

## Advance Care Planning: Making Decisions with Dignity and in Good Time

Lizbeth De la Torre López | Neuropsychologist

**What would happen if we could no longer express how we wanted to be treated or cared for?** Advance care planning, also known as advance decisions or living wills, allow us to make these decisions in advance and set out our preferences for situations in the future when we may not be able to communicate them personally. In Spain, this right is recognized in Law 41/2002. Article 11 establishes that a competent person of legal age may express their wishes in advance regarding healthcare and treatment, as well as the disposition of their body or organs after death (Jefatura del Estado, 2002).

**Advance care planning does not mean giving up one's own will; rather, it means preserving it.** The document can outline your preferences regarding healthcare, specific treatments, palliative care and other relevant decisions, as well as your personal values to help interpret these preferences. You can also designate a representative to liaise with the healthcare team when the time comes (Ministerio de Sanidad, n.d.).

**Although the decision is personal, it doesn't have to be made alone.** Talking to trusted individuals and healthcare professionals beforehand can help you to reflect on what appropriate care means to you, and to identify situations that are consistent with your values and preferences. It is especially important to plan ahead when there is a risk of gradually losing the ability to make or communicate decisions, as can happen with some neurodegenerative diseases. Spain's autonomous communities recommend that the document be the result of a reflective process and provide specific resources to assist with its creation.

**Advance care planning takes on special importance following a dementia diagnosis.** Receiving this diagnosis can prompt a rethink of many aspects of life, care and future decisions. The key word here is '**anticipation**': it is advisable to make these decisions while the person still has the mental capacity to understand, deliberate and express their preferences. There is no need to wait for the disease to progress. An appropriate time to do so is immediately after diagnosis, or when there is sufficient stability to reflect calmly on one's values, preferences and needs. It can also be helpful to review these instructions when there are significant changes in one's personal, family or health situation.

**The process can be summarized in five steps: dialogue, reflection, documentation, registration and review.** In Spain, Law 41/2002 establishes the basic framework for advance directives, and each autonomous community develops its own procedures for formalizing and registering them. Therefore, the specific requirements may vary depending on the place of residence. The Ministry of Health maintains the National Advance Directive Registry, ensuring the effectiveness and recognition of these documents throughout the country. Advance care planning can be revoked at any time by providing written notice.

**Advance care planning is ultimately a way of participating in one's own care, even when it is no longer possible to do so directly.** Rather than deciding how every future circumstance should be handled today, it is about expressing values, preferences, and sources of support that can help preserve autonomy and guide healthcare decisions when they are most needed.

**Advance care planning is supported by legal and human rights frameworks, and the World Health Organization emphasizes its importance, particularly in the context of dementia. Find out about the applicable legislation and procedures where you live, and make informed decisions with dignity in good time.**

## References

- Jefatura del Estado. (2002). Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica. Boletín Oficial del Estado, 274. <https://www.boe.es/buscar/act.php?id=BOE-A-2002-22188>
- Ministerio de Sanidad. (s. f.). Registro Nacional de Instrucciones Previas. <https://www.sanidad.gob.es/areas/profesionalesSanitarias/rnip/home.htm>
- Ministerio de Sanidad. (2007). Real Decreto 124/2007, de 2 de febrero, por el que se regula el Registro nacional de instrucciones previas y el correspondiente fichero automatizado de datos de carácter personal. Boletín Oficial del Estado, 40. <https://www.boe.es/buscar/act.php?id=BOE-A-2007-3160>