

3 **Pacemaker deactivation: withdrawal of support**
4 **or active ending of life?**

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8 **Abstract** In spite of ethical analyses assimilating the palliative deactivation of
9 pacemakers to commonly accepted withdrawals of life sustaining therapy, many
10 clinicians remain ethically uncomfortable with pacemaker deactivation at the end of
11 life. Various reasons have been posited for this discomfort. Some cardiologists have
12 suggested that reluctance to deactivate pacemakers may stem from a sense that the
13 pacemaker has become part of the patient's "self." The authors suggest that Daniel
14 Sulmasy is correct to contend that any such identification of the pacemaker is mis-
15 guided. The authors argue that clinicians uncomfortable with pacemaker deactivation
16 are nevertheless correct to see it as incompatible with the traditional medical ethics of
17 withdrawal of support. Traditional medical ethics is presently taken by many to
18 sanction pacemaker deactivation when such deactivation honors the patient's right to
19 refuse treatment. The authors suggest that the right to refuse treatment applies to
20 treatments involving ongoing physician agency. This right cannot underwrite patient
21 demands that physicians reverse the effects of treatments previously administered, in
22 which ongoing physician agency is no longer implicated. The permanently indwelling
23 pacemaker is best seen as such a treatment. As such, its deactivation in the pacemaker-
24 dependent patient is best seen not as withdrawal of support but as active ending of life.
25 That being the case, clinicians adhering to the usual ethical analysis of withdrawal of
26 support are correct to be uncomfortable with pacemaker deactivation at the end of life.

27
28 **Keywords** Pacemaker deactivation · Withdrawal of support · End of life care ·
29 Medical ethics · Physician assisted suicide

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32 While physicians have become accustomed to withholding and withdrawing life-
 33 sustaining therapies, withdrawing is more difficult with some therapies than with
 34 others. Deactivating implantable cardiac defibrillators (ICDs) and pacemakers has
 35 been especially problematic for many physicians.¹ Accepted ethical analyses of
 36 withdrawal of these devices have assimilated them to other life sustaining
 37 treatments that physicians readily withdraw, such as hemodialysis or mechanical
 38 ventilators [1]. According to such analyses, withdrawal of these medical interven-
 39 tions is justified by the patient's right to refuse treatment. And refusal of treatment
 40 in the form of an ICD or pacemaker ought to be no different than refusal of
 41 mechanical ventilation. In the past 10 years, this analysis has, perhaps, persuaded
 42 most clinicians that ICDs can legitimately be withdrawn at the end of life. ICDs can
 43 clearly be burdensome as death approaches, and the analogy to other forms of life
 44 sustaining therapy which can also be burdensome and which clinicians readily
 45 withdraw has, by and large, been accepted. This has not been the case with
 46 pacemakers, which many clinicians remain reluctant to withdraw (when they are
 47 life-sustaining), even in the face of patient or family requests. Although response
 48 rates to surveys exploring this issue have been low, several have found a significant
 49 proportion of physicians to be uncomfortable with deactivating pacemakers [2, 3].
 50 Almost one-third of physicians responding to a 2008 survey equated pacemaker
 51 deactivation in a pacemaker-dependent patient with physician-assisted suicide [3].

52 Many possible reasons have been posited as to why physicians find the
 53 withdrawal of pacemakers to be especially problematic. It has been suggested that
 54 their small size, their location within the body, and their lack of interference with
 55 patient quality of life (in most circumstances) are all potentially important in
 56 distinguishing these devices from modes of therapy physicians are more comfort-
 57 able withdrawing [4]. While the Heart Rhythm Society has issued guidelines
 58 suggesting that both pacemakers and ICDs can be legitimately deactivated in the
 59 right circumstances [5], some cardiologists have not been persuaded that the act of
 60 pacemaker deactivation, in particular, can avoid equivalence to active euthanasia if
 61 the patient involved is pacemaker-dependent [6].

62 Clinician reluctance to deactivate pacemakers has seemed mysterious to those
 63 familiar with the conventions of clinical ethics, according to which any patient has a
 64 right to refuse treatment and hence an unequivocal right to device deactivation. Daniel
 65 Sulmasy has recently analyzed objections to pacemaker deactivation. He argues that a
 66 potent source of such objections may be a sense that the pacemaker has become a part
 67 of the patient and, hence, is no longer properly subject to requests for deactivation or
 68 removal [7]. Patients can legitimately demand withdrawal of a ventilator but not of a
 69 heart transplant. Perhaps clinicians see pacemakers as analogous to heart transplants
 70 rather than to ventilators. Sulmasy considers the character of medical interventions
 71 that have become "part of the patient." He suggests that such interventions replace

IFL01 ¹ ICDs are implanted devices that terminate lethal cardiac rhythm disturbances by automatically
 IFL02 detecting them and administering an electric shock. Pacemakers are implanted devices that sense the
 IFL03 electrical function of the heart and provide pacing impulses if those provided by the native cardiac
 IFL04 electrical system are insufficient for normal cardiac function. Many pacemakers are not life-sustaining or
 IFL05 are only so intermittently. Our argument in this paper is in regard to pacemakers that serve a life-
 IFL06 sustaining function, such that a patient's death might be reasonably anticipated after deactivation.

72 physiological functions as part of the organic unity of the organism. Having
73 scrutinized pacemakers in light of his tentative criteria for replacement therapies that
74 become “self,” he concludes that pacemakers do not actually become “self” and
75 hence ought not to be considered “part of the patient.” As they are thus conventional
76 medical treatments, they can and should be withdrawn, that is, deactivated, when
77 patients ask for withdrawal or deactivation.

78 We believe that Sulmasy is correct to suggest that if replacement therapies
79 become part of the person, physicians ought not to be obligated to accede to requests
80 for deactivation or withdrawal. But we shall argue that this is too high a bar to set
81 for the class of interventions that physicians might legitimately regard as active
82 ending of life. Patients have the right to refuse ongoing medical treatment; but we
83 shall argue that they do not have the right to demand that physicians undo
84 treatments previously completed. What sets apart medical interventions that
85 physicians may refuse to withdraw or deactivate is the absence of ongoing physician
86 agency. Organ transplants and other treatments that have become part of the patient
87 are, of course, among such treatments. But so are others, including, as we shall
88 suggest, pacemakers.

89 **Withholding and withdrawing treatment**

90 Conventional doctrine in medical ethics on withholding and withdrawing treatment
91 has developed from the core notion of the patient’s right to refuse treatment [8]. That
92 right clearly justifies a patient’s demand to deactivate a pacemaker if the pacemaker is
93 “treatment”—ongoing intervention by a physician or physicians aimed at sustaining
94 or improving health. We shall return to that issue. But it is important to establish
95 whether other generally accepted reasons for recommending withdrawal of life
96 sustaining therapy apply to the withdrawal of pacemakers or whether patient refusal is
97 the sole acceptable justification for pacemaker withdrawal in conventional medical
98 ethics. To answer this question, we begin with an account of the usual physician
99 perspective on the ethics of withholding and withdrawing treatment.

100 Physicians seek to act in the interests of the patient. The determination of medical
101 interest is generally made by the physician, in part, independently of the patient’s
102 wishes. The legitimacy of such a mode of proceeding would, of course, be hotly
103 disputed by many ethicists, who would likely argue that a patient’s medical interests
104 ought not to be construed as independent of the wishes of the patient. Many
105 physicians would reply that while a patient’s wishes must always be taken into
106 account, they do not necessarily determine what would be good for that patient,
107 medically speaking—that is, good for the patient from the standpoint of that
108 patient’s life and health.

109 Physicians approach the issue of withholding and withdrawal, at least initially,
110 from the latter standpoint. They consider the likely benefits and burdens of a given
111 life-sustaining intervention in deciding whether to offer and recommend that
112 treatment to a patient. If a patient is receiving such a treatment, the decision to
113 recommend withdrawal would also turn upon a calculation of burdens and benefits.
114 Recommendations based upon such calculations are subject to a further traditional



imperative: physicians generally hold themselves obliged to act without intending the patient's death. If death can be foreseen to likely follow the withdrawal of life sustaining treatment, the physician invokes the principle of double effect, according to which acts causing bad outcomes may sometimes be permissible if such outcomes are a side effect, rather than the intended effect, of the act [9]. In the case of withdrawal of life-sustaining therapy, the intended effect is relief of the burden of a no-longer-beneficial treatment. The physician, in so relieving the patient of the burden of, say, mechanical ventilation, does not kill him; she allows him to die of his underlying disease.

This traditional view of how a physician's obligation not to kill might be compatible with the withdrawal of life sustaining treatment is, of course, deeply controversial. One of the most important arguments in favor of physician-assisted suicide or active euthanasia is the contention that withdrawal of life-sustaining therapy is, in fact, a life-ending act that is not in principle different from active euthanasia, presuming the patient's complicity and the physician's beneficent intent. On this view, there is no morally significant difference between doing and allowing in cases such as physician killing and so-called allowing-to-die; and the doctrine of double effect fails to identify a meaningful distinction between intended and foreseen outcomes. Physicians actively end the lives of patients when they withdraw life-sustaining treatment and they should face up to the fact [10].

While this attack on traditional medical ethics is important in the ethics literature and likely also among physicians who practice physician-assisted suicide in states such as Washington and Oregon, it has not yet prevailed in the medical mainstream. That being so, it is fair (we believe) to contend that the medical practice of withholding or withdrawing life sustaining treatment generally follows guidelines according to which the withdrawal of such therapy may be recommended (and undertaken) if one of the following holds:

1. It is judged by physician and patient that the burden of such treatment exceeds any benefit conveyed by the treatment to the patient, and the physician in withdrawing the treatment intends relief of the burden and not the death of the patient (although the death of the patient following withdrawal may be foreseen).
2. The patient demands withdrawal; irrespective of the physician's judgment of burden and benefit, life-sustaining treatment may and must be withdrawn if the patient demands withdrawal. The patient always has the right to refuse treatment even if such treatment is judged by the physician to be medically beneficial (or essential).

Deactivating ICDs and pacemakers

ICDs and pacemakers fare somewhat differently when their withdrawal is considered in light of the above analysis of traditional medical thinking about withdrawal. ICDs can clearly be burdensome to patients in some circumstances; in end-stage congestive heart failure, it might be judged likely that a patient would

157 suffer repeated shocks from an ICD without any fundamental improvement in the
 158 heart's function or in its propensity to fatal arrhythmias. In such a case, the burden
 159 of an ICD might easily be judged by both physician and patient to exceed any
 160 benefit gained from the device. Cardiologists are generally willing to deactivate
 161 ICDs in such circumstances.

162 The withdrawal of pacemakers is not so straightforward; patients are generally
 163 insensible to pacemakers and it is difficult to conceive of circumstances in which
 164 burdens undergone by patients are attributable to a pacemaker (rather than to
 165 underlying disease). In such cases, it is difficult to argue that deactivating a
 166 pacemaker is not aimed at the patient's death if the patient is pacemaker-dependent.
 167 Any attempt to invoke the doctrine of double effect in exculpating the physician
 168 from a charge of intending the patient's death in such a case would be vulnerable to
 169 a traditional charge of abuse of that doctrine: that the actor can justify any act that
 170 causes ill effects simply by manipulating her intentions. The terror bomber might
 171 say that in bombing the innocent he intends not their deaths but a quicker end to the
 172 war. The legatee might say that in killing his father he intends not his father's death
 173 but simply to enjoy his inheritance the sooner [11]. Similarly, the physician in
 174 deactivating the pacemaker might claim to intend something other than the patient's
 175 death—but if there is no burden borne by the patient on account of the pacemaker,
 176 what might that be? According to double effect reasoning, a given outcome can be a
 177 side effect only if it is neither itself a bad outcome or (exclusively) the means to
 178 such an outcome. In the absence of any burden conveyed to the pacemaker-
 179 dependent patient by the pacemaker, the only outcome from its deactivation
 180 available as an end to the deactivator is the patient's death. And the pacemaker's
 181 deactivation can then only be a means to that end, whatever the deactivator might
 182 claim to otherwise intend.

183 The physician adhering to traditional medical ethics might, therefore, demur
 184 from recommending pacemaker deactivation in a pacemaker-dependent patient
 185 because in performing such an act, she would be implicated in active euthanasia. In
 186 the absence of a pacemaker-induced burden to be relieved, pacemaker deactivation
 187 can be the means only to the patient's death and thus must be impermissible. The
 188 only exception to such impermissibility would be cases in which the patient himself
 189 demands deactivation. In such cases, the patient's right to refuse treatment would
 190 allow the deactivating physician to intend an end other than the patient's death, i.e.,
 191 honoring the patient's refusal of a treatment. And the doctrine of double effect
 192 would then justify the physician's act as an act primarily of withdrawing an
 193 undesired treatment, of which the patient's death (from the physician's standpoint)
 194 would be an unfortunate side effect.

195 **A possible source of clinician resistance to considering pacemaker deactivation**
 196 **to be withdrawal of a treatment: the pacemaker as “replacement therapy”**

197 The above analysis of pacemaker deactivation in the case of a patient who demands
 198 such deactivation would be standard for many physicians that accept traditional
 199 medical ethics (that is, a medical ethics that rejects active euthanasia and parses

200 physician actions that hasten death, such as withdrawal of life-sustaining therapy, in
 201 terms of double effect). While patient refusal of continued treatment is a relatively
 202 narrow ground for justifying pacemaker withdrawal, it is clearly one of the reasons
 203 for the withdrawal of life-sustaining therapy that are traditionally regarded as
 204 acceptable. Perhaps this analysis has not been sufficiently considered by the many
 205 physicians who continue to regard pacemaker deactivation in pacemaker-dependent
 206 patients to be active euthanasia, even in cases when patients or families request such
 207 deactivation. While it is likely true that clinicians do not, in general, concern
 208 themselves with the niceties of medical ethics, clinical practice in regard to the
 209 withdrawal of other forms of life-sustaining therapy certainly conforms to this
 210 standard analysis. By the early 1990s, professional organizations in the United
 211 States had produced statements asserting the propriety of withdrawing life-
 212 sustaining therapy if it is judged to be futile (or if patients demand such withdrawal).
 213 These statements took care to deny that such withdrawals have to constitute active
 214 euthanasia [12, 13]. And by this time, most clinicians did not regard most
 215 withdrawals of life-sustaining treatment to be active euthanasia [14]. The
 216 importance of distinguishing active euthanasia from the withdrawal of life-
 217 sustaining treatment (allowing-to-die) has been reiterated in more recent profes-
 218 sional statements [15]. Clinicians readily withdraw life-sustaining therapy in dying
 219 patients (or in patients who request such withdrawal) and construe such acts as
 220 allowing-to-die. Why would the same clinicians not assimilate pacemaker
 221 deactivation to their other practices of withdrawing treatments when patients refuse
 222 them?

223 Clinicians who equate pacemaker deactivation to active euthanasia do not
 224 necessarily offer clear or cogent reasons for their position. As mentioned above,
 225 Goldstein's qualitative research points to the small size and location within the body
 226 of the pacemaker as features that may generate clinicians' reluctance to deactivate
 227 [4]. The best articulated instance of a position opposing pacemaker deactivation, of
 228 which we are aware, is that of G. Neal Kay and Gregory Bittner [6]. Kay and Bittner
 229 invoke the distinction between ordinary and extraordinary care and suggest that a
 230 pacemaker in place is ordinary care, implying that it ought not to be withdrawn or
 231 deactivated. For their equation of pacemaker deactivation to active euthanasia,
 232 however, they appear to rely more on a different kind of argument. They draw upon
 233 Sulmasy's distinction between medical treatments that become part of the patient's
 234 "self" and treatments that remain separate from the patient [7]. Sulmasy took note
 235 of clinician objections to deactivating ICDs and pacemakers and sought to consider
 236 whether there were medical therapies that required a re-drawing of the line between
 237 killing and allowing-to-die, which the medical profession had drawn in the case of
 238 treatments like mechanical ventilation and hemodialysis.

239 Sulmasy begins by distinguishing between regulative and constitutive therapies;
 240 the latter do not merely adjust natural corrective mechanisms (regulative therapies)
 241 but replace physiological functions. Antipyretics are regulative; therapies such as
 242 pacemakers or insulin are constitutive. Constitutive therapies may be further divided
 243 into those that are "substitute" and those that are "replacement." The latter are not
 244 only substitutive but also part of the patient's organic unity. A ventilator is a
 245 substitute therapy; an organ transplant is an archetypal replacement therapy.



246 Sulmasy plausibly argues that the more a treatment can be seen as a replacement
 247 therapy, the less it may seem morally appropriate to withdraw. He offers criteria for
 248 deciding whether a therapy is replacement, including responsiveness to the
 249 environment, growth and self-repair, independence from external control or supply,
 250 immunologic compatibility, and physical integration into the body.

251 Kay and Bittner contend that a pacemaker meets these criteria sufficiently to be
 252 considered replacement therapy. If they are correct, deactivating a pacemaker would
 253 be an act that is analogous to injecting potassium chloride into a transplanted heart
 254 to stop it. Clearly such an act would be a killing rather than an allowing-to-die and
 255 would thus be unacceptable in any ethics that forbade active euthanasia. It seems
 256 doubtful, however, that Kay and Bittner are correct in contending that pacemakers
 257 are replacement therapies in Sulmasy's sense. Even if it is granted that pacemakers
 258 are constitutive therapies, replacing rather than merely regulating an aspect of the
 259 heart's function (in this case its generation of electrical impulses that stimulate heart
 260 muscle contraction), it is not at all clear that they become part of the organic unity of
 261 the patient.

262 While pacemakers exhibit some responsiveness to the environment and limited
 263 independence from external energy sources and control, they clearly do not grow or
 264 repair themselves. They are immunologically compatible with the body but this is
 265 not because they are immunologically self; rather, they are immunologically inert.
 266 And in spite of their implantation within the body, they are not physically integrated
 267 with it. Pacemakers, in spite of their small size and intra-body location, seem clearly
 268 to be "other" rather than "self"; as such, they seem more similar to constitutive
 269 therapies such as ventilators than to organ transplants. If that is correct, they are
 270 substitutive rather than replacement therapies, in Sulmasy's terminology, and the
 271 special character of replacement therapies offers no grounds for distinguishing
 272 pacemakers from other substitutive therapies such as ventilators.

273 Some have suggested grounds other than organic integration for considering that
 274 an implanted device might be "part of" the patient (and thus ineligible for
 275 compulsory removal or deactivation by physicians on the ground of a patient's right
 276 to refuse treatment). Jeremy Simon suggests that if an implanted device not only
 277 restores organ function but allows independent living, it has become analogous to a
 278 transplanted organ and cannot be the object of a withdrawal or deactivation request
 279 that physicians must honor. He offers the hypothetical example of an artificial heart
 280 completely independent of external support, which, as he says, is a very conceivable
 281 if not yet realized example of artificial organ technology [16]. Simon plausibly
 282 proposes that a physician might legitimately refuse a patient's request that such an
 283 artificial heart be explanted or deactivated. Simon extends his analysis beyond
 284 implanted devices, arguing that hypothetical backpack ventilators might have a
 285 similar status. For Simon, the aspects of such devices that make them part of the
 286 patient they support are (1) replacement of physiological function and (2) functional
 287 independence of the person supported by the device or treatment [17].

288 This line of argument is resisted by Ruth Fischbach and Katrina Bramstedt, who
 289 suggest that devices such as LVADs or artificial hearts are more analogous to
 290 mechanical ventilators than to organ transplants and, thus, ought to be considered
 291 ongoing treatments subject to withdrawal upon request rather than "part of the



292 patient” and, thus, improper objects for such requests. If such devices are
 293 deactivated, Bramstedt and Fischbach argue, the patient dies of the underlying
 294 disease, not from device deactivation. Such a death is, then, passive rather than
 295 active euthanasia [17, 18].

296 In suggesting that physicians would hesitate to deactivate an implanted artificial
 297 heart that allowed a patient to live independently, Simon is likely correct; such
 298 physician reluctance would mirror well-documented physician reluctance to
 299 deactivate pacemakers in pacemaker-dependent patients. It seems a stretch,
 300 however, to base this reluctance upon an alleged status of the artificial heart as
 301 “part of” the patient. And considering a hypothetical backpack ventilator to be part
 302 of the patient seems even less plausible than considering an artificial heart to be so.
 303 Felicitas Kraemer has pointed out some of the difficulties in deciding when internal,
 304 external, or hybrid devices might be part of the patient or not [19].² At least insofar
 305 as the notion of being “part of” an organism implies organic integration, as
 306 typically it does, arguments that implanted devices become part of the patients in
 307 whom they are implanted face an uphill climb. For Simon, Kay, and Bittner, such
 308 arguments appear to serve the purpose of rationalizing the reluctance that many
 309 clinicians feel when asked to deactivate certain of these devices, but as far as we can
 310 see, such arguments have not successfully achieved such rationalization.

311 **A different ground for rejecting a right to pacemaker deactivation:** 312 **as an instance of the right to refuse treatment**

313 We shall suggest that clinician assessments that some device deactivations are
 314 active rather than passive euthanasia do have validity, but we shall offer grounds for
 315 this assessment that do not construe the devices in question as part of the patients in
 316 whom they are implanted. Sulmasy’s distinction certainly does identify a class of
 317 medical interventions that patients cannot demand to reverse based on their right to
 318 refuse treatment. Pacemakers and LVADs are not clearly replacement therapies
 319 (in Sulmasy’s terminology); but we contend that therapies organically integrated
 320 into the body may not be the only medical treatments to which a right of refusal
 321 does not apply.

322 It is instructive to consider Katrina Bramstedt’s analysis of the total artificial
 323 heart as a therapy that falls under a patient’s right of refusal (which physicians
 324 would be, therefore, obligated to deactivate upon the patient’s request) [18].
 325 Bramstedt considers the total artificial heart (TAH) as a replacement of function
 326 therapy (meaning not organic integration, as per Sulmasy, but merely replacement
 327 of physiological function) and is led to ask whether one should view deactivation of
 328 the TAH differently from that of other replacement of function therapies such as
 329 ventilators. She answers in the negative, suggesting that in each case the important
 330 factor to consider is the therapy’s replacement of function. Life sustaining therapies

2FL01 ² Kraemer’s suggested solution to the problem, which we shall not address here, is to posit that the
 2FL02 patient’s perception of the device can guide our thinking as to whether the device is part of him/her or not
 2FL03 and, hence, as to whether device deactivation is active or passive euthanasia in a given case. We suspect
 2FL04 that this approach to the problem is too subjective to be satisfactory.

331 such as ventilators, extra-corporeal membrane oxygenation (ECMO), and TAHs are
 332 all on a par in that their withdrawal allows an underlying disease to take its course.
 333 This analysis would also extend, presumably, to pacemakers in pacemaker-
 334 dependent patients, although Bramstedt does not explicitly mention pacemakers. In
 335 all such cases, the patient's death after withdrawal is rightly attributed to the
 336 underlying disease rather than to the deactivation of the life sustaining therapy; and
 337 the physician's action in deactivating the therapy is thus passive rather than active
 338 euthanasia. Fischbach takes a similar line on LVADs, suggesting that deactivating
 339 an LVAD leads to the patient's death from heart failure. Fischbach also invokes the
 340 partially external character of the LVAD in support of this position, suggesting that
 341 for her not only the replacement of function but also the character of an intervention
 342 as internal or external are material to whether death induced by its withdrawal is
 343 active or passive euthanasia [17].

344 The Bramstedt/Fischbach analysis, we think, proves both too little and too much.
 345 It proves too much because it is unclear that this view would exclude organ
 346 transplants from patient requests for explantation or deactivation (perhaps through
 347 intracardiac KCL, in the case of a heart). If the replacement of function (referring to
 348 physiological replacement) of a therapy confers inclusion in the group of therapies
 349 whose removal or deactivation physicians must honor on request, heart transplants
 350 would appear to fall within that group. Bramstedt would likely resist this
 351 conclusion; she offers an example of a patient who sustained a massive stroke
 352 after coronary artery bypass grafting. She asks whether one might consider his
 353 bypass grafts to be "life support" and thus amenable to requests for the removal of
 354 life-sustaining therapy after the stroke. She answers in the negative because "graft
 355 explant would actively cause the patient's death, irrespective of his disease state"
 356 [18]. Bramstedt would likely view explantation of a transplanted heart in a similar
 357 light. But this seems inconsistent. Why, on Bramstedt's view, ought we to consider
 358 a transplanted heart (or bypass grafts) differently from an artificial heart in regard to
 359 the character of the physician's action in deactivating or removing them? All three
 360 replace an impaired physiological function the absence of which would result in the
 361 patient's death. Her view implies that removing the physician-inserted therapy in
 362 any of these cases is simply to allow an underlying disease to take its course. In the
 363 case of organ transplants, bypass grafts, prosthetic valves, and other such
 364 interventions, such a view is implausible.

365 The analysis proves too little because it is simply not clear that withdrawals or
 366 deactivations of LVADs or pacemakers or artificial hearts simply "allow [the]
 367 disease to take its course." The thrust of the Bramstedt analysis is to suggest that
 368 medical treatments such as ventilators or artificial hearts do not fundamentally alter
 369 the fatal processes against which they are directed, such that removing such
 370 treatments simply allows the disease to take its course. Simon's riposte is to suggest
 371 that in fact some treatments, such as artificial hearts, do not merely obstruct a fatal
 372 process but instead bring about a new homeostasis. Given that an organism is in
 373 ongoing physiological equilibrium, even if in an equilibrium inferior to that of its
 374 natural healthy state, an interference that upsets this equilibrium must be "doing"
 375 rather than merely "allowing." And an interference that hastens death is then active
 376 killing rather than allowing to die.

377 We do not believe that there is an obvious right choice between the Bramstedt
 378 and Simon construals of an organism subjected to a life-sustaining medical
 379 treatment such as a hypothetical self-contained artificial heart. Whether one
 380 construes such an organism as being on an arrested trajectory toward death or as in a
 381 new (albeit inferior) equilibrium seems more a function of one's own interests than
 382 of any feature of the treated organism itself. If this is correct, Bramstedt and Simon
 383 are at an impasse.

384 We wish to suggest a different approach to characterizing withdrawals of support
 385 in medicine—as “doing” or “allowing.” It is important initially to be clear about
 386 the concepts to which these terms refer. Neither merely characterizes acts or
 387 omissions within a causal chain or web. Consider, for example, Dan Brock's pair of
 388 cases involving a terminally-ill woman on a ventilator [20]. In one case, her greedy
 389 nephew, anticipating an inheritance, sneaks into her hospital room and disconnects
 390 the ventilator. In the other case, her physician, carrying out her wishes to withdraw
 391 support, disconnects the ventilator. Both nephew and physician perform the same
 392 act qua intervention in a causal sequence. But we label one as a doing (an active
 393 killing) and the other as an allowing-to-die. Labeling acts such as these as “doing”
 394 or “allowing” is characterizing the actor's agency, as expressed in the act, as
 395 positive or negative. And the character of agency expressed in an act (or omission)
 396 is determined not only by the fit of the act into a causal structure but by the identity
 397 of the actor and by the contextual norms and obligations that bear upon said actor. In
 398 Brock's pair of cases, the nephew's agency is positive because the nephew has no
 399 proper role in the management of the aunt's ventilator. Any interference with it by
 400 the nephew is positive agency. The physician's agency is negative because he is
 401 positively implicated in the ventilator's ongoing presence and efficacy (properly
 402 so)—so that removing it in the face of terminal illness in accordance with the aunt's
 403 wishes is an allowing.

404 This analysis, we believe, offers the clue to the proper labeling of withdrawal or
 405 deactivation of medical therapies as doing or allowing. The important consider-
 406 ations for proper labeling is not the treatments' degree of organic integration, their
 407 role in the patient's physiology, their internal or external character, or the degree of
 408 independence they allow the patient to assume. It is the role of ongoing physician
 409 agency in the treatment's presence and efficacy. This is what distinguishes heart
 410 transplants, prosthetic valves, permanent indwelling sutures, and bypass grafts from
 411 ventilators for purposes of characterizing withdrawal or deactivation. If tissue or a
 412 device inserted by a physician is playing a critical role in maintaining a patient's
 413 physiological equilibrium (and, hence, his/her life), the removal of said tissue or
 414 device may be a doing (killing) or an allowing-to-die in so far as the physician is not
 415 or is actively involved in the tissue/device's presence and activity.

416 We stipulate “may be” because scenarios are conceivable that complicate the
 417 analysis. What if a physician becomes homicidal and surreptitiously disconnects a
 418 ventilator from a ventilator-dependent patient who is expected to recover (or who is
 419 terminally ill)? Such an act is clearly a doing rather than an allowing. It is so, once
 420 again, because of the norms that bear on the physician's action in such a case. Only
 421 in the case of physicians acting properly in the interests of their patients is a
 422 withdrawing of life-sustaining treatment involving ongoing physician agency an

423 allowing-to-die. As we have suggested, in the traditional analysis, these would be
424 limited to cases in which the burden of treatment is judged to exceed the benefit or
425 to cases in which treatment is refused.

426 This traditional analysis does not bear on treatments in which ongoing physician
427 agency is absent, such as heart transplants, orthopedic hardware, permanent sutures,
428 and prosthetic valves. Once such medical interventions are in place, the physician's
429 agency is no longer involved in their continuing efficacy. The physician has become
430 a bystander rather than an agent in regard to the function of such interventions. Such
431 interventions were put into place to arrest a harmful sequence of events—
432 mechanical forces interfering with healing in the case of orthopedic hardware and
433 sutures or disordered cardiac physiology in the case of prosthetic valves. The
434 functions of these interventions are analogous to those of interventions involving
435 ongoing physician agency, such as mechanical ventilation or hemodialysis, which
436 also obstruct harmful physiological processes. Interventions in place, however,
437 become different from ongoing interventions (in regard to the meaning of physician
438 interference) when physician agency ceases to be involved in their continuing
439 action.

440 The right to refuse treatment is an instance of a broader right not to be interfered
441 with. In the case of patients and physicians, it is the right of the patient to demand an
442 allowing, perhaps an allowing-to-die. Patients may demand that physicians stop
443 doing something—generally that they stop interposing an obstacle to a harmful or
444 fatal sequence of bodily events. While patients have a right to refuse ongoing or
445 future physician interventions, a negative right against interference does not confer
446 a right to demand that physicians undo the effects of treatments previously
447 administered, in the present effects of which the physician's ongoing agency plays
448 no part (presuming, of course, that the previously administered treatments were
449 performed in accord with the patient's wishes).

450 How does this point bear on LVADs, ICDs, and pacemakers? These devices are
451 not, of course, quite as independent of continuing physician agency as are prosthetic
452 heart valves. We would suggest that a patient right of refusal would apply to those
453 aspects of these treatments that involve ongoing physician agency. Patients may
454 rightly refuse a renewal of the power supply for these devices or physician
455 monitoring and adjustment of them. If we are correct, patient demands to remove or
456 deactivate them, if they are sustaining life and do not of themselves confer a
457 disproportionate burden on the patient (such as an ICD often might), are demands
458 for a physician to actively hasten death rather than to allow disease to take its
459 course. They are not refusals of treatment but demands for undoing previous
460 treatment. As such, they do not fit into the traditional analysis of legitimate
461 physician withdrawal of support.

462 Conclusion

463 Clinician reluctance to deactivate pacemakers in pacemaker-dependent patients has
464 seemed anomalous in the context of the same clinicians readily withdrawing other
465 forms of life sustaining therapy when such therapy is deemed futile or when patients

466 request withdrawal. A persuasive rationale for such clinician reluctance in the case
 467 of pacemakers has seldom been articulated. Kay and Bittner's effort in this regard is
 468 not wholly convincing. Our argument, if it is successful, shows that clinician
 469 misgivings about pacemaker deactivation are in fact well-founded. On our reading,
 470 the traditional ethical analysis of the withdrawal of life sustaining therapy does not
 471 permit the withdrawal of a pacemaker (or of other completed treatments) on the
 472 grounds of a right to refuse treatment. As we have argued, the physician is a
 473 bystander in regard to the pacemaker, which is (in large part) a treatment completed
 474 rather than ongoing; and a patient right to refuse treatment cannot apply to
 475 completed treatments.

476 Clinician discomfort or even "moral distress" associated with particular forms of
 477 caregiving may often be unwarranted [21]. It may, however, point to real ethical
 478 difficulties even when the clinicians involved have difficulty articulating just where
 479 the ethical difficulty lies. We believe that clinician discomfort with pacemaker
 480 deactivation is such a case. Contrary to previous ethical analyses, pacemaker
 481 deactivation (in pacemaker-dependent patients) is better seen as doing than
 482 allowing, as active ending-of-life rather than as the withdrawal of an ongoing
 483 treatment that patients have a right to refuse. Clinicians persuaded by the usual
 484 ethical analyses of withholding and withdrawing therapy and who accept a
 485 prohibition on active euthanasia ought not to advise patients to consider pacemaker
 486 deactivation or accede to patient requests for it. Compassionate and effective end-
 487 of-life care need not involve hastening death through means the end of which can
 488 only be such hastening rather than the relief of burdens or the honoring of patient
 489 rights.

491 **Conflict of interest** None.
 490

492 References

- 493 1. Mueller, P.S., C.C. Hook, and D.L. Hayes. 2003. Ethical analysis of withdrawal of pacemaker or
 494 implantable cardioverter-defibrillator support at the end of life. *Mayo Clinic Proceedings* 78:
 495 959–963.
- 496 2. Mueller, P.S., S.M. Jenkins, K.A. Bramstedt, and D.L. Hayes. 2008. Deactivating implanted cardiac
 497 devices in terminally ill patients: Practices and attitudes. *Pacing and Clinical Electrophysiology* 31:
 498 560–568.
- 499 3. Kapa, S., P.S. Mueller, D.L. Hayes, and S.J. Asirvatham. 2010. Perspectives on withdrawing pace-
 500 maker and implantable cardioverter-defibrillator therapies at end of life: Results of a survey of
 501 medical and legal professionals and patients. *Mayo Clinic Proceedings* 85: 981–990.
- 502 4. Goldstein, N.E., D. Mehta, E. Teitlbaum, E.H. Bradley, and R.S. Morrison. 2007. "Its like crossing a
 503 bridge" complexities preventing physicians from discussing deactivation of implantable defibrillators
 504 at the end of life. *Journal of General Internal Medicine* 23(Suppl. 1): 2–6.
- 505 5. Lambert, R.L., D.L. Hayes, G.J. Annas, et al. 2010. HRS expert consensus statement on the man-
 506 agement of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or
 507 requesting withdrawal of therapy. *Heart Rhythm* 7: 1008–1026.
- 508 6. Kay, G.N., and G.T. Bittner. 2009. Should implantable cardioverter-defibrillators and permanent
 509 pacemakers in patients with terminal illness be deactivated? An ethical distinction. *Circulation*
 510 *Arrhythmia and Electrophysiology* 2: 336–339.
- 511 7. Sulmasy, D.P. 2007. Within you/without you: Biotechnology, ontology, and ethics. *Journal of*
 512 *General Internal Medicine* 23(Suppl 1): 69–72.
- 513 8. *Cruzan v. Director, Missouri Department of Health*. 1990. 497 U.S. 261.

- 514 9. Sulmasy, D.P., and E.D. Pellegrino. 1999. The rule of double effect: Clearing up the double talk.
515 *Archives of Internal Medicine* 159: 545–550.
- 516 10. Miller, F.G., R.D. Truog, and D. Brock. 2010. Moral fictions and medical ethics. *Bioethics* 24:
517 453–460.
- 518 11. Anscombe, G.E.M. 1961. War and murder. In *Nuclear weapons: A catholic response*, ed. W. Stein.
519 London and New York.
- 520 12. Bone, R.C., E.C. Rackow, and J.G. Weg. 1990. Ethical and moral guidelines for the initiation,
521 continuation, and withdrawal of intensive care. *Chest* 97: 949–958.
- 522 13. American Thoracic Society. 1991. Withholding and withdrawing life-sustaining therapy. *Annals of*
523 *Internal Medicine* 115: 478–485.
- 524 14. Solomon, M.Z., L. O'Donnell, B. Jennings, et al. 1993. Decisions near the end of life: Professional
525 views on life-sustaining treatments. *American Journal of Public Health* 83: 14–23.
- 526 15. Truog, R.D., M.L. Campbell, J.R. Curtis, et al. 2008. Recommendations for end-of-life care in the
527 intensive care unit: A consensus statement by the American Academy of Critical Care Medicine.
528 *Critical Care Medicine* 36: 953–963.
- 529 16. Simon, J.R., and R.L. Fischbach. 2008. LVADs and the limits of autonomy. *Hastings Center Report*
530 38(3): 4–5.
- 531 17. Simon, J.R., and R.L. Fischbach. 2008. Case study: “Doctor, will you turn off my LVAD?”. *Hastings*
532 *Center Report* 38(1): 14–15.
- 533 18. Bramstedt, K. 2003. Contemplating total artificial heart inactivation in cases of futility. *Death Studies*
534 27: 295–304.
- 535 19. Kraemer, F. 2011. Ontology or phenomenology? How the LVAD challenges the euthanasia debate.
536 *Bioethics*. doi:10.1111/j.1467-8519.2011.01900.x. Accessed Oct 27, 2011.
- 537 20. Brock, D. 1992. Voluntary active euthanasia. *Hastings Center Report* 22(2): 10–22.
- 538 21. Hamric, A.B., and L.J. Blackhall. 2007. Nurse-physician perspectives on the care of dying patients in
539 intensive care units: Collaboration, moral distress, and ethical climate. *Critical Care Medicine* 35:
540 422–429.
- 541

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