



End of Life Planning

Advance Care Planning

Advance care planning is a process that promotes patient independence in which a patient identifies his/her values, preferences, and goals regarding future health care. This includes a surrogate decision-maker in the event the patient loses decision-making capacity. Many decisions about quality of life relate to independence and ability to care for one's self. Advance care planning should include discussing these values and preferences with healthcare providers and potential surrogate decision-makers, documenting them in the patient's medical record, and completing an advance directive (AD) or a living will. Having a written legal record of the care you would choose for yourself during a terminal illness or injury will insure you get the care you want.

Device Deactivation

Few patients with ICDs know that deactivation of the device is possible. While many patients with ICDs have an AD, few mention the device specifically. Many options are available with regard to the extent of deactivation of therapy. These range from programming off certain feature such as shock therapy, discontinuation of all therapy, or not replacing a depleting device battery. Generally the therapy for fast and/or life threatening arrhythmias will be disabled, while leaving on the pacemaker function. In the last weeks of an ICD patient's life, twenty percent receive shocks which are painful and known to decrease quality of life and which greatly contribute to the distress of patients and their families. Patients who engage in AD planning are less likely to experience shocks while dying because ICD deactivation has occurred. If you have a DNR (Do Not Resuscitate) in your records, this does NOT consent to turning off your device.

Life-Sustaining Treatment

When regarding a life-sustaining treatment, a patient's decisions have priority over a physician's decisions. A life-sustaining treatment is an intervention provided and managed by physicians that prolongs life but may or may not reverse the underlying disease. Examples of life-sustaining treatments are hemodialysis, mechanical ventilation, and medically assisted nutrition and hydration. Most physicians who care for patients with ICDs regard shock therapy as life-sustaining. When carrying out a patient's request for withdrawal of a life-sustaining treatment that a patient perceives as unwanted, the physicians intent is to discontinue the unwanted treatment and allow the patient to die naturally of the underlying disease—not to terminate the patient's life. The right to refuse or request the withdrawal of a treatment is a personal right of the patient and does not depend on the characteristics of the particular treatment involved. Requests to deactivate ICDs occur because patients may reach a point

where the therapies delivered become a burden, not a benefit, and are no longer consistent with their healthcare wishes. Because benefit and burden can only be determined by the patient, a patient may decide the burden of ICD therapy outweighs the benefit, even if the patient is not terminally ill.

Palliative Care

Changing or deactivating device settings can result in gradual worsening of symptoms. It is important to involve palliative care for patients before device settings are altered. Studies show that patients who receive palliative care have better quality of life at the end of life. Palliative care also plays a key role in supporting families of patients with an advanced disease, who themselves undergo declines in physical and mental health. Hospice care is provided to those patients with a prognosis of six months or less who have decided to forgo all treatments aimed at curing their underlying terminal illness. While these patients may receive some therapies aimed at treating reversible causes, hospice is fundamentally for those patients who are very near the end of life and for whom the primary goal is solely comfort.

Turning off the Device

Deactivation of ICD therapies requires a written order from the responsible physician. A representative of the device company will then come to patient and deactivate the therapies with a programmer. A 10 gauss magnet can achieve the same effect until a representative arrives. Elimination of shock therapy is less likely to result in immediate death unless the patient is experiencing increasingly frequent sudden death arrhythmias. Sometimes, patients request removal of a generator and/or leads rather than reprogramming. The same effect can be obtained by reprogramming than removal. Surgical intervention increases the chances of infection and mechanical complications of lead extraction. Legally patients have the right to refuse any treatment, but they do not have the right to demand mistreatment. Physicians have no ethical or legal obligation to meet the request of removing the device.

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