



When to consider Implantable Cardioverter Defibrillator (ICD) deactivation

A guide for patients and family

This booklet will help answer your questions about deactivating the shock function of an ICD.





Acknowledgements

Heart & Stroke gratefully acknowledges CorHealth Ontario as the original creators of this content. CorHealth Ontario would like to acknowledge the contributions of the patients, family members and healthcare providers who provided their valuable thoughts and insights into developing this booklet.



This publication **When to consider Implantable Cardioverter Defibrillator (ICD) deactivation, A guide for patients and family** is for informational purposes only and is not intended to be considered or relied upon as medical advice or a substitute for medical advice, a medical diagnosis or treatment from a physician or qualified healthcare professional. You are responsible for obtaining appropriate medical advice from a physician or other qualified healthcare professional prior to acting upon any information available through this publication.

What is ICD deactivation?

There may come a time when you no longer want to receive shocks to prevent sudden cardiac death. When the shock function of an Implantable Cardioverter Defibrillator (ICD) is turned off, this is known as ICD deactivation. After ICD deactivation, the ICD continues to work like a pacemaker, but will no longer treat dangerous heart rhythms with a shock.

In Canada and many countries around the world, ICD deactivation is considered both ethically and legally acceptable. It is not considered similar to Medical Assistance in Dying (MAID) or euthanasia. The intent of ICD deactivation is not to hasten death, but rather, allow people to die naturally.

It is important that you talk about ICD deactivation with your family and health care team members so that everyone understands what is involved and you can make your personal wishes clear.

What does an Implantable Cardioverter Defibrillator (ICD) do?

An Implantable Cardioverter Defibrillator (ICD) monitors every heart beat for any problems that may cause you to faint or die suddenly from a cardiac arrest. See **Figure 1** for a picture of an ICD.

Your ICD device can treat both slow and fast heart rates. All ICDs can work as both a pacemaker and a defibrillator. The pacemaker works by preventing your heart from going too slow, but it can also stop a fast heart rate painlessly.

If the pacing doesn't stop the fast heart rate, the ICD will deliver one or more shocks as needed. While a shock only lasts for a split second, some people describe this as being unpleasant or painful, similar to a 'kick' in the chest. However, receiving a shock can also be reassuring, as it shows you that your ICD is working to help prevent sudden death.

Some people with heart failure have a special type of ICD that is able to pace both the right and left side of the heart which helps to improve the symptoms of heart failure. This is known as a **C**ardiac **R**esynchronization **T**herapy **D**efibrillator or CRT-D.

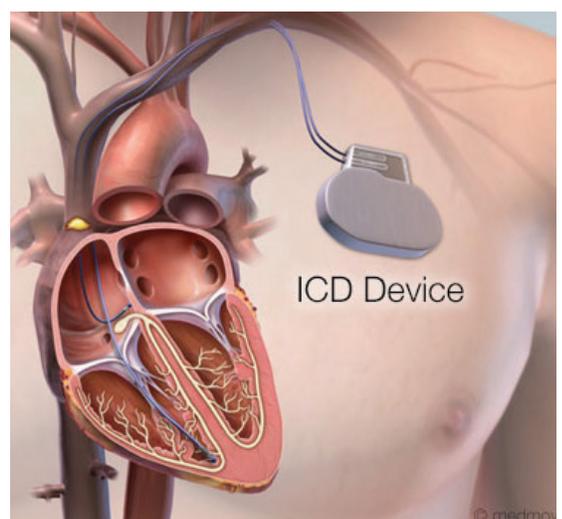


Figure 1. Implantable Cardioverter Defibrillator (ICD)
Illustration copyright [medmovie.Com](http://medmovie.com)

When should I consider the option of turning off the shocks?

A change in your health

Some people may consider turning off the shock function of their ICD when they are no longer happy with their quality of life. For some people, this may be due to worsening heart problems, or for others, it may be from a new problem such as cancer or a severe stroke. If a person has an ICD and they are nearing the end of their life, there is a risk that they will receive painful shocks, causing distress to both them and their family. Receiving shocks from an ICD at a time when you are dying from an irreversible condition is unlikely to prolong your life in a way that you may want.

When my ICD battery needs a replacement

Often people want to talk about ICD functions at the time when their ICD device battery is low and they need it replaced to keep the ICD functions active. It is important that you talk with your family and health care team about what you would prefer for your care and treatment.

It is best to talk about your wishes while you are well enough to make choices. If you prefer not to have these conversations, others may have to make those choices for you in an emergency or urgent situation without knowing your wishes.



Who should I discuss these options with?

It is usually best to think and talk about ICD deactivation when you feel good so that your family and health care team understand the reasons for your decision.

If these matters have not been discussed with you and you would like more information, please talk to a member of your health care team. If that health care professional cannot help you, ask them to contact someone who can, for example the nurse or doctor from your ICD team.

The people that you may want to discuss this with may include:

- Family, partner or close friends
- Family doctor
- Social worker or counselor
- Pastoral care or Spiritual advisor
- ICD health care team members
- Cardiologist or heart specialist
- Heart failure team (if you have one)
- Palliative care team (if you have one)
- Substitute Decision-Maker (if you have one)

A Substitute Decision-Maker is someone who makes healthcare decisions on behalf of a patient if they are incapable of healthcare decision-making. To learn more about the role of a Substitute Decision-Maker, please visit the website of the Canadian Hospice Palliative Care Association at www.chpca.net. They have a number of resources available on the website.



Who will make the decision to turn off the shocks?

The decision to turn off the shock function of an ICD will usually be made by you, supported by your health care team and, if you wish, by your family or others who are close to you. Thinking and talking about ICD deactivation is hard. People may want to think about what they find valuable and important in their lives and what they hope for in the future. You may want to have several discussions to make sure that you are happy with your decision. These conversations should be done at the place and time that you feel is best for you.

Please remember that the deactivation of an ICD is reversible. In other words, the ICD shock function can be turned back on (reactivated) if you change your mind or if your condition improves.

Sometimes a decision to deactivate an ICD has to be made when you are very ill and you are not able to make the decision yourself. Whenever possible, the doctor will ask your Substitute Decision-Maker to make a decision on your behalf. This decision would be based on any wishes or preferences that you have previously shared with them. Any such decision would be made in your best interests and would be handled with care and understanding by your health care team.

Talking about your wishes in advance will help to make sure that any decisions that need to be made for you are the ones that you would have wanted.

There are tools that can help you in making these choices called decision aids. Please see the following websites for decision aids and additional resources.

- Canadian Hospice Palliative Care Association (www.chpca.net)
- An inventory of decision aids for many health topics is available from the Ottawa Hospital Research Institute. You can get to the website by typing 'decision aids and Ottawa Hospital' in a google search or go directly to website, www.decisionaid.ohri.ca
- A short video that is a decision aid to learn more about shared decision-making about Cardio-Pulmonary Resuscitation (CPR) can be accessed from the website that has resources about advance care planning. The website is www.advancecareplanning.ca. Type in 'decision aid for CPR' in the search box on the website to access this video.

Where and how is the ICD shock function turned off?

Usually turning off the ICD shock function will take place in the ICD clinic. Most of the time, this is done at the same hospital where your ICD was implanted.

There are two ways to deactivate the shock function of your ICD.

1. By using a programmer similar to the one used in the ICD clinic for routine checks of your ICD

A specially trained health care provider uses a laptop ICD programmer to turn off your shock function. Even though the shock is turned off, the pacemaker functions stay on. This means that if your heart beats too slowly, the pacemaker function will still work. ICD deactivation takes only a few minutes and is painless. You do not need to have your ICD removed to turn off the shock function.

2. By using a large magnet for emergency or urgent situations

If the ICD cannot be deactivated using a programmer right away, the shock function can be turned off using a medical grade magnet. The magnet is placed on your skin directly over the ICD and secured with adhesive tape.

As long as the magnet is secured in place, the ICD will not deliver shocks. For some people the magnet will need to be removed for a few seconds and taped back in place every 7 hours.

Note: If a magnet is used, the ICD still needs to be deactivated with a programmer. These arrangements should be made as soon as possible to avoid skin breakdown from the weight of the magnet putting pressure on your skin.



Trained Clinician and Computer Programmer Merlin™ Patient Care System (PCS) Merlin and St. Jude Medical are trademarks of St. Jude Medical, Inc. or its related companies. Reproduced with permission of St. Jude Medical, ©2017. All rights reserved.



Magnet taped in place over ICD

It is important to know that when the shock function is turned off, the pacemaker part of the ICD stays on. If you have a CRT-D device, you will continue to receive pacing to help improve your symptoms of heart failure.

Summary

If you decide to have your ICD shock function turned off:

- You will not feel any pain.
- You will not receive any shocks.
- It will make no difference to how you feel in general.
- It will not hasten death but allow you to die naturally.
- The ICD shock functions can be turned back on again if you change your mind.

You will not feel any pain or discomfort when your ICD shock function is turned off.

Overall, make sure that your health care team, your family, and Substitute Decision-Maker (if you have one) know your wishes about if, and when, you would want your ICD shock function turned off.

Important contact information

Hospital where I go for ICD check-ups: _____

Hospital name: _____

Contact information: _____

Name: _____ Phone number: _____

Substitute Decision-Maker (if you have one): _____

Name: _____ Relationship: _____ Phone number: _____

Device Name, Model, Serial Number (Found on your card given at time of implant):

Notes:

