

Deactivating (turning off) the defibrillator function of your pacemaker

Other formats

If you need this information in another format such as audio tape or computer disk, Braille, large print, high contrast, British Sign Language or translated into another language, please telephone the PALS desk on 01271 314090.

What is an implantable cardioverter defibrillator (ICD)?

ICD stands for implantable cardioverter defibrillator. It is slightly larger than a small matchbox and is connected to your heart by one or more leads. The ICD, which contains a battery and electronic circuit, is usually implanted under the skin in your upper chest, with the leads passed along a blood vessel to your heart.

As well as monitoring your heart, the ICD can deliver stimulation if required to change its rhythm – perhaps because it is too slow or too fast.

If required, the ICD can also produce bigger shocks to stop a dangerous heart rhythm. This is known as defibrillation. While the shocks are life-saving, they can also cause distress as well as physical pain, which many people have described as like being 'thumped in the chest'.

However, while the ICD can help you live longer by treating life-threatening heart rhythms, it will not prevent you from dying from other illnesses such as cancer, lung disease and heart failure.

Why might I consider turning off my defibrillator?

Defibrillation shocks during advanced stages of illness can be understandably distressing for both the individual and for family members. There is also a great risk that the defibrillator will fire inappropriately.

As part of the discussion about your preferences for end-of-life care, your doctor or nurse may therefore wish to talk about the option of turning off the defibrillator function of your ICD. You might, for example, have made a decision not to be resuscitated if your heart stopped beating.

When faced with a new diagnosis or deteriorating health, many people feel that their priority for care is to remain comfortable in their remaining time. In these circumstances, turning off or re-programming your ICD so that you no longer receive shock therapy can increase the chances of a more peaceful death.

What do my family and I need to consider when reviewing my options to turn off defibrillation?

Deciding whether to turn off you're the defibrillation function of your ICD is not simple, but depends on the needs and wishes of both you and your family. It may be helpful to consider the following when discussing your options:

- Has your doctor/nurse indicated that you may be nearing the end of your natural life?
- Has your quality of life deteriorated in a way that you no longer want the ICD to deliver a shock in the event of an irregular heart rhythm?
- Have you reached a point where dying suddenly from a change in heart rhythm might be seen as a good a way as any for your life to end?
- Would it be better to avoid the risk of being shocked repeatedly without meaningful or long-term prolongation of your life?

What will happen if I decide to turn off my defibrillator?

It is important that you understand a few important aspects about turning off or reprogramming your defibrillator:

- The ICD defibrillator can be turned off without affecting its other functions, which would continue to provide support for a slow or poorly- functioning heartbeat.
- Turning it off would not be painful. It is turned off using the same device used to talk to your ICD when you have your routine checks.
- Turning off the defibrillator would not cause you to die and is not suicide. It simply
 means that, when symptoms of a terminal illness cannot be managed any longer,
 you can allow nature to take its course.

Who should I talk to?

These are clearly big decisions that cannot be hurried. You may therefore find it helpful to discuss your thoughts and concerns with:

- Your partner/family/carer
- Your GP/consultant
- Your nurse
- The cardio-respiratory team (ICD clinic)

What will happen next?

If you decide to have the defibrillator function of your ICD turned off, your GP or consultant will ask you to sign a consent form. This will be sent to the cardio-respiratory department to request deactivation.

If you are already a patient in the hospital, deactivation can usually be completed the same day.

If you are at home, the cardio-respiratory department will contact you to arrange an appointment at North Devon District Hospital. This can usually be arranged within a few days.

Further information

Arrhythmia Care Coordinator – 01271 311633

Heart Failure Team – Nurse Specialists 01271 311633

Cardiac Physiologist – 01271 322745

British Heart Foundation - Telephone: 020 7936 0185

Website: www.bhf.org.uk

Arrhythmia Alliance – Telephone: 01789 450787

Website: www.arrhythmiaalliance.org.uk

References

NICE (2006) Implantable cardioverter defibrillators (ICDs) for arrhythmias. Understanding NICE guidance – information for people with arrhythmias, their families and carers, and the public.

NICE (2014) Implantable cardioverter defibrillators and cardiac resynchronization therapy for arrhythmias and heart failure (review of TA95 and TA120)

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern call 01271 314090 or e-mail ndht.pals@nhs.net. You can also visit the PALS and Information Centre in person at North Devon District Hospital, Barnstaple.

Have your say

Northern Devon Healthcare NHS Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

'Care Opinion' comments forms are on all wards or online at www.careopinion.org.uk.

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