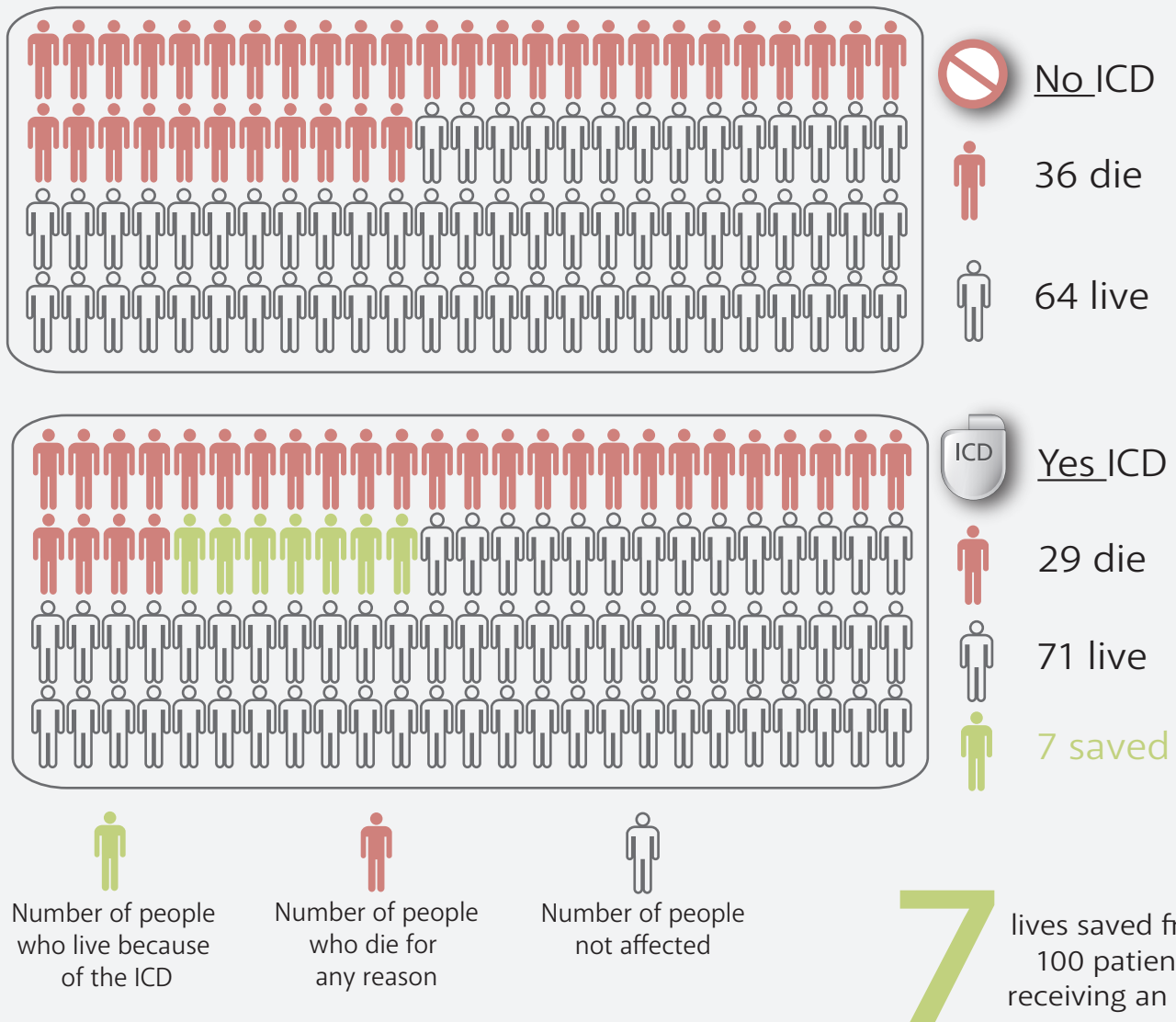
You may survive a dangerous heart rhythm only if you are treated within a few minutes with an external defibrillator shock. However, many patients die before emergency help can reach them.

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 an ICD over a 5-year period.

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



*SCD-HeFT. Bardy, GH, et al. NEJM 2005;352:225-237.

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?

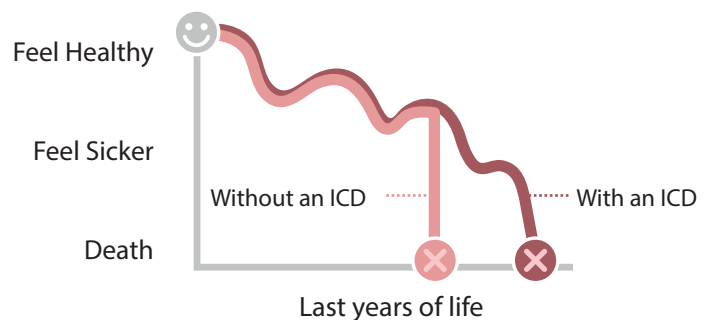
Yes. It is possible to turn off the ICD without surgery. This is recommended if a person is approaching a time when they are dying from any illness or it may be if they need to undergo some operations.

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?



How can I decide?

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 may stay one night in the hospital. In about 5-10 years, when the battery runs down, 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.	You will not get a shock from an ICD.
What are the risks of getting an ICD?	6 in 100 patients will require a second procedure to reposition a lead. 1 in 100 patients will have air around their lung which delays them going home. Less than 1 in 100 will have bleeding or heart damage. Less than 1 in 100 will have an infection which may require the removal of the ICD Some patients develop anxiety or depression from being shocked.	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 failure.
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 approaching a time when they are dying from any 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?

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!

Questions...

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."

What questions do you have?

Life-size ICD images

