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## **Advance directives between respect for patient autonomy and paternalism**

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Abstract	<p>Advance directives frequently demand a certain degree of interpretation by the responsible physician or healthcare team. In implementing advance directives, healthcare professionals find themselves in an area of conflict between respect for autonomy, on the one hand, and paternalism on the other. Legal standards and ethical criteria for assessing the validity of advance directives are introduced and briefly discussed. The ethical criteria presented (accuracy of fit, plausibility/authenticity, lack of contradictions and coherent value system) can serve as important guides for appropriate and consistent interpretation of advance directives. In addition, the effect of advance directives on relationships is addressed from the perspective of the ethics of care.</p>	

# Chapter 11 1

## Advance Directives Between Respect 2

### for Patient Autonomy and Paternalism 3

Manuel Trachsel, Christine Mitchell, and Nikola Biller-Andorno 4

### 11.1 Introduction 5

There are two main types of advance directives. One type simply designates a substitute decision-maker, sometimes called a healthcare agent, proxy or surrogate. A more comprehensive advance directive (sometimes called a living will) specifies particular principles or considerations intended to guide action with regard to specific future healthcare decisions and possible medical conditions (Jaworska 2009).

At the time an advance directive is composed, the individual anticipates a future situation in which s/he (1) will have lost decision-making capacity and (2) will be in a condition that requires consent for or refusal of a medical intervention. Currently competent individuals can thus make anticipatory decisions for possible future healthcare situations.

The existence of an advance directive does not necessarily mean, however, that it will be clear to the responsible physician in every case what the patient would have decided. Problems with advance directives include, for instance, vagueness, concerns about authenticity, applicability, the competence of the executor, implausibility, internal contradictions, acceptability, and the suitability of the designated surrogate decision-maker, as well as the question whether the anticipatory decisions are what the patient would actually want now.

Notwithstanding these problems, advance directives are increasingly widely recognized as a legal instrument: in many countries, including the US and most

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26 Western European states, the wishes expressed in an advance directive have to  
27 be respected regardless of the type and stage of disease (Vollmann 2012), unless  
28 the directive is legally invalid. However, patients have no *claim right*—i.e. they  
29 have no right to demand particular treatments, especially when these are expected  
30 to be futile (see e.g. Engelhardt 1989). Instead, patients have the right to consent to  
31 or refuse a particular recommended treatment, since every medical treatment  
32 represents an intrusion into a person's physical and mental integrity and therefore  
33 requires consent.

34 In many cases, a more or less broad range of interpretation is needed with regard  
35 to the meaning and implementation of an individual's healthcare decisions made in  
36 advance of their illness. This interpretative process is guided by a number of legal  
37 standards and ethical criteria, designed to avoid the traps of paternalism and neglect  
38 of autonomy.

## 39 11.2 Between Respect for Autonomy and Paternalism

40 In cases where decision-making incapacity is diagnosed, two situations can be  
41 broadly distinguished: either an advance directive is on hand or no written<sup>1</sup> advance  
42 directive is on hand.

### 43 11.2.1 Advance Directive on Hand

44 Advance directives are designed to ensure that individual wishes expressed when  
45 the person was competent to do so are still respected in the event of decision-  
46 making incapacity. Ideally, the wishes formulated in the advance directive are in  
47 accordance with the patient's current best interests. However, the wishes expressed  
48 in the advance directive may sometimes be regarded as contrary to the incompetent  
49 patient's well-being.

50 According to Olick (2001), advance directives reflect "critical interests" with  
51 regard to personal dignity and well-being. Therefore, they have to be respected even  
52 if they conflict with current sensations of pleasure and pain. In this case, *respect for*  
53 *autonomy*—one of the four bioethical principles advocated by Beauchamp and  
54 Childress (2001)—is given more weight than the principle of *beneficence*. One

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<sup>1</sup> Verbally expressed wishes are often taken into account in exploring the presumed wishes of the patient. However, they are clearly less authoritative than a properly executed written document. In the US, medical orders for life-sustaining treatment (MOLST) are treated like advance directives even though they are not initiated by the patient; they merely record the healthcare provider's conversation with the patient in the form of an order kept in the patient's medical record and applicable across various healthcare locations, such as hospitals, nursing homes, ambulances, hospices and the patient's home.

example would be a patient's wish, expressed in an advance directive, not to receive 55  
 pain medication that could impair consciousness. Now, the patient, suffering from 56  
 end-stage cancer, is in a palliative situation in which only opioids could provide 57  
 significant pain relief. According to the advance directive, the physician is not 58  
 supposed to administer opioids, no matter how excruciating the patient's pain may be. 59

### 11.2.2 No Advance Directive on Hand

60

For patients who have not prepared an advance directive, treatment decisions are 61  
 made by surrogates such as family members (see e.g. Zellweger et al. 2008). Under 62  
 such circumstances, the principle of *beneficence* may sometimes be given greater 63  
 weight than *respect for autonomy*, as in the following case. An otherwise happy 64  
 elderly person with multiple chronic conditions and decision-making incapacity has 65  
 temporary kidney failure that could be reversed with dialysis. The patient does not 66  
 have an advance directive, but when still competent she stated repeatedly to family 67  
 members and medical care providers that she would not wish to be “dependent on 68  
 machines” to continue living. Nevertheless, in this case, the responsible 69  
 physician—having consulted the patient's relatives, who see this as a temporary 70  
 health crisis in an otherwise stable health situation with an apparently fair quality of 71  
 life—decides to treat the patient's kidney failure. 72

Tensions between respect for autonomy and beneficence frequently arise, 73  
 whether or not a patient has an advance directive. In attempting to resolve such 74  
 tensions, healthcare providers may err on the side of paternalism or on the side of 75  
 unwarranted respect for supposedly autonomous decisions which do not in fact 76  
 reflect competent choices. 77

### 11.2.3 Paternalism

78

*Paternalism* can be defined as “the interference of a state or an individual with 79  
 another person, against their will, and defended or motivated by a claim that the 80  
 person interfered with will be better off or protected from harm” (Dworkin 2010). 81  
 According to this definition, paternalism always involves a certain degree of 82  
 constraint on a person's freedom or autonomy for particular reasons. The following 83  
 two examples illustrate paternalistic behaviour: 84

1. Out of compassion, a forensic physician tells the parents of a victim of violence 85  
 that their daughter died instantly, whereas in fact she suffered a dreadful death. 86
2. The wife of an alcoholic hides her husband's liquor bottles because she is 87  
 worried about his health. 88

Paternalistic behaviour may be characterized as weak (soft) or strong. According 89  
 to *weak paternalism*, “a man can rightly be prevented from harming himself 90

91 (when other interests are not directly involved) only if his intended action is  
92 substantially nonvoluntary or can be presumed to be so in the absence of evidence  
93 to the contrary” (Feinberg 1971). *Strong paternalism* is embraced when a person is  
94 protected “against his will, from the harmful consequences even of his fully  
95 voluntary choices and undertakings” (Feinberg 1971).

96 An example of weak paternalism is the situation in which a patient specifies in  
97 his advance directive a desire to continue taking some sort of complementary  
98 medication; his physician, however, discovers that the medication causes signifi-  
99 cant harm to the patient, which she presumes the patient was not aware of. As she  
100 can no longer discuss this with the patient, who is now incompetent, she overrides  
101 the patient’s advance directive, stopping the treatment for the patient’s benefit.

102 An example of strong paternalism is a case where a patient whose valid advance  
103 directive clearly states that he refuses hospitalization for any medical reason is  
104 hospitalized overnight to receive intravenous hydration for life-threatening  
105 dehydration.

106 The motivation for potentially justifiable—weak or strong—paternalism is usu-  
107 ally the desire to avoid harm (non-maleficence) and/or to benefit the person whose  
108 autonomy is overridden or compromised.

109 One could simply argue that, in sum, paternalistic behaviour probably produces  
110 more good than harm. But is this really true? According to Gerald Dworkin (2010),  
111 this largely depends on our understanding of the good. If the good simply comprises  
112 longer life, better health or relief from pain, paternalism might well be an effective  
113 strategy. However, for many people, the good also includes elements such as the  
114 right to make self-guided decisions. While paternalism can be considered an  
115 acceptable moral stance when autonomy is absent or at least in doubt, overriding  
116 an individual’s explicit, autonomous choice for the sake of promoting his or her  
117 well-being is difficult to justify morally.

#### 118 **11.2.4 Respect for Autonomy**

119 *Autonomy* or *self-determination* is a person’s ability to make his or her own self-  
120 guided decisions. The principle of *respect for autonomy* obligates healthcare  
121 professionals to honour competent patients’ informed, voluntary decisions.

122 According to Ronald Dworkin (1993), a person with the capacity for autonomy  
123 needs (1) the ability to espouse a “genuine preference or character or conviction or a  
124 sense of self”, which could be called the *ability to value*, and (2) the ability to act  
125 out of one’s sense of conviction, which Jaworska (2009) calls “the ability to enact  
126 one’s values in the complex circumstances of the real world”. These crucial abilities  
127 are missing in many disorders, such as severe dementia or loss of consciousness.

128 If it is possible to apply a specific advance directive directly to a given situation,  
129 a *conflict between respect for autonomy and paternalism* may not occur. In this  
130 case, the expressed wishes can be transformed into action without restriction.

However, the conflict becomes relevant if an advance directive is formulated 131  
vaguely or cannot be directly applied to the present medical situation. In this 132  
more difficult case, the advance directive can only serve as a decision aid or a 133  
source for inferring the patient's presumed wishes. For example, if an advance 134  
directive contains a detailed statement of treatment preferences for end-stage 135  
cancer, this statement is not necessarily useful if the patient suffers not from cancer 136  
but from end-stage liver cirrhosis with hepatic encephalopathy and loss of consci- 137  
ousness. This example refers to the *accuracy of fit* that is part of the *validity* of 138  
advance directives (see Sect. 11.3). 139

But even if choices are clearly expressed and obviously apply to a specific 140  
situation, the range of choices that need to be respected is not unlimited: for 141  
example, certain preferences would impose an undue risk or burden on others, 142  
costly but futile interventions would place an unjustifiable burden on a limited 143  
public healthcare budget, and refusal of basic hygiene might be intolerable for those 144  
who care for the patient. The exact scope of what can be claimed or refused is 145  
controversial. Disagreements over what wishes need to be respected and what one 146  
person can legitimately ask of another are illustrated by the case of active 147  
euthanasia. 148

### **11.3 Legal Standards and Ethical Criteria for Assessing 149 the Validity of Advance Directives 150**

#### **11.3.1 Legal Standards 151**

In most countries, legal standards for a valid advance directive require a written 152  
form that is personally signed by a person who is of age (legal majority), has 153  
decision-making capacity, is informed about the decision to be taken (including 154  
alternatives to the chosen action), and is able to make and communicate a free 155  
(uncoerced) choice. 156

At the time of composing an advance directive, a person is required to have 157  
*decision-making capacity*. The following criteria are typically used for medical 158  
decision-making capacity: (1) ability to understand the relevant information, 159  
(2) ability to appreciate the medical consequences of the situation, (3) ability to 160  
reason about treatment choices, and (4) ability to communicate a choice 161  
(Appelbaum and Grisso 1988). Criteria may differ slightly from country to country, 162  
but the basic concept is the same (see e.g. Swiss Academy of Medical Sciences 163  
2005). A variety of instruments aid the assessment of decision-making capacity 164  
(Sessums et al. 2011). 165

*Decision-making incapacity* is caused by a broad range of clinical conditions, 166  
such as loss of consciousness due to severe somatic illness, dementia (e.g. 167  
Alzheimer's disease or Lewy body disease), brain injury and psychiatric diseases 168  
(e.g. schizophrenia or severe depression). 169

170 It is especially difficult to assess *retrospectively* whether a patient had decision-  
171 making capacity at the time he or she composed an advance directive. Frequently, a  
172 patient diagnosed as incompetent to make a particular healthcare decision has an  
173 advance directive that was written many years ago. If, for instance, a patient suffers  
174 from slow progressive dementia, it can be difficult to establish whether the person  
175 was still competent 5 years ago when he or she wrote the advance directive. The  
176 ethical criteria presented below can be used to test the moral appropriateness of  
177 heeding the contents of an advance directive. In addition, it may be helpful to  
178 interview relatives, friends, physicians and other care professionals who have been  
179 in contact with the person over a longer period.

180 *Free choice* means that a person composing an advance directive has to be able  
181 to make an autonomous decision and to communicate the choice without feeling  
182 threatened, under duress or external pressure. Ideally, the living will originates from  
183 a person's idiosyncratic substrate of wishes and values. According to Beauchamp  
184 and Childress (2001), three conditions constitute an *autonomous decision*: (1) the  
185 act was carried out intentionally, (2) the act was carried out with an understanding  
186 of the important facts and circumstances and (3) the act was carried out without  
187 external "controlling influences".

188 If these legal standards are not met, the advance directive cannot be used to  
189 justify medical decisions. If the legal standards are met, an analysis based on ethical  
190 criteria can follow.

### 191 11.3.2 Ethical Criteria

192 When an advance directive is formulated vaguely or cannot be directly applied to  
193 the present medical situation, criteria are needed to judge its ethical validity,  
194 helping to prevent unwarranted paternalism or undue respect for autonomy in  
195 cases where there was no competent choice. Four main characteristics have been  
196 proposed as *ethical criteria* for assessing the validity of advance directives (see also  
197 Trachsel et al. [forthcoming](#)):

- 198 1. accuracy of fit
- 199 2. plausibility/authenticity
- 200 3. lack of contradictions
- 201 4. coherent value system

202 *Accuracy of fit* means that the clinical situation in question corresponds to the  
203 situation envisaged in the advance directive. This does not necessarily imply that  
204 advance directives have to be overly specific, as it may be difficult or impossible for  
205 the patient to fully anticipate the details of their diagnoses and prognoses, and to  
206 make an informed choice based on an appreciation of the options available.  
207 However, it is certainly helpful for the patient, family members and the health  
208 professionals concerned if the patient's preferences and values are clearly stated, as

well as any particular wishes about interventions such as blood transfusions or mechanical life support in the form of ventilators, artificial hearts, etc. 209 210

An advance directive is *plausible* and *authentic* when it is in accordance with one's distinctive wishes, personality, character and lifestyle. For relatives and physicians who know the patient, an advance directive will be easiest to accept as representative of the patient's wishes when the content is consonant with his or her personal traits. 211 212 213 214 215

The concept of *authenticity* has been extensively debated (e.g. Golomb 1995; Wood et al. 2008). According to a widely shared position (Frankfurt 1988; Glannon 2008), persons are authentic if they can identify with their mental states. For example, wishes expressed with regard to pain medication are authentic if they are formulated by a person who has suffered from chronic pain (mental state) for years, and if the person is able to attest through her or his higher-order reflective capacity that this chronic pain is relevant to the wishes specified in the advance directive. 216 217 218 219 220 221 222 223

However, authenticity is not a legal requirement for the validity of advance directives, and it is contentious as an ethical criterion (Brauer 2008). Legally, a person is free to refuse a certain treatment regardless of his or her reasons and even in the absence of particular reasons. Accordingly, Olick (2001) states that an advance directive is not required to be an authentic expression of its author. The requirement of authenticity would open the floodgates to paternalistic actions, as it would be quite easy to evaluate an advance directive as non-authentic and non-autonomous. Instead, it is sufficient to see an advance directive as an "intentional plan to assert control over one's dying process" (Olick 2001). 224 225 226 227 228 229 230 231 232

It seems self-evident that an advance directive should not contain internal contradictions or contradictory instructions with regard to one and the same medical situation. For instance, a patient's living will cannot be honoured when one part of the advance directive refuses withdrawal of treatment in every imaginable situation and requests that everything possible be done to obtain a lung transplant, while another part of the same advance directive requests withdrawal of treatment in end-stage cystic fibrosis. 233 234 235 236 237 238 239

The ethical validity of an advance directive is more obvious when the wishes expressed are evidently based on a *coherent value system*. This can be defined as a set of values that are interconnected in a logical and hierarchical manner and that guide a person's preferences, decisions and actions. The value system need not be highly complex and abstract, nor does the absence of an identifiable coherent value system render an advance directive invalid. In fact, it is controversial whether and how ethical values should be communicated to healthcare professionals and relatives via an advance directive at all (Brauer 2008). 240 241 242 243 244 245 246 247

The ethical criteria described above can provide important guidance in assessing the validity of advance directives that are, for instance, formulated vaguely or cannot be directly applied to the clinical situation (see also Trachsel et al. forthcoming). However, it is important to discuss the precise role of these criteria in the assessment. Some, such as accuracy of fit and lack of contradiction, are fairly uncontroversial as a matter of principle but may be applied more or 248 249 250 251 252 253

254 less strictly. Others, such as authenticity and a coherent value system, remain  
255 controversial as regards both interpretation and appropriateness. Even so, they  
256 capture important aspects of the debate on advance directives and can help to  
257 articulate the reasons for moral disagreement.

258 The criteria discussed in this section focus on the choices expressed by a rational  
259 individual moral agent. However, the situations advance directives aim to antici-  
260 pate are likely to be characterized to a great extent by dependence on others. It is  
261 thus of interest to explore what a relational perspective can add to the discussion on  
262 advance directives.

## 263 11.4 Advance Directives and Relationships: The Ethics 264 of Care Perspective

265 The fundamental conflict between *respect for autonomy* and *paternalism* is part of  
266 every social relationship. Alongside other ethical approaches, the ethics of care  
267 (Held 2005) provides an important theoretical perspective on this conflict.

268 The *ethics of care* is a form of *relational ethics* in the sense that “its central focus  
269 is on the compelling moral salience of attending to and meeting the needs of the  
270 particular others for whom we take responsibility” (Held 2005). The ethics of care  
271 respects the fact that persons depend on others for most of their lives. The ethics of  
272 care “addresses rather than neglects moral issues arising in relations among the  
273 unequal and dependent, relations that are often emotion-laden and involuntary”  
274 (Held 2005). The family context is prototypical for such relations.

275 Degrees of dependence may vary over the life course; for instance, children or  
276 persons in situations of illness or after accidents will need a lot of care. But even  
277 healthy adults are likely not to be completely self-sufficient, but need others even  
278 for their everyday professional and private activities. Later in life, many people  
279 need care every day, and some individuals with disabilities may be dependent on  
280 care throughout their lives.

281 Most people composing an advance directive do so with a view to a future  
282 situation of involuntary dependence in which they need the care of others. Focusing  
283 on individual preferences and trying to extend individual autonomy may not do  
284 justice to the challenges posed by this new state of significant need and dependence.

285 On the other hand, advance directives are not necessarily antithetical to a care  
286 perspective. The ethics of care does not postulate that there is no room for private  
287 decisions that may also go against the expectations or wishes of close persons.  
288 Advance directives can specify the relational network in which the individual is  
289 situated and highlight trustful relationships. Also, advance directives need not be a  
290 vote of no confidence in the treating physicians or caring relatives; they may even  
291 serve as an “icebreaker”, making it easier for healthcare professionals and relatives  
292 to communicate about the patient’s preferences and interests. Not surprisingly,  
293 a randomized controlled study found that advance care planning including the

formulation of an advance directive “improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives” (Detering et al. 2010).

Furthermore, the ethics of care values sympathy, antipathy, anger, responsiveness or other feelings as important *moral emotions* that should guide behaviour no less than rational arguments. This puts a new complexion on the conflict between respect for autonomy and paternalism. Even if an advance directive is not fully consistent and rational, this does not mean that it is completely irrelevant and that the only option is to override it in a paternalistic manner. Instead, it is advisable to place more reliance on the emotions expressed in the document, which can provide an important basis for discussing the implementation of an advance directive.

**11.5 Consistency in the Implementation of Advance Directives**

Ethical criteria for assessing validity need to be calibrated in such a way as to strike a balance between paternalism and a form of consumerism that would let patients have their way even if their advance directive is not an expression of a competent choice. Even though some of the requirements (e.g. for a coherent value system) may be controversial, measuring individual advance directives against these ethical criteria can help to promote consistent implementation among physicians and healthcare teams. Beyond individual judgements, the ethical criteria also provide a framework for discussing consistent implementation of advance directives within medical communities (e.g. groups of providers or medical subdisciplines).

The requirement for consistency is fairly straightforward: if two similar patients with similar health problems compose similar advance directives, the patients should be treated similarly. If the two patients, their health problems or their advance directives differ in essential respects, it is perhaps not appropriate to treat the two patients similarly. Yet this claim raises a lot of questions. Should patients with decision-making incapacity who have the same disease (e.g. end-stage brain cancer) and a very similar advance directive be treated similarly, even if one patient is 30 and the other 90 years old? Perhaps both have stated in their advance directive that they do not wish to receive further surgical treatment for their cancer once they become incapable of decision-making. Intuitively, one may be more inclined to accept this living will if the patient is 90 because of the whole life span we could imagine ahead of the 30-year-old patient. Yet this would constitute an age bias that is not part of the advance directive concept. An advance directive is valid regardless of the patient’s age. For instance, even a child of 10 years can have decision-making capacity with regard to some vitally important decisions.

There may be other sources of potential bias: physicians may be more inclined to implement an advance directive if they agree with the wishes expressed by the patient. Thresholds for the validity of an advance directive might be raised when physicians

334 completely disagree with the content of an advance directive, particularly with regard  
335 to morally highly charged issues such as assisted suicide. Economic factors might  
336 also influence the acceptance of an advance directive. Relatives might, for instance,  
337 not want to let go of their loved one and argue for a very strict interpretation of  
338 standards; conversely, they might be worried about the costs accumulating for the care  
339 of their relative, whose quality of life they consider to be very poor. The requirement  
340 of consistency calls for a given advance directive to be interpreted in the same way  
341 regardless of biasing factors.

## 342 11.6 Conclusions

343 In cases where decision-making incapacity is diagnosed, the existence of an advance  
344 directive does not necessarily mean that it will be clear to the responsible physician  
345 in every case what the patient would have decided. Problems with advance directives  
346 include vagueness, the question of authenticity, applicability, the competence of the  
347 executor, implausibility, internal contradictions, acceptability, or the question  
348 whether the anticipatory decisions are what the patient would actually want now.

349 Because advance directives are not always clearly formulated, a certain degree  
350 of interpretation is demanded of the responsible physician. In interpreting advance  
351 directives, healthcare professionals find themselves in an area of conflict between  
352 respect for autonomy, on the one hand, and paternalism on the other.

353 Besides legal requirements, it is important to apply ethical criteria—including  
354 accuracy of fit, plausibility/authenticity, lack of contradictions and a coherent value  
355 system—for assessing the validity of advance directives, although there is certainly  
356 room for discussion as to the specific requirements which these criteria should entail.

357 The fundamental conflict between respect for autonomy and paternalism is part  
358 of every social relationship. Alongside other ethical approaches, the ethics of care  
359 (Held 2005, 2006) provides an important theoretical perspective on this conflict.  
360 Advance directives are composed for a future situation of involuntary dependence,  
361 in which someone needs the care of others. Advance directives are not a vote of no  
362 confidence and could even ease the burden on close relationships, serving as critical  
363 icebreakers for communication between patients, relatives and healthcare profes-  
364 sionals regarding the care patients receive when they are no longer able to speak  
365 for themselves.

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# Author Queries

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Queries	Details Required	Author's response
AU1	Please confirm the corresponding author.	
AU2	Please provide citation for Grisso and Appelbaum (1998).	
AU3	Please update Trachsel (forthcoming).	

Uncorrected Proof