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Living wills protect the most vulnerable

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How many of us have thought about making a living will? Living wills — or, more accurately, advance decisions — enable adults with mental capacity to make a decision to refuse treatment if they lose capacity in the future.

One of the most common reasons why people lose capacity and require medical treatment is dementia. According to the Alzheimer's Society, 225,000 people in the UK will develop dementia this year, or one person every three minutes. By 2025 there will be more than a million people with dementia in the UK.

Even though dementia is common, living wills are relatively rare. Only 5 per cent of people in the UK have made one. This ranges from 1 per cent of those aged 18 to 34, to a still modest 12 per cent of people over 75. Of course, some may have made a positive choice against making a living will, and others may have signed a lasting power of attorney that covers medical treatment. It seems likely, however, that many of us simply prefer not to think about the issue.

Sir Nicholas Francis, giving judgment in the High Court last week, expressed strong support for living wills. The case concerned an elderly patient with advanced dementia. He was unable to swallow and was being fed by a nasogastric tube. Nasogastric tubes are uncomfortable for patients

In accordance with best practice, the hospital trust's plan for the patient was to insert a percutaneous endoscopic gastrostomy tube, to enable the patient to be fed directly into the stomach. The patient's relatives objected to the procedure. Although the nature of their objections was less than clear, the court gave detailed consideration to the advantages and disadvantages of the proposed treatment and concluded that the procedure should go ahead.

Before giving judgment, Mr Justice Francis observed that people should be encouraged to make living wills, noting that "these cases would be resolved much more easily". He suggested that there should be a national campaign to promote living wills along the lines of the organ donation campaign.

This proposal has clear advantages. Litigation about medical treatment is difficult and distressing for all concerned: family members, supporters and clinicians. The costs of litigation are usually borne by the state. Crucially, living wills enable people to retain autonomy over their treatment after they lose capacity, providing protection for the human rights of the most vulnerable in society. Valid advance decisions are legally effective by virtue of section 26 of the Mental Capacity Act 2005.

It remains to be seen whether Mr Justice Francis's words will bring about a wider campaign. Many of us will know someone with a terminal condition. Perhaps his words will encourage people to start having difficult conversations about the future, and to address these very personal issues with clarity as well as compassion.

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