

Mental disorders and advance directives about healthcare. Responses of Belgian Law to a future incapacity to make (one's own) decision

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Do you know there is a new case of dementia in the world every 4 seconds¹?

Planning later life is also planning future medical care. Of course, mental disorders are not the only reason to do so but, as a growing part of population is likely to suffer from dementia² at some point, the interest for Advance Care Planning could increase in our aging societies.

This contribution will focus on advance directives provided by Belgian law in the field of medical interventions, with the idea that it could be of a particular interest for people with dementia.

A short presentation of these advance directives will allow us to realize that they seem disparate and do not take part in a broader reflection. So I will briefly review Belgian law in the light of the concept of Advance Care Planning, to show that law would be more useful and realistic if it opted for a global approach.

Belgian law provides for three kinds of advance directives: advance refusal, advance designation of a surrogate decision-maker and advance euthanasia declaration.

First, advance refusal. Actually, the right to consent to any intervention of a health professional³ goes along with the right to refuse any intervention. In principle, a refusal is binding for health professionals.

Belgian Patient's Rights Act extends this right to refuse to future situations of incapacity: "If, when he was still able to exercise [his] rights (...), the patient has indicated in writing that he refuses consent to a specific intervention of the health professional, this refusal must be respected ..."⁴. In addition, such a refusal must be informed, as a direct refusal would be. So it seems quite simple to write a binding advance refusal, but more technical problems are not covered.

¹ World Health Organization, "Dementia, a public health priority", 2012, www.who.int

² Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – leading to disturbance of multiple functions like memory, thinking, orientation, comprehension, judgment, ... (World Health Organization, "Dementia, a public health priority", 2012, www.who.int)

³ According to Belgian Patient's Rights Act (PRA), the terms "professional practitioner" designate physicians and pharmacists as well as nurses, midwives, physiotherapists, ambulance first-aid and paramedics. In this contribution, I will then use the expression "healthcare professionals".

⁴ Art. 8, §4 PRA, original text : "Si, lorsqu'il était encore à même d'exercer les droits tels que fixés dans cette loi, le patient a fait savoir par écrit qu'il refuse son consentement à une intervention déterminée du praticien professionnel, ce refus doit être respecté aussi longtemps que le patient ne l'a pas révoqué à un moment où il est lui-même en mesure d'exercer ses droits lui-même" (freely translated in the text).

For example, the assistance of a health professional in the writing of an advance refusal is not compulsory but, without this help, it could be difficult to fulfill specificity and information requirements. Moreover, at the time the advance refusal could be useful, the health professional must know it exists. Belgian law does not provide for any registration system so that it is up to the patient to make sure his advance refusal will be taken into account. Finally, it is unlikely a health professional will comply with an advance refusal if he has serious doubts about its reliability, for example because the document was written a long time before.

In conclusion, the implementation of an advance refusal might be more complex than it first seems.

This is for advance refusals. What about advance positive requests?

Patient's Rights Act does not say anything about advance positive instructions of patients, so that basic principles apply: taking into account patient's preferences is part of normal medical practice, but physicians are entitled not to perform a useless or mutilating intervention, even on demand of the patient and regardless of whether this demand is direct or advance.

Belgian Patients' Rights Act also provides for the **advance designation of a surrogate decision-maker**, who will exercise patient's rights when the patient himself is no longer capable⁵. Concretely, a written mandate must be signed by both parties.

The surrogate is supposed to act in the interest of the incapable patient. So, if his decision is likely to harm the patient, the health professional may depart from this decision, unless the surrogate can prove his decision is consistent with patient's will⁶: a surrogate who refuses a life-saving treatment must be able to prove that it is indeed the will of the patient, for example because of an advance refusal.

Conversely, if a surrogate decides against an advance refusal, advance refusal should theoretically prevail. In practice, however, this situation could make health professional doubt reliability of the advance refusal and lead to its rejection.

Here again, application of the legal text can be complex.

Finally, Belgium is one of the three countries – together with the Netherlands and recently Luxemburg – which has decriminalized euthanasia. According to these legislations, euthanasia is “the act performed by a third party who intentionally ends the life of a person at the request of this person”. An important precision is that physicians can never be compelled to perform euthanasia and that nobody else can be forced to take part in euthanasia.

⁵ Art. 14, §1 PRA.

⁶ Art. 15, §2 PRA.

Euthanasia Act provides for an “**advance euthanasia declaration**” but this declaration may only be implemented in a situation of “irreversible unconsciousness”⁷, then in situations of irreversible coma or permanent vegetative state.

The scope of advance euthanasia declaration is then quite small. But here, law provides for a registration system and for a declaration template⁸.

Belgian Parliament is now examining an extension of the scope of the advance euthanasia declaration: a bill suggests allowing people to write an advance euthanasia declaration for when they are irreversibly “no longer aware of [their] own person, of [their] mental and physical condition and of [their] social and physical environment”⁹. According to the Bill’s authors, this wording would include irreversibly comatose patients and patients in a permanent vegetative state, but also patients with dementia at an advance stage.

A quick word about this bill: first, nothing is said about how to assess such a kind of “personal and social unconsciousness” and it seems actually very difficult to determine, except maybe at a very advance stage of dementia. But doubtfully it is only the very late stage of the disease that scares people; it is also – and maybe more – the progressive loss of personality and independence. Second, we should pay attention to Dutch experience in that field. In Netherlands, euthanasia on the basis of an advance declaration is possible for patients with dementia if physician is convinced of the “hopeless and unbearable suffering of the patient”¹⁰. However, even when this condition is satisfied, it appears that Dutch physicians are very reluctant to apply advance euthanasia declarations of seriously demented patients and will rather use them to support a restricted treatment policy¹¹.

Fear of being demented is common and must be taken seriously in our society but an extension of the scope of advance euthanasia declaration does not look like a generally workable response. It is necessary to exploit other ideas.

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⁷ Art. 4 Euthanasia Act. The physician must also respect several procedural conditions: another and independent physician must express his views about the irreversibility of the unconsciousness of the patient, the referring physician must also discuss the decision with the medical team who takes care of the patient and the eventual trusted person mentioned in the advance declaration or relatives of the patient... The referring physician may add to his intervention any condition he deems to be appropriate.

⁸ Advance euthanasia declaration can be – but must not – be registered near municipal administration (Art. 4 Euthanasia Act and Royal Decree : Arrêté royal du 27 avril 2007 réglant la façon dont la déclaration anticipée en matière d'euthanasie est enregistrée et est communiquée via les services du Registre national aux médecins concernés).

⁹ Proposition de loi modifiant la loi du 28 mai 2002 relative à l’euthanasie, Développements, *Doc. parl.*, Sénat, 2011-2012, n° 5-1611/1.

¹⁰ Art. 2, §1, b. of Dutch Euthanasia Act.

¹¹ M. L. RURUP, B. D. ONWUTEAKA-PHILIPSEN, *et al.*, « Physicians’ Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands », *J. Am. Geriatr. Soc.*, 2005, 53, pp. 1138-1144.

The second part of this contribution will **briefly review Belgian law in the light of the concept of “advance care planning”** in order to include advance directives in a broader reflection.

Advance Care Planning can be defined as a continuous consultation process between patient, healthcare professionals and eventually patient’s relatives, in order to define a common orientation about care and interventions to implement – or not – when the patient is incapable. For patients and health professionals to benefit fully from this process, advance directives must not be considered in isolation, but as part of this process, as tools contributing to a more global project.

However, it seems that advance directives as presented by Belgian law miss the essence of Advance Care Planning. I will try to explain briefly why and how law could be improved in that respect. Of course, law cannot resolve every specific problem but it can give impulse to good practices, through global orientations.

First characteristic: **Advance Care Planning is a consultation process**, which means patient and health professionals dialogue, in order to determine a kind of “healthcare guideline” which will be followed as much as possible when the patient becomes incapable. This consultation may include patient’s relatives who could be implied in a future decision-making process.

But advance directives as presented in Belgian law give the feeling that the patient is alone to decide about his future medical care, because law does not expressly imply health professionals or patient’s relatives in the writing of an advance directive. However, implication of health professionals and patient’s relatives should be promoted.

On the one hand, if health professionals find an advance directive unclear or misinformed, they may depart from it, which is the opposite effect of the one intended. A real consultation process with health professionals could help to ensure future respect of advance directives.

On the other hand, relatives can be of a real support in an Advance Care Planning and their non-implication increases the risk of conflicts with health professionals when a decision must be made for the incapable patient.

Autonomy is not to be confounded with solitary independence and it can best be supported through a real consultation process than through unilateral documents.

This leads us to the second characteristic of Advance Care Planning: it is a **continuous process**. An agreed guideline takes time to emerge and then it might still evolve, so that continuous attention must be paid to values and wishes of the patient.

However, Belgian law seems to emphasize the importance of documents, of papers, to the detriment of relation. Of course documents can be very useful during and after the

consultation process: they are traces, eventually proofs and they can help information transfer. But documents are not *in themselves* the guarantee of a real Advance Care Planning. For example, they should never give patients the feeling that the matter is settled once and for all. What is important is real continuous support, while documents are only tools.

Finally, **Advance Care Planning does not only stress what the patient does not want or wants to avoid**, but also what he wants and needs.

In the field of medical interventions, it is remarkable that Belgian law only pays attention to advance refusal and advance euthanasia declaration. Taking into account advance positive wishes is part of normal medical practice but that fact should not have prevented the legislator from mentioning positive aspect of advance care planning: the patient must be encouraged to express all he wants rather than what he does not. Reducing advance directives to “do not’s” or “euthanize me” is *no advance care planning but*, in the context of terminal disease, a *death planning*. A global discussion about what patient would like for his life – because end-of-life is still life – is also certainly easier to address for everyone implied than a death project.

Under these elements, I allow myself **some ideas for a more appropriate legal approach**:

From a formal point of view, I would suggest that Patients’ Rights Act only provides for a definition of Advance Care Planning and insists on its main characteristics. Concrete aspects as preservation and communication of written documents can be developed in Royal Decrees¹². The idea is to underline the difference between fundamental aspects of Advance Care Planning and resolution of more technical problems, to avoid reducing Advance Care Planning to documents.

Another distinction could be made between “generic Advance Care Planning” described by the Act and sub-categories concerning specific circumstances, such as crisis situations in psychiatry or end-of-life. For the latter, some professionals consider that a sub-sub-category would be needed for demented patients, regarding the particular complexity of this disease. Again the law could provide that a Royal Decree will develop guidelines for specific categories, in consultation with field people.

Concerning more fundamental aspects, acknowledgment of Advance Care Planning as a complex instrument would already be a good step forward. Not that law should be complex in order to reveal complexity of questions raised by Advance Care Planning, but now law makes it look simplistic and does not seem to be concerned about important collateral questions, such as capacity assessment..

Finally, in the field of intuitions, at that stage at least, I wonder if it is really necessary to provide for binding instructions. If a real Advance Care Planning takes place, there is no reason for health professionals not to follow it when necessary. Conversely, without a real

¹² Belgian legal instruments issued by Government and providing for details about implementation of an Act.

consultation process, the implementation of an advance directive may be compromised, so maybe the only question we should focus on is “how to ensure a real advance care planning?”

What would also appear to me as a great achievement would be a more specific system of conflicts resolution between patient or patient’s relatives and health professionals concerning Advance Care Planning and capacity assessment. Belgian Patient’s Rights Act already provides for a “patient’s rights mediation service” but a mediator does not have the power to decide. So if the conflict persists, the ideal could be an independent experts’ court which would quickly arbitrate conflicts but also provide for a follow-up of parties, after the decision...

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To conclude before dreaming too much, I would like to recall that, in 2002, Patient’s Rights Act and Euthanasia Act innovated by providing for the three types of advance directives mentioned before. Following this innovation, Advance Care Planning became a matter of concern in practice: initiatives have been taken, in a number of hospitals and nursing homes. So law inspired practice but now, more than ten years later, it is time for law to learn from practice and to support good practices as well as possible.

Now I hope you also want to share your own reflections on the matter... So thank you for your attention and let’s discuss, I came to hear from you too!