

Deactivating the shock function of an implantable cardioverter defibrillator (ICD) towards the end of life

A guide for patients and carers

This leaflet is for people who have an implantable cardiac defibrillator (ICD) and may be helpful also to their family or close friends.

It discusses when it may be best for you to have the shock function of your ICD turned off (deactivated). It may be important to consider this if you develop a terminal illness, become very frail or decide that you no longer wish to receive shocks from your ICD.

Your specialist nurse, cardiac physiologist, cardiologist or other member of the ICD team will be happy to discuss this. In fact, they may have mentioned this when you first received your ICD.

It is important that you and your family or close friends have the opportunity to discuss this so that everyone understands what is involved and you can make your own personal wishes clear.

What does an ICD do?

An ICD constantly monitors your heart to identify abnormalities of its rhythm that could cause you to collapse or die suddenly.

If one of these rhythms occurs the ICD will recognise it and either:

- pace your heart very quickly to interrupt the abnormal rhythm or
- deliver a shock to your heart to put the rhythm back to normal.

Whilst the shock only lasts for a split second, some people describe the shock as being very unpleasant or painful, similar to a “kick in the chest”. However, receiving a shock can also be reassuring, by showing that your ICD is working and preventing sudden death.

If your heart beats abnormally slowly your ICD may also work as a pacemaker to keep your heart beating at the correct rate. Some people have an ICD that is combined with cardiac resynchronisation therapy (CRT-D), which may help to improve the efficiency of the heart's pumping action.

A member of your ICD team will be able to explain which type of ICD you have.

The pacemaker function, resynchronisation function and defibrillator (shock) function can be adjusted independently of each other. This will usually be done by a cardiac physiologist, using a similar programmer to the one used for routine checks on your ICD in the clinic.

Why would an ICD be deactivated?

In the future you may decide that you no longer wish to receive treatment from your ICD, particularly shock treatment. It is possible that your health may deteriorate and the focus of your care will be on your comfort rather than trying to prolong your life. For some people this may be due, for example, to progression of advanced heart disease or lung disease, or for others it may be due to development of a new problem such as advanced cancer or a severe stroke.

When someone's health deteriorates in one of these ways they usually want to make sure that the last stages of their life are as comfortable as possible. If a person has an ICD and is at or nearing the end of their life there is a risk that they will receive shocks from their ICD, in particular during the last few hours or days of their life, causing distress

both to them and to their family. Receiving shocks from your ICD in those circumstances, when you are dying from an irreversible condition, is unlikely to prolong your life in a way that you would want.

Therefore, it is important that you discuss your preferences and wishes for your care and treatment with your healthcare team. This should include discussions about whether you wish to have your ICD deactivated, if so when you may wish that to happen, and also whether or not you would want to have attempted resuscitation.

It is best to consider and discuss your wishes whilst you are well enough to make choices. If you prefer not to do that, others may have to make those choices for you if your health deteriorates and you are too unwell to decide for yourself.

If these matters have not been discussed with you and you would like more information please talk to a member of your healthcare team. If that person cannot help you, ask them to contact someone who can, for example your Specialist Nurse or Cardiac Physiologist.

Who will make a decision to deactivate my ICD?

This decision will usually be made by you, supported by your healthcare team and, if you wish, by your family or others who are close to you. You may want to have several discussions to make sure that you are happy with the decision and that deactivation of your ICD can be carried out in the right place and at the time that you feel is right for you.

Please remember that deactivation of an ICD is reversible. That is, the ICD shock function can be turned back on (re-activated) if you change your mind or if your condition improves.

Sometimes a decision to deactivate an ICD has to be made as a matter of urgency by the doctor responsible for your care. This would usually be necessary if you become very ill and are unable to make choices about your treatment yourself. Any such decision would be made in your best interests and would be handled with care and sensitivity. Whenever possible, this would be undertaken with advice from your family or other people who know you well, unless you have stated that you do not want them involved.

Discussing your views and preferences in advance will help to make sure that any decisions that are made for you are the ones that you would have wanted.

How is an ICD deactivated?

There are two ways of deactivating the shock function of your ICD:

1. Using a programmer similar to the one used in the clinic for routine checks on your ICD. The shock function is turned off but all the other functions remain active. This means that if your heart beats too slowly, the pacemaker function will still work. If your ICD also provides CRT, this will continue to help the pumping action of your heart. Deactivation takes only a few minutes and is usually done by a physiologist or ICD nurse, usually in the clinic or occasionally at home.
2. If deactivation is needed urgently and it is not possible to arrange immediately for your ICD to be deactivated using a programmer, it can be deactivated by using a large magnet. The magnet is placed on the skin directly over the ICD and secured with adhesive tape.



This will stop the ICD delivering shocks. For some people it will be necessary to remove the magnet momentarily and tape it back in place every 7 hours.

When a magnet is used for urgent deactivation, it is best regarded as an emergency, temporary arrangement. In most cases the ICD should be deactivated with a programmer as soon as this can be arranged.

It is important to remember that although the shock function of the ICD is deactivated, the pacemaker function is still working, either for treatment if your heart beats too slowly or for resynchronisation therapy for heart failure.

These pacemaker functions can be disabled too, but this is hardly ever necessary because:

- you are unlikely to be able to feel the tiny electrical signals that pace the heart, so pacing does not cause pain or discomfort;
- you are likely to feel worse if your heart beats too slowly or if the pacemaker function is withdrawn when it has been helping to reduce symptoms from heart failure.

Where will the ICD be deactivated?

Whenever possible it is recommended that an ICD is deactivated in your local ICD or Pacemaker Clinic. This is most likely to be at the hospital where you attend for your regular checks on your ICD.

If you are too unwell to attend a clinic and you are in a nursing home, a hospice, community hospital or your own home it may be possible to arrange deactivation there. However, this would need to be planned carefully so that a physiologist can attend. If you decide that you would like your ICD deactivated but think that you would be unable to attend a clinic please ask what arrangements can be made for you locally.

Who should I discuss this with?

It is usually best to talk about deactivation of an ICD when you are well and active so that all the people who care about you understand what the decision involves, the reasons for considering it and the reasons for the decision you make.

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

- your family, partner or carers;
- your cardiologist or heart failure consultant;
- your heart failure nurse if you have one;
- your General Practitioner (GP);
- your palliative care specialist if you have one;
- your cardiac physiologist or arrhythmia nurse;
- your pastoral care adviser if you have one.

These people can help you, if you wish, together with your family or others close to you to reach a decision about ICD deactivation that you are comfortable with.

If your family, partner or carers need further information or explanation about deactivation, a member of the healthcare team will provide this if you wish them to.

Summary

Deactivation of an ICD:

- Is completely painless;
- Will make no difference to how you feel, other than making sure that you do not receive shocks that may be painful;
- Will not cause death but in time allows a natural death - it simply means that as you reach the last stages of your illness you will remain free from shocks;

Is a reversible process and if the situation changes or you wish to change your mind it can be turned on again (“reactivated”)

If you decide that you do not wish to have your ICD deactivated it will be left active.

The decision can be reconsidered and discussed at any stage as your condition changes or if you wish to change your mind.

The following space is for you to write down any questions that you may have for your healthcare team.

Who else can I talk to about this?

[Contact information to be added locally. Wherever possible, direct contacts to be given so that the healthcare team is not the “gatekeeper” to further support.

- *Counsellors*
- *Pastoral carers*
- *Independent advocacy services*
- *Patient support groups*

Arrhythmia Alliance (www.heartrhythmcharity.org.uk), British Heart Foundation (www.bhf.org.uk), Dying Matters (www.dyingmatters.org) and National Council for Palliative Care (www.ncpc.org.uk).

If you feel that you have not had the chance to have a proper discussion with the healthcare team, or you are not happy with the discussions you have had, please contact *<add local details for PALS and/or other relevant services>* who can help you or the people close to you and deal with your suggestions, worries or complaints.