



Advance care planning for a pacemaker or defibrillator

patient information

WHAT IS THE IDEA BEHIND A PACEMAKER AND A DEFIBRILLATOR?

A pacemaker (PM) is a device that is implanted under your skin or directly into your heart. It consists of a battery and a small computer connected to the heart via leads. If your heart rhythm is too slow, the pacemaker delivers an impulse to contract the heart muscle.

A defibrillator (implantable cardioverter defibrillator or ICD) is a device which, in the same way as a pacemaker, is implanted under your skin and usually is connected to your heart with leads. In addition to detecting slow arrhythmias, an ICD can also recognise fast arrhythmias that may lead to sudden death. The ICD attempts to stop life-threatening fast arrhythmias painlessly. If that fails, the ICD delivers a noticeable and sometimes painful electric shock. In this way, an ICD can prevent sudden cardiac death caused by fast arrhythmias (ventricular fibrillation or ventricular tachycardia).

END-OF-LIFE QUESTIONS

When growing older, it's possible that the condition of your heart may deteriorate, that you may develop another serious or even life-threatening illness or that certain impactful events may cause you to view your life differently. At such a moment, it's important to reflect on your treatment preferences and to coordinate with your doctor and/or cardiologist about what should happen with your pacemaker or ICD.

For more information, we kindly refer you to our general 'Advance care planning at UZ Leuven' guideline. An English version is available at www.uzleuven.be/en/vroegtijdige-zorgplanning.

WHEN SHOULD A PACEMAKER OR ICD BE DEACTIVATED?

Stopping a therapy, such as deactivating a pacemaker or ICD, may happen in the following situations:

- ✓ a well-considered **request of the patient** (or their legal representative in case of legal incapacity)
- ✓ or a **medical decision** of your doctor, if recovery is no longer possible and death is expected in the near future.

A properly working pacemaker is important for a patient's comfort, also during palliative and terminal phases. Deactivating the pacemaker may result in a slow heart rhythm similar to before implantation, which could reduce your quality of life. A functioning pacemaker does not prevent death because the electrical impulse it delivers can only work if the heart muscle tissue is still able to conduct the impulse and convert it into a muscle contraction. If the heart muscle cells acidify or don't get enough oxygen, the impulse will no longer be able to stimulate the heart and it will stop beating despite the pacemaker's impulses. For this reason, a pacemaker is generally not deactivated. There's no evidence to suggest that a pacemaker prolongs the dying process.

The ICD's shock function can interfere with a natural dying process and unwanted and even painful electric shocks may occur. The ICD can still produce shocks or sounds, even after death, which can be very upsetting for those left behind. For this reason, it is advisable to deactivate the ICD during the final stage of life, before the dying process begins. This does not affect the pacemaker function, which is present in every ICD.

DIFFERENCE WITH DNR (DO NOT RESUSCITATE)

A patient's request to deactivate an ICD is sometimes linked to a request not to be resuscitated.

If you choose not to be resuscitated, your ICD is not automatically deactivated.

During resuscitation, artificial ventilation and sedation are common and there is a risk of brain damage. The rapid intervention of an ICD usually prevents this. In other words, it is possible to opt for a Do Not Resuscitate policy while still choosing to keep your ICD active (temporarily). When discussing or revising your wishes regarding resuscitation, it's important to actively consider the settings of your ICD.

If you choose to deactivate your ICD, you're also choosing not to be resuscitated.

This decision should be discussed in depth and repeatedly with your cardiologist, GP and family.

LAST WILL OR EUTHANASIA

When drawing up a last will or a request for euthanasia, take your time to think about, along with your next of kin and your GP, when your ICD should be deactivated and discuss this with your cardiologist. If your cardiologist has questions or concerns about this, they can refer you.

HOW IS AN ICD DEACTIVATED?

The ICD settings are adjusted using the same computer (programmer) used for technical check-ups at the hospital. Patients don't feel anything. There is no risk of sudden or unexpected death as a result of the deactivation.

WHAT DOES IT MEAN IN PRACTICE?

If you can no longer recover from a serious illness, your doctor may discuss with you whether further treatment of life-threatening cardiac arrhythmias via ICD shocks is still a good idea in this palliative context. In consultation with your cardiologist, the ICD can be deactivated.

Patients may also ask to deactivate the device. If this is a well-considered request, the doctor will honour it. Preferably, the device is deactivated in the hospital where your check-ups occur by a cardiologist familiar with your case. However, your doctor may refer you if they have questions about the procedure.

To avoid concern about unwanted shocks, it's best to arrange this when you're still mobile and able to come to the hospital yourself. If you're no longer mobile, your GP should contact the hospital where your check-ups usually take place to discuss other options.

IN SHORT

Discuss in good time what you wish to happen with your pacemaker or defibrillator at the end of your life.

Deactivation of the shock function of your ICD:

- ✓ prevents unwanted shocks during and after the dying process.
- ✓ does not cause sudden death at the moment of deactivation.
- ✓ ensures that no further shocks are delivered in response to life-threatening fast cardiac arrhythmias.

A pacemaker is generally not deactivated, in order to avoid uncomfortable symptoms caused by a slow cardiac rhythm.

PRACTICAL

Do you have any questions after reading this brochure?
Contact the telecardiological referral centre of the cardiovascular diseases department on tel. 016 34 04 62 or 016 34 50 35.

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