

## Patient information factsheet

# Deactivating your implantable cardioverter defibrillator (ICD)

We have given you this factsheet because you have an implantable cardioverter defibrillator (ICD). This device monitors your heart rhythm and is programmed to deliver a life-saving shock to your heart if it detects a life-threatening rhythm.

It is possible to switch off (deactivate) the shock therapy option on the device, if you choose to. This factsheet explains what ICD deactivation involves and why some people consider this option. We know this can be a difficult topic and are here to support you with whatever you choose to do. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

### What is ICD deactivation?

ICD deactivation involves 'switching off' the shock therapy option on your ICD so that the device stops trying to treat any rapid, dangerous heart rhythms with a life-saving shock.

It is a simple and painless procedure that you can usually have done as an outpatient (without staying overnight in hospital).

It is important to note that deactivation does **not** affect your ICD's pacing function, so your ICD will continue to provide support if your heart beats too slowly.

### When is ICD deactivation considered?

In the future, there may come a time when you would prefer not to receive any shocks. As you look ahead, you may decide to have the shock therapy option on your ICD switched off.

We understand that this can be a very difficult decision. You will need to take time to think it through and discuss it with others.

Some people may consider ICD deactivation if:

- the shock therapy is unlikely to extend their life
- the shock therapy is causing them distress or discomfort
- their heart condition has worsened significantly, causing them to experience frequent shocks and a poor quality of life
- they have another terminal condition (a condition that cannot be cured) and are approaching the end of life (some people feel that a sudden death from a heart rhythm problem is preferable to a slow decline from another terminal condition)
- they have signed a DNAR (do not attempt resuscitation) order

Switching off the shock therapy option on the ICD can increase a person's chance of a more peaceful end of life, as they won't experience the distress of receiving unnecessary shocks.

## Who makes the decision?

Ideally, you will make the decision as to whether you would like to deactivate the shock therapy option on your ICD. We will discuss the option of deactivation with you in advance, so you have time to consider your feelings and share your wishes with your family and medical team. We will support you with any decision you make.

If you are unable to express your wishes about ICD deactivation, your next of kin and doctors will discuss this together and make a decision on your behalf. This decision will be made in your best interests and will take into account any preferences or wishes you have made known to your family or medical team.

It is important that you consider deactivation and discuss your wishes with your family and medical team while you are able to, to ensure any decisions made for you are what you would want.

## What will happen during the ICD deactivation procedure?

The procedure to deactivate the shock therapy option on the ICD is performed in an outpatient setting by a cardiac rhythm management (CRM) physiologist (a healthcare professional specialising in heart rhythm disorders). It is similar to an ICD check.

The CRM physiologist will place a programmer over your device. They will then switch off the tachyarrhythmia settings (this may include the shock therapy and antitachycardia pacing functions). If your ICD provides pacing for slow heart rhythms, this will continue as normal and will not be affected by the shock therapy function being deactivated.

## What will happen after the ICD deactivation procedure?

After the procedure, you will not feel any different. ICD deactivation or reprogramming does not cause death, pain, or make your condition worse. Many people go on to live for months or years after the shock therapy option is turned off on their device.

Please note that the pacemaker part of your ICD will still work if needed.

## Can I change my mind?

Yes, ICD deactivation is a reversible procedure. If you decide later that you would like the shock therapy option on your ICD reactivated (switched back on), this can be done at any time. If this is the case, please contact us using the details at the end of this factsheet.

## Emotional support and advance care planning

Making decisions about your ICD can feel overwhelming and it is normal to experience a range of emotions. It is important to take time to think about this decision. We advise talking openly with your family and loved ones about your wishes and asking your healthcare team about advance care planning (a process for people to discuss their wishes for the future and record their views, preferences and priorities for care and treatment) to ensure your preferences are clearly documented.

If you have any questions or would like more information or support, please speak to your doctor or your specialist nurse.

You may also find it helpful to seek emotional support from:

- a counsellor
- patient support groups
- palliative care services

# Patient information factsheet

If you would like additional emotional or practical support, please let us know and we can signpost you to appropriate services. We have also included a list of online resources in the 'Useful links' section below that you may find helpful.

## Contact us

If you have any questions or concerns or would like to discuss ICD deactivation in more detail, please contact us.

Cardiac rhythm management (CRM) nurse team  
Telephone: **023 8120 8436** (Monday to Friday, 8am to 5pm)  
Email: [crmnurses@uhs.nhs.uk](mailto:crmnurses@uhs.nhs.uk)

You can also speak to your medical or specialist nurse team.

## Useful links

### NHS

[www.nhs.uk/tests-and-treatments/end-of-life-care](http://www.nhs.uk/tests-and-treatments/end-of-life-care)

### British Heart Foundation

[www.bhf.org.uk](http://www.bhf.org.uk)

ICDs and end of life

[www.bhf.org.uk/information-support/heart-matters-magazine/medical/icds-and-end-of-life](http://www.bhf.org.uk/information-support/heart-matters-magazine/medical/icds-and-end-of-life)

### Resuscitation Council UK

Deactivating the shock function of an implantable cardioverter defibrillator (ICD) towards the end of life: A guide for patients and carers

[www.resus.org.uk/sites/default/files/2020-05/CIEDs%20leaflet\\_patients.pdf](http://www.resus.org.uk/sites/default/files/2020-05/CIEDs%20leaflet_patients.pdf)

### UHS

[www.uhs.nhs.uk/departments/blood-heart-and-circulation/cardiac-rhythm-management](http://www.uhs.nhs.uk/departments/blood-heart-and-circulation/cardiac-rhythm-management)

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **PFSH@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**

Join our family of charity supporters with a monthly donation! It's a wonderful way to show your ongoing support of our patients and staff.

Scan the QR code or visit [southamptonhospitalscharity.org/donate](http://southamptonhospitalscharity.org/donate)



**Southampton  
Hospitals  
Charity**

Charity Registration Number 1051543

