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GUIDELINE

The discontinuation of implantable cardioverter defibrillator shock therapies towards the end of life: consensus guideline from the British Heart Rhythm Society

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Abstract

Implantable cardioverter defibrillators (ICDs) are implanted in increasing numbers of patients with the aim of treating ventricular arrhythmias in high-risk patients and reducing their risk of dying. Individuals are also living longer with these devices. As a result, a greater number of patients with an ICD will deteriorate either with worsening cardiac failure, another non-cardiac condition or general frailty and will have a limited prognosis. Frequently, they will be cared for by non-cardiac teams who may be less familiar with ICDs. Therefore, to ensure the person receives high-quality end-of-life care, they should have the opportunity to consider and discuss the option to deactivate the shock function of their ICD. If the ICD shock therapy is not discontinued, there is an increased risk that, as a person reaches the last days of life, the ICD may deliver multiple, painful shocks that are distressing. There is also a risk that the device may delay the person's natural death, which the person would not have chosen if they had been given the opportunity to discuss discontinuation. The British Heart Rhythm Society has developed a practical guideline to support all healthcare professionals who are caring for patients who have an ICD. This includes descriptions of different device types, ethical and legal aspects, timing and nature of ICD discussions and practical advice regarding how the devices may be deactivated. It aims to promote awareness and timely discussion between professionals and patients and to encourage best practice.

Keywords: implantable cardioverter defibrillator; deactivation; shock; arrhythmia; older people

Key Points

- Numbers of patients with ICDs are increasing.
- Many clinicians with limited cardiology experience will care for these patients as they approach the end of life.
- Opportunities to deactivate ICD therapy are frequently missed.
- These guidelines provide practical guidance regarding when and how to approach ICD deactivation.

Patients with implantable cardioverter defibrillators (ICDs) are frequently cared for by non-cardiology clinical teams, and both elderly care and palliative care teams will frequently be involved when patients are approaching the end of their lives. These clinicians may be unfamiliar with ICDs, and the opportunity to deactivate an ICD is frequently missed with significant consequences for the patients and their relatives.

Purpose and scope

The British Heart Rhythm Society (BHRS) has commissioned a consensus guideline that aims to support and highlight key important areas of best practice when considering this clinical scenario. The guideline was written by a panel consisting of expert cardiologists and physiologists who had been elected to the BHRS council. National experts in the field of palliative care were also approached to contribute. The document was approved by the wider BHRS council members. Both the BHRS and the British Cardiovascular Society (BCS) have endorsed the document. It aims to provide clear practical guidance that is useful for both specialist cardiac teams implementing device deactivation and other clinicians who will be involved in the decision-making. This guideline has been developed to support all healthcare professionals who are caring for patients who have an ICD. It aims to promote awareness and timely discussion between professionals and patients and to encourage best practice. It should be used in a hospital, hospice and community settings. It may be adapted to allow implementation in line with existing local pathways and service provision. It is based on the useful documentation from Resuscitation Council UK but has been expanded to include more background, depth and operational guidance, especially around safe magnet use [1].

Background

ICDs are used for patients who have had either a previous cardiac arrest or are at high risk of sudden cardiac death from an arrhythmic cause. Over time, there may be a change in a patient's condition where it becomes appropriate to discontinue defibrillation therapies, e.g. advanced disease. We aim to discuss implantable defibrillators and the role of discontinuing shock therapy.

An ICD can deliver either rapid burst pacing or a shock, with the aim of terminating a ventricular arrhythmia (ventricular tachycardia or ventricular fibrillation) and restoring sinus cardiac rhythm. Most ICDs also function as a pacemaker to either prevent slow heart rates or as part of cardiac resynchronisation therapy (CRT or biventricular pacing). CRT devices synchronise contraction of the left and right ventricles and thereby reduce symptoms in some people with heart failure. A CRT device may function solely as a pacemaker (CRT-P) or also function as an ICD—these are referred to as CRT-D devices. The pacemaker and ICD functions of each device are programmable independently of each other.

Most ICDs are implanted in the left or right upper pectoral region and leads run through the veins into the heart. A recent development is the use of subcutaneous ICDs (S-ICDs), where the leads run in the anterior chest wall. These devices have very limited pacing functions. The generator is typically found in the left lateral chest wall beneath the axilla.

Due to the increasing indications for ICD implantation, the number of people with ICDs has increased. People are also living longer with these devices. As a result, an increasing number of patients with an ICD will deteriorate either with worsening cardiac failure, another non-cardiac condition or general frailty and will have a limited prognosis. Therefore, to ensure the person receives high-quality end-of-life care, they should have the opportunity to consider and discuss the option to deactivate the shock function of their ICD.

If the ICD shock therapy is not discontinued, there is an increased risk that as a person reaches the last days of life, the ICD may deliver multiple, painful and distressing shocks as they die [2]. The device may also delay natural death, something which the person would have preferred if they had been given the opportunity to discuss this.

Ethical and legal aspects

If a person with capacity requests withdrawal of treatment, despite being fully informed of the likely consequences, healthcare professionals must comply with that request, even when they consider the request unwise or illogical or when the withdrawal of treatment is contrary to medical advice. Should an individual appropriately trained healthcare professional be unwilling to carry out the deactivation themselves (where there is a properly established decision to do so), they should identify another healthcare professional to do this. Some people may be concerned that ICD discontinuation could be interpreted as a form of assisted dying and as analogous to voluntary euthanasia or assisted suicide. That is not the case [1].

Who should have discussions regarding ICD shock therapy discontinuation?

Decisions about discontinuation of any device should be made with full involvement of the patient themselves and the healthcare team caring for them and must be based on careful assessment of the individual's circumstances at the time. When people lack capacity, decisions must be made in their best interests, must be made according to the law in that jurisdiction and must involve those with legal power to make decisions on their behalf. This is more straightforward if there is an identified individual with Power of Attorney for the patient. The views of those close to the patient should be considered when making a best-interests decision in such circumstances. If a patient has learning disabilities,

it is important to involve local learning difficulty advisory teams to support decision-making.

It may be necessary to involve several members of the healthcare team and to have serial discussions with patients and those close to them before reaching a shared decision with which they are comfortable. The appropriate members of the healthcare team to contribute to this will vary.

Depending on individual circumstances, the healthcare professionals who initiate and undertake these discussions or provide support and information to patients and those close to them may include:

(1) cardiologists
(2) heart failure specialist nurses
(3) arrhythmia specialist nurses
(4) cardiac physiologists (especially those involved in device management)
(5) general practitioners
(6) non-cardiologist physicians or surgeons
(7) palliative care doctors or specialist nurses
(8) geriatricians

An immediate decision may not be needed, and so conversations can occur over time, allowing the subject to be introduced and discussed further. It is sensible to mention at the time of implant that deactivating shock therapy may well be discussed in the future and can be conducted by changing the programming without the need for surgery.

What should we explain about ICD shock therapy discontinuation?

Conversations about end-of-life and device discontinuation can be uncomfortable and challenging for patients and health professionals. There are some common myths regarding ICD shock discontinuation that are important to address. Some of the important information to share is outlined below.

(1) Near the end of a person's life, the ICD may deliver shocks that are painful and distressing and are of no benefit.
(2) Discontinuation of shock therapy from an ICD is not the same as completing a DNACPR order, but one may prompt discussion of the other.
(3) Discontinuation of shock therapy from an ICD will not cause immediate death. However, once an ICD has been deactivated, it will not deliver a shock in the event of a heart rhythm change that could cause death.
(4) Discontinuation of shock therapy of an ICD does not deactivate its pacemaker function.
(5) Discontinuation of shock therapy from an ICD is painless and does not require surgery. However, it does need to be done face-to-face.
(6) Magnet discontinuation of ICD shocks requires a medical grade magnet and is only temporary. A programming device provides reliable, permanent discontinuation of shocks.
(7) If a patient's clinical condition improves unexpectedly or they change their mind, the ICD can be reactivated.
(8) It is best to think and decide about ICD discontinuation in advance and in the context of more comprehensive advanced care planning rather than in a crisis.

Patients should be offered written information about ICD shock discontinuation, e.g. Resuscitation Council UK guidance for discontinuation of the shock function of an ICD towards the end of life: A guide for patients and carers [3].

Any discussions and decisions should be clearly documented in the patient's clinical record and shared with all members of the healthcare team, including the primary care team.

When should ICD shock therapy discontinuation be discussed?

Any discussions regarding ICD discontinuation should be introduced as early as possible and at a time that is appropriate to the individual patient and their family. Ideally, these conversations should be part of wider advance care planning rather than in isolation. This will vary, but specific situations that may trigger a conversation about possible device discontinuation may include the following. The shared decision-making prior to ICD implantation should include discussions around possible shock therapy discontinuation in the future (an example of a shared decision-making aid is available on the BHRS website [4]).

(1) Prior to implantation, at the time of consultation, as part of the informed consent process.
(2) When requested by a patient or family member.
(3) During assessment for device replacement (elective replacement due to battery depletion or advisory).
(4) Multiple shocks being delivered as a result of disease progression.
(5) A change in clinical status; worsening of condition or new comorbid condition with a poor prognosis (e.g. advanced malignancy, advanced dementia).
(6) Frailty has been shown to reduce the efficacy of ICD therapy. Frailty indices such as the clinical frailty scale may be helpful [5].
(7) Repeated hospitalisations for heart failure.
(8) Repeated emergency department visits.
(9) Refractory symptoms of a cardiac condition despite optimal therapy.
(10) Deemed ineligible for advanced heart failure therapies (e.g. mechanical circulatory support or transplant).
(11) Deteriorating quality of life and functional status.
(12) The presence of a DNACPR order, although the two are separate decisions.

(13) When referred to hospice or a nursing home facility.
(14) At a minimum, during an annual device clinic visit or during other device clinic visits.

Many patients now receive remote follow-up for their ICDs. These patients should be encouraged to get in touch with the clinical teams if they feel their condition has changed or if they would like to make some plans for their future care, such as deactivating the shock aspect from the defibrillator.

A decision not to attempt resuscitation in the event of a cardiorespiratory arrest (DNACPR) should always prompt consideration of ICD shock therapy, but it should not be assumed that this will always be appropriate.

It is preferable that any discussions regarding ICD shock therapy discontinuation should take place in advance. Unfortunately, these discussions often occur in emergency situations, which can cause distress and present practical challenges to facilitate urgent device discontinuation. A proactive approach to identify patients who may be approaching the time for shock discontinuation can reduce stress and distress for the patient, family and healthcare professionals. All members of the team involved in the follow-up of these patients should be encouraged to flag any general deterioration in the patient's health or functional status to the device follow-up team. It may be that ICD shock discontinuation is discussed many times before an eventual decision is made. Palliative care teams can help with their expertise in advanced care planning and conversation skills.

Generator replacements

When patients with an ICD are approaching generator replacement due to battery depletion, consideration should be made to whether shock therapy is still appropriate. This is particularly important in an ageing patient population. Considerations should include whether the patient's cardiac function has changed, any therapies from the device during its lifetime and the patient's general health and goals as outlined above. We recommend that all patients should have been reviewed (as a minimum) in the year prior to generator change to ensure that the clinical circumstances have not changed, and the factors outlined above have been reviewed.

If patients have had shock therapies discontinued on their device, their battery may still deplete. The device follow-up team should aim to stop any unnecessary device function to prolong the battery. In patients who have had ICD shock discontinuation, it may be necessary to carry out a generator replacement in patients who have pacing requirements to prevent slow heart rates or to treat their heart failure. In this case, a new ICD generator with immediate shock discontinuation may be an acceptable alternative to implantation of a new lead to allow downgrading of the device to a pacemaker. If patients have no pacing needs, it may be reasonable to allow battery depletion to continue without generator replacement once the ICD shocks are deactivated. The device manufacturers are wary of supporting this approach, but anecdotally, the incidence of adverse events is felt to be low. If this approach is followed, there should be a shared decision-making process, including the risks and benefits associated, and this should be clearly documented.

Device management after death

The mortician/funeral director should be informed of the device status. Typically, devices will need to be removed before any cremation, and it is crucial that any ICD therapies are switched off with a device programmer prior to this. If a magnet was applied at the time of death, it should remain in place until formal device deactivation can take place in the funeral home/mortuary. If the patient is in a hospital setting at the time of death, then they should remain in the hospital mortuary until the device is deactivated. Some regions are unable to attend devices in community funeral parlours, and local pathways may need to be followed. The device follow-up centre should be informed of this.

How should we deactivate ICD shocks?

The flowchart (Figure 1) summarises the process for discontinuation of ICD shock therapy. Where possible, device therapy discontinuation should occur in a device follow-up setting (typically a hospital). This is more likely to be possible if device deactivation is considered early in patients who are deteriorating.

The team should document shock deactivation in the patient record. Trust policies vary; this may require a specific form in the patient record completed by the responsible clinician and subsequently signed by the cardiac physiologist/scientist. Some centres may require the patient to sign the form, and others may allow verbal consent to be documented. This may be electronic. Examples of forms are included in the Appendix 1 and outline what should be documented in the patient record in the absence of a specific form.

Planned ICD shock discontinuation

ICD shock therapy discontinuation is a simple and quick procedure carried out through a device programmer by an appropriately trained member of the team. Programmers are manufacturer specific; therefore, the patient's implantable device manufacturer must be known to allow the appropriate programmer to be used. If management plans change, ICD shocks can be reactivated using a similar procedure. All centres that follow-up devices (even if not an ICD centre) should be able to discontinue ICD shocks and should be the first contact if a patient is an inpatient. We would encourage training as many individuals as possible to be able to perform this. This may include junior physiologists/echocardiographers/arrhythmia nurses and cardiologists. Appendix 2

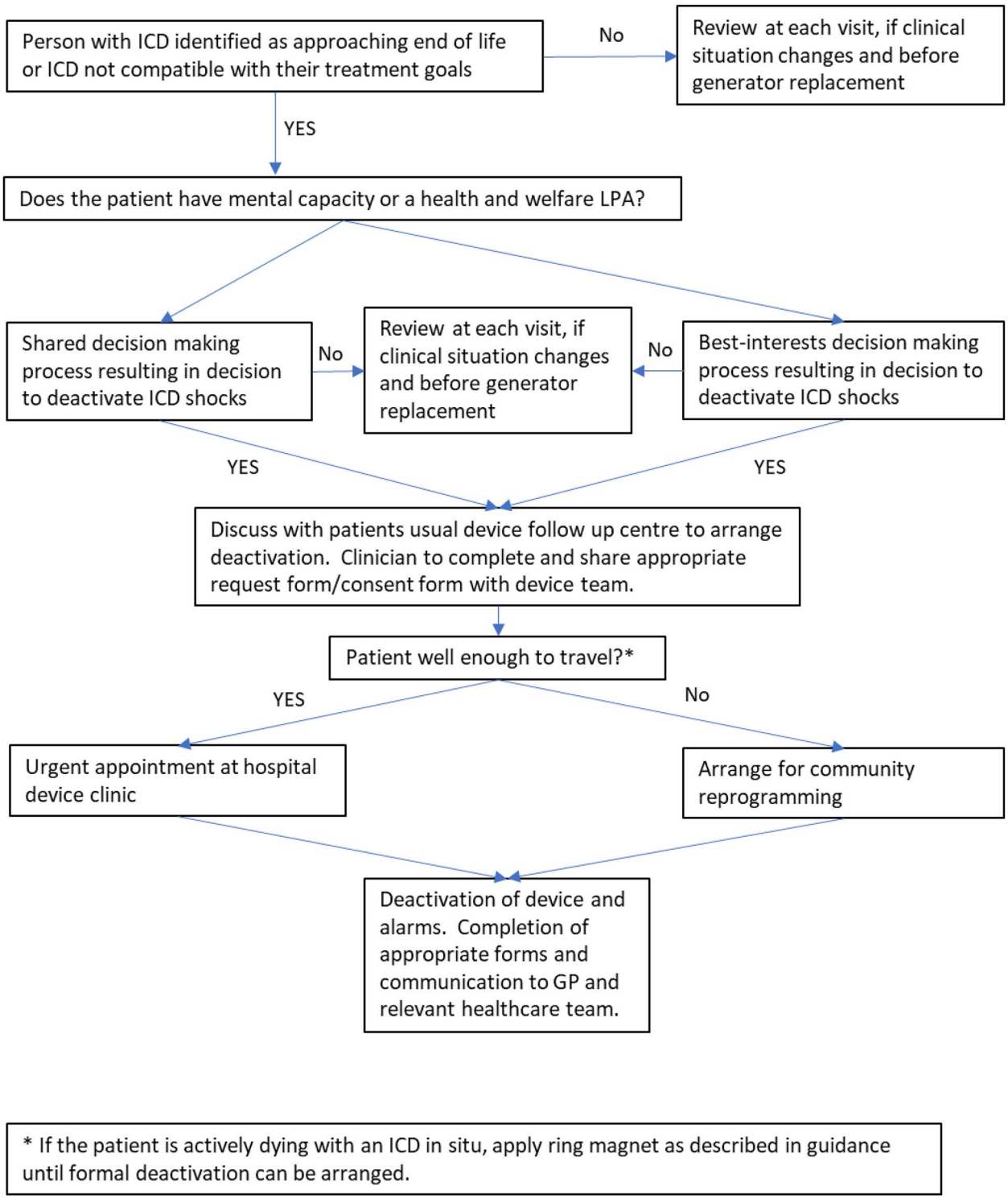

Figure 1. Flowchart for ICD shock therapy discontinuation.

includes some simple guidance for ICD discontinuation with different manufacturers, including screenshots that may be useful to support the process.

If the patient cannot attend the clinic, then the local cardiac physiology team should arrange a domiciliary or community-site device discontinuation. This can be challenging to deliver in a timely manner, particularly out of usual office hours. This will require support and usually the presence of the community team at the time of device discontinuation. Cardiac device services may have collaborative regional agreements to support delivery of community services across their areas. Once the decision to

Figure 2. ICD magnet positioning and securing.

discontinue shock therapy is made, the responsible clinical team should contact the patient's usual follow-up service as soon as possible so appropriate arrangements can be made to attend to the discontinuation in the most appropriate location.

A list of email and phone contacts within the region should be available in local policy documents in addition to any specific paper or electronic referral pathway information. Appropriate forms should be completed (as outlined in the roles and responsibilities) section, and device discontinuation should be communicated to the wider healthcare team. In the future, remote deactivation may become readily available [6].

Emergency ICD shock discontinuation

If there is a delay in facilitating ICD shock discontinuation with a programmer, application of a clinical magnet (typically ring/donut) will allow temporary discontinuation of ICD therapies. It will not affect pacing function. Magnets are typically available in hospital cardiology departments, cardiac wards and emergency departments. They may also be available from the ambulance service or local hospice services. If struggling out of hours, the local acute cardiology unit should be able to advise. This should only be a temporary measure, as magnet applications may be unreliable and uncomfortable. The following steps should be taken when a magnet is used.

(1) Ask the patient to feel and point to where the ICD is located (if possible); if not, then look for the scar, usually located to the left below the clavicle. Alternative placement could be on the right or down under the left arm around the sixth rib.
(2) Feel for the ICD, which will be a solid lump under the skin.
(3) Place the magnet over the lump—you may hear a quiet alarm/vibration as the magnet disables therapies.
(4) Secure the magnet in place with micropore/transpore, as pictured in (Figure 2) to ensure the magnet does not move.

Magnets temporarily stop the ICD delivering shock therapies, but only whilst in position over the ICD and normal function is restored as soon as it is removed. Some manufacturers' devices will reactivate ICD therapies after 8 hours of magnet application. If a patient is known to have a Biotronik ICD (or the manufacturer is unknown), the magnet should be removed and reapplied every 7 hours.

Manufacturer specific magnet application guidance

Different manufacturers have specific guidance regarding precise magnet positioning. In real-world practice, positioning the magnet directly over the device has usually been found to be effective. If it is possible to ascertain the patients' device manufacturer, then the advice outlined in Appendix 3 should be followed regarding specific magnet positioning. Patients should have a device ID card that will state the manufacturer; they may also have a home monitor and can share the name on the unit. It may be possible to access this information from the patient's usual device follow-up service or the electronic patient records. Some manufacturers' devices will beep or vibrate on magnet applications, but others do not.

Roles and responsibilities

Responsibilities of staff working in primary care, acute hospital services or palliative care once decision is made to deactivate ICD shock therapy

(1) Informing the patient and their carers of the options and the advantages/disadvantages for turning the tachycardia therapies off as part of a shared decision-making process.
(2) Contacting the patient's usual follow-up centre at their earliest convenience, to ask for support with equipment, local contacts or actual reprogramming of ICD shock therapies.
(3) Completing appropriate documentation for the patient record to document the decision-making process, including specific consent/discontinuation request forms if required.
(4) If the patient is not currently under the active care of specialist services, it is the responsibility of the patient's GP/community team to alert such services.

Responsibilities of cardiac device follow-up service

(1) All centres that offer device follow-up (even if this is not for ICDs) should have appropriate training and infrastructure to allow them to respond to needs for device discontinuation in patients in their hospital sites or local community.
(2) It is the duty of local cardiac physiology staff who deactivate the ICD to document the details in patients' notes and to communicate the same to the patient's usual follow-up centre with a copy to their GP.

(3) Completing appropriate documentation for the patient record, including specific consent/discontinuation request forms if required.
(4) The GP and other relevant health professionals should be directly informed and/or sent a copy of any completed ICD therapies discontinuation form.
(5) Ensure any patient alerts/alarms are deactivated alongside ICD shock therapy discontinuation to prevent any unnecessary patient distress.
(6) The usual follow-up centres should, on being informed of discontinuation/reactivation of a patient's device, amend the device's database and patient file.
(7) Where community device deactivation is carried out, teams should, adhere to the lone worker policy relevant to their employer, providing contact details during any community visits, and adheres to any work-related vehicle use policy. Immediate plans should be made to transfer or safely store programming equipment.
(8) Typically, when community discontinuation is arranged, a member of the community healthcare team should be present with the patient when the secondary care cardiac physiologist attends to deactivate the device.

Summary

ICD implants are increasingly prevalent in the ageing population. Management of these patients is frequently carried out by teams with limited experience in these devices. Early identification that a patient who is likely to be approaching the end of their life has an active ICD is crucial to facilitate discussions with the patient and those close to them. All the members of the multidisciplinary team can be involved in these discussions with the aim of avoiding distress during the final stages of a patient's life. The devices are simple to deactivate and by following an appropriate local pathway with effective channels of communication this can usually be carried out promptly. We encourage clinicians to explore their local clinical pathways. Magnet application is an option where ICD deactivation is urgent and formal deactivation is not possible.

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