

## DECISION AID

# For Patients Considering an ICD Who Are At Risk For Sudden Cardiac Death But Don't Have Heart Failure

ICD for diagnoses other than HF



## ► Why am I being offered an ICD?

Your doctor thinks that you might benefit from having an **implantable cardioverter defibrillator (ICD)** placed. This is because your heart condition makes you more likely to develop a dangerous heart rhythm – one that could cause the heart to suddenly stop beating (called sudden cardiac arrest). This can cause you to die within minutes if not treated. An ICD can help monitor for and treat these dangerous heart rhythms.



### Reasons an ICD might be recommended

Although most ICDs are used in patients with heart failure, there are many other reasons an ICD may be offered, including:

- Hypertrophic cardiomyopathy
- Arrhythmogenic right ventricular dysplasia/ cardiomyopathy
- Long QT syndrome
- Cardiac sarcoid, giant cell myocarditis, Chagas disease
- Strong family history of sudden cardiac death
- LV noncompaction

**Talk with your health care team about the reasons you are being asked to consider an ICD.**

**Whether you get an ICD or not is your choice. Use this decision aid to help.**

## Whether or not to get an ICD is a choice – your choice!

It's important to:

1. Take time to learn about how an ICD works.
2. Talk with your health care team so that you understand your personal risk, or chance, of sudden cardiac death and how much an ICD might lower that risk.
3. Think about what matters most to you.

This booklet was created, with input from experts and patients, to help:

- **Explain how an ICD works** and why your doctor is recommending one.
- **Answer common questions** and present key considerations other patients have found helpful.
- **You gather information to be able to make a decision** to have an ICD placed or not, based on your values and wishes.

It follows the basic steps for shared decision-making.



**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.** This will help you make a decision that you feel good about.

1

**Understanding that there is a decision to be made** - whether or not to have an ICD placed - that is based on the evidence and your wishes.

**PAGE 2**

2

**Learning why** an ICD is being recommended, how it works, possible tradeoffs of having one or not, and the benefits and harms.

**PAGE 3**

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**Gathering additional information**, including what life with an ICD might look and feel like, and other lifestyle considerations.

**PAGE 7**

4

**Thinking through your own values and preferences** and if you want a device.

**PAGE 11**

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**Reviewing and reflecting on your care team's recommendations and your personal treatment goals.** Following up to ask any remaining questions.

**PAGE 14**

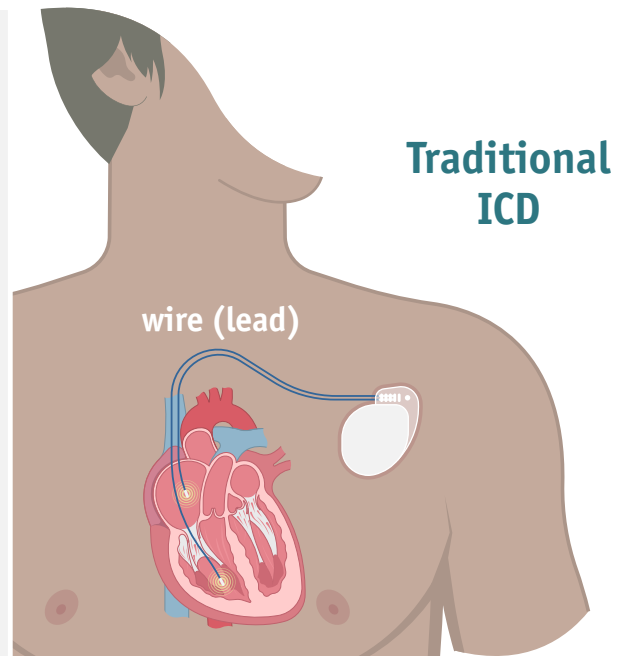
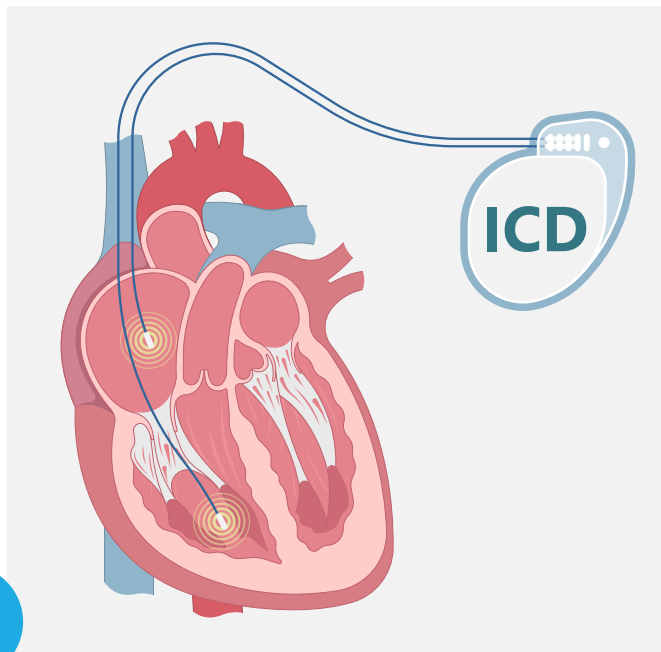
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**Arrive at your decision** together with your health care team.

## ▶ What is an ICD?

An ICD is a small, battery-powered device. It is used to monitor your heartbeats and correct for a dangerous heart rhythm. Having an ICD can help lower your chance of dying from a dangerous heart rhythm.

How? Depending on the type of ICD, one or more wires (called “leads”) connect to or sit near the heart. This allows the ICD to detect dangerous heart rhythms. When the ICD senses a dangerous heart rhythm, it gives the heart an electrical shock. This helps reset the heart to beat normally.



### Other questions about an ICD

#### Does getting an ICD require surgery?

It is surgically placed under the skin through a small incision. The surgery takes a few hours. You may 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. Sometimes this takes some getting used to.

#### Are there different types of ICDs?

There are different types of ICDs. All ICDs work to deliver a shock if they detect a dangerous heart rhythm. Some ICDs have wires that go through the blood vessels and into the heart. Other ICDs (called “subcutaneous” or “extra vascular”) have leads that are placed outside the heart. There are several companies that make ICDs. If you choose to get an ICD, you and your health care team will talk about which type is best for your condition.



## 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 health care team about the differences between these devices.

## How is it different from a pacemaker?

An ICD is different from a pacemaker. A pacemaker helps the heart beat at a regular pace, but it does not deliver a shock like an ICD. Most ICDs have the ability to work like a pacemaker if needed.

## Can the ICD be taken out?

It is best not to remove the ICD. ICDs are usually only removed if there is concern about an infection or if the device isn't working properly.

## 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 function turned on. Talk about this with your health care team.

## What does an ICD look like?

Here are life-size images of different brands of ICDs.



Side view



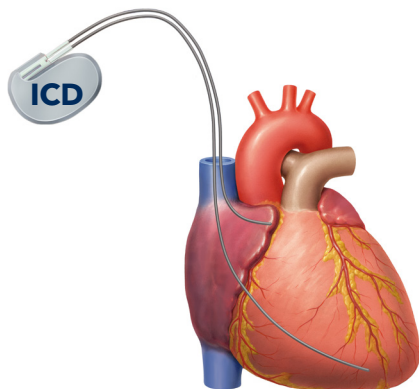
## ► Understanding what it means to have an ICD or not, as well as the benefits and harms

There can be two ways to think about what this decision might mean for you. For example, which option do you relate to more?

### Option 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 your heart condition, which may get worse over time.

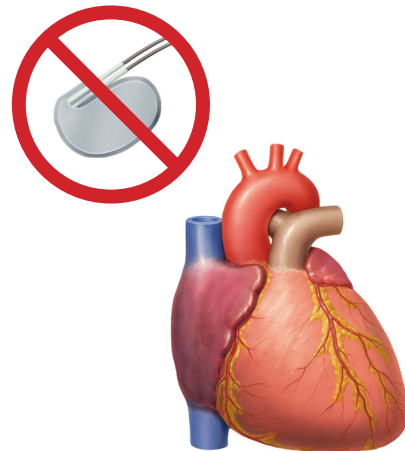


*"I'm not ready to die. I have so much to live for. Even if it means getting shocked, I'm willing to do anything that can help me live longer."*

### Option 2

#### **You may choose NOT to get an ICD.**

You may be feeling like you usually do and then a dangerous heart rhythm could happen. You may die naturally or suddenly from the dangerous heart rhythm, possibly at an early age.



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

## 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 shock by an automated external defibrillator (AED) or by a paramedic. However, many patients die before emergency help can reach them.

## What are the main benefits and risks?



### What are the **BENEFITS** of getting an ICD?

#### ICDs are used to:

- Correct for a dangerous heart rhythm.
- Help prevent sudden cardiac arrest and someone 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?

#### Problems do occur:

- 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.

## Will I live longer with an ICD?

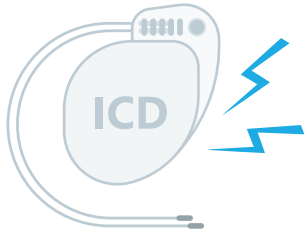
Patients with an ICD are less likely to die suddenly of a dangerous heart rhythm. How much the ICD lowers your risk of dying depends on your specific heart condition. Talk with your health care team to better understand how much an ICD might benefit you.



## ▶ Other important questions to consider

Answers to some of these questions have been helpful to other people when making a decision about getting an ICD or not.

### 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. Before a shock is delivered, the ICD will try to correct your dangerous heart rhythm.

### How often will I receive a shock?

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.** *(These numbers are from patients with heart failure, which is the most studied population.)*

### 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.

## How might an ICD affect my lifestyle or how I manage other conditions?

Many people consider their lifestyle and other illnesses when deciding whether or not to get an ICD. You may want to discuss these questions with your health care team.



For some people, how the ICD impacts their lifestyle is the most important question.

- How will I look after I have had the ICD implanted?
- Will I be able to be as active as before my ICD implant? Will I be able to play sports?
- When dating or having sex, will other people think of me as fragile?
- Will getting an ICD affect my ability to have children?
- This is scary. I haven't really thought about sudden cardiac death or mortality before.

Other people may have many medical problems. For these people, other considerations may be more important.

- How invasive will this procedure be?
- Is it worth it for me?
- Are there specific concerns with having an ICD given my other conditions [or my stage of life]?
- How will an ICD affect my other medical conditions?



**Everyone is different. You are a unique person with your own goals, values and other challenges. Talk to your health care team about how these might influence your decision to get an ICD or not.**



## ▶ What is it like to live with an ICD?

Many people have questions about what life will be like with an ICD. Here is what you might expect, though everyone is different, so it's best to ask your health care team.

### The first few weeks

In the first few weeks after getting an ICD, you may need to limit some of your activities to allow your body to heal. Talk with your health care team about what activities are important to you, and when you can return to doing them.

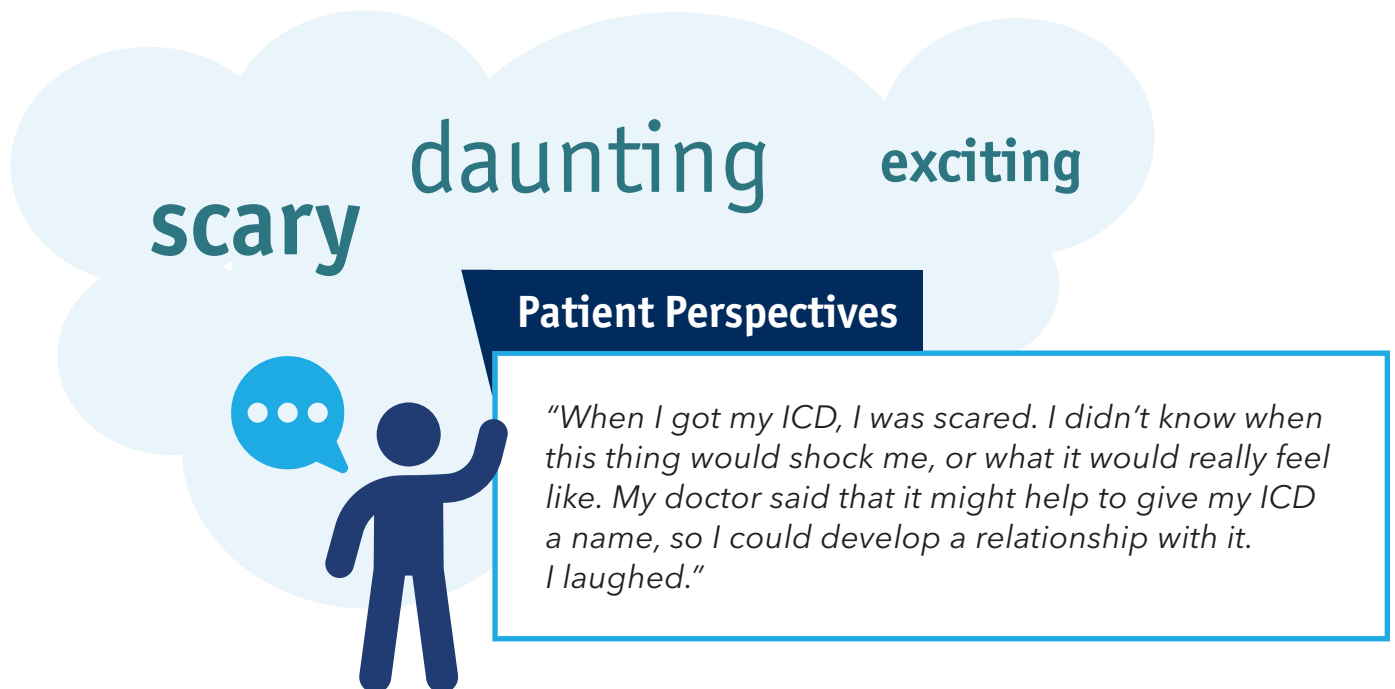
### Make a plan with your cardiologist for:

- Regular ICD checks
- Setting up a home monitor, if needed
- What to do if your ICD starts making noise
- What steps to take if you get a shock from your ICD

Generally, an ICD shouldn't interfere with your daily life.

### Emotional side of an ICD

There is an emotional side to having an ICD. Many patients say this is not often talked about. While many people also say it is reassuring to have an ICD, it may take some time to get used to it. Some people may not like how it feels or they may worry about being shocked. Some people find it harder than expected to see their scar. Be sure to find support from others and be aware of your feelings.



## Lifestyle Considerations



Certain household appliances, communication devices, industrial equipment, and security screening systems give off energy called electromagnetic fields. These may affect how the ICD works. It's always best to check with the company that makes your device to get an up-to-date 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 health care team. It is OK to walk through security systems at department stores. With newer devices, this is becoming less of an issue.



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 care team about the driving laws in your area.



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



It is OK 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 care team about how your specific heart condition may affect your pregnancy.



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

## ▶ Making a decision with your values and wishes in mind

### Isn't the decision just up to my doctor?

It's important to remember that the decision to get an ICD - or not - is yours to make. Either choice - that is, deciding to get an ICD or not - is reasonable. What matters to you might be very different from what matters to someone else.

### How important is it to prevent sudden death?

Many people say that this is the most important question for them to consider when thinking about an ICD. Some people are not ready to die and are willing to have surgery and be shocked to have a better chance of staying alive if and when their heart has a dangerous rhythm. For others, it is important to die quickly, and they want to avoid surgery or getting shocked. Knowing what is most important to you can help you figure out which decision is right for you.

### Talking it through

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. Also, share your questions and concerns with your health care team before making a final decision.



**You know what is important to you better than anyone else. Any decision about your treatment should be based on your goals and values! Remember, these may change over time.**

**It's also important that you have all of the information you need to make a decision that is right for you.**

### Patient's thoughts

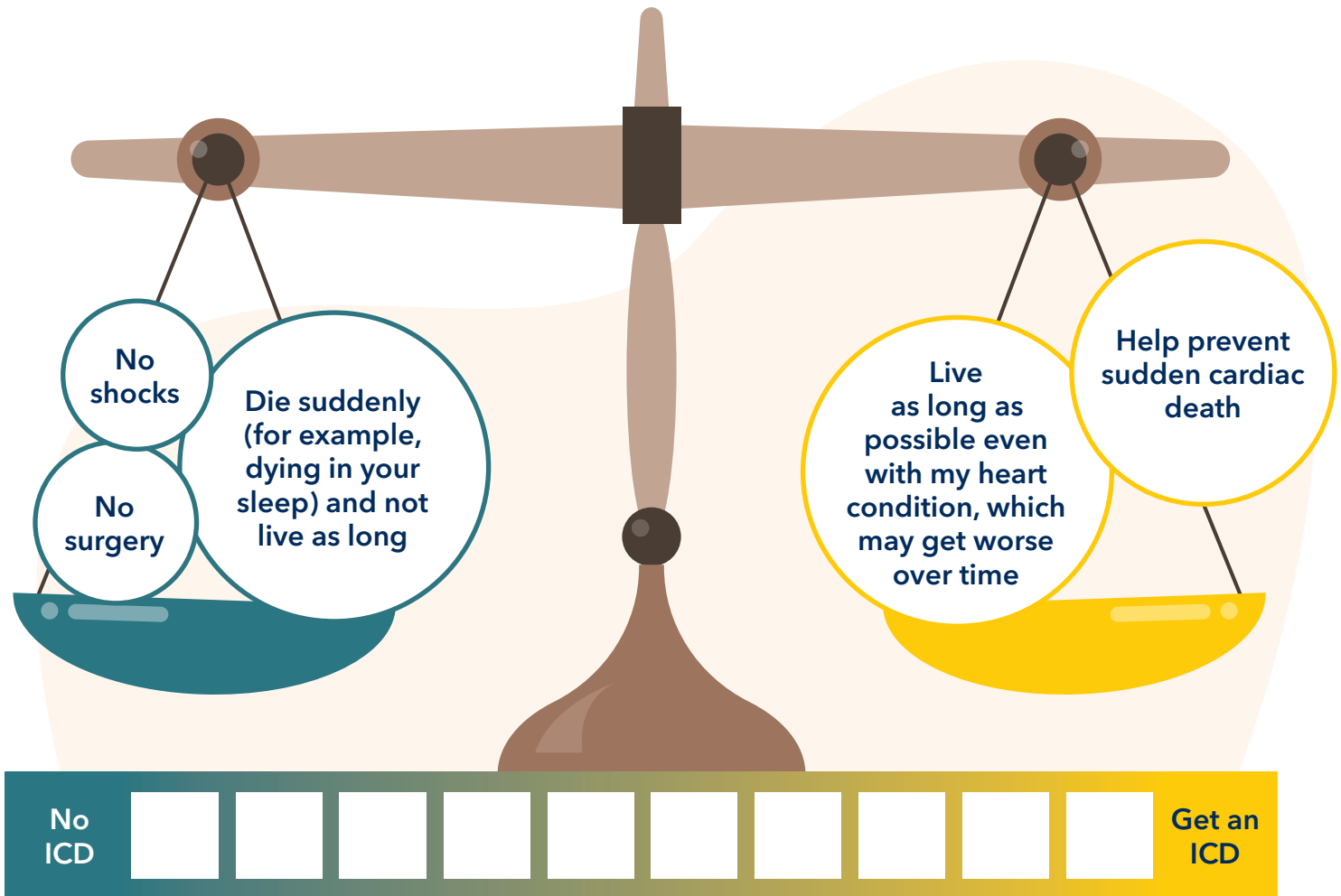
**Jim:** *"The whole thing is just getting all the information from any trusted source that you can. And take it all in and the final decision is up to you. You have to make that decision, not your doctor. And too many patients think the doctor is God, but the doctor doesn't know your body the way you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

## 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 one box)



## Your needs and wishes may change over time

For example, if you end up facing end-of-life decisions due to cancer or other reason, talk with your care team. Some people wish to turn off their ICD to avoid unwanted shocks. This can be done at your doctor's office and does not require surgery.

## In summary

Here is a brief summary of some of the common questions other patients had when considering an ICD.

FAQ	Implant an ICD	Do not implant an ICD
<b>What does an ICD do?</b>	An ICD can detect a dangerous heart rhythm – one that could cause the heart to suddenly stop beating. If it does, it sends a shock to reset the heart to beat normally again.	Without an ICD, you have a higher chance of dying suddenly if a dangerous heart rhythm happens.
<b>What is involved?</b>	An ICD is placed under the skin through a small incision in your chest near your heart. Some ICDs have wires (leads) that go through the blood vessels and into the heart. Other ICDs (called “subcutaneous” or “extra vascular”) are placed outside the heart. You will probably stay one night in the hospital. In about 10 years, when the battery runs out, the ICD will need to be replaced.	You can continue to use medicine to treat your heart problem. Ask if there are other procedures for your specific heart condition.
<b>Will I live longer with an ICD?</b>	Patients with an ICD are less likely to die suddenly of a dangerous heart rhythm. Talk with your care team to better understand how much an ICD might benefit you.	Patients without an ICD are more likely to die suddenly from a dangerous heart rhythm.
<b>Will I get shocked by the ICD?</b>	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 if you don’t get an ICD.
<b>What will a shock feel like?</b>	<p>It is different for everyone. Some common reports include:</p> <ul style="list-style-type: none"> <li>• Getting a hard, forceful kick in the chest</li> <li>• Feeling pressure or an electrical current though the chest like a lightning bolt</li> </ul> <p>Some people pass out before they get shocked and, therefore, don’t feel it.</p>	You will not get a shock from an ICD if you don’t get an ICD.
<b>What are the possible harms of getting an ICD?</b>	As with other surgeries, there is a risk of bruising (or bleeding), infection, or other problems. Some people also don’t love the idea of a device in them and worry about getting an unnecessary shock, though this is rare.	You will not have the possible harms of placing an ICD.

FAQ	Implant an ICD	Do not implant an ICD
Will an ICD improve my symptoms?	Having an ICD will not improve your symptoms or cure your heart problem.	Does not apply
Are there things I can't do?	This depends on your heart problem. Talk to your care team about driving limitations and other activities.	Even without an ICD, talk with your care team 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

## Reflection ...

	with an ICD?	without an ICD?
What benefits do you think you might experience:		
What possible harms are you worried about having:		
How might your life change:		
What frightens you about living with or without an ICD:		



