

02 DISABILITY PERSPECTIVES ON PUBLIC POLICY IN ADVANCE CARE PLANNING

D Coleman¹ *1Not Dead Yet, USA*

10.1136/bmjspcare-2012-000250.2

Many disabled people have had health care providers suggest and even urge that they forego life-sustaining treatment. Terrie Lincoln's story (see <http://stories-2.com/HowWeDie/story?sid=4>) describes her medical encounters following her spinal cord injury at age nineteen. She was initially unconscious and needed a ventilator for about five months. Doctors repeatedly urged first her parents and then herself to "pull the plug" because her quality of life would be unbearable. She and her parents resisted fifteen years ago, and she went on to complete college, work a full time job and begin raising a baby daughter.

At least four concerns should be discussed:

- ▶ A recent study shows that having an advance directive makes it less likely that a person will get medical treatments they actually want.
- ▶ Futile care policies and laws allow physicians to withhold treatment that they feel is inappropriate, even if they are overruling the individual, surrogate or advance directive.
- ▶ Studies show that elder abuse is a significant problem. The perpetrator is often the spouse or adult child, yet these are the first priority surrogate decision makers designated by statute, without protections to prevent an abuser from making health care decisions that are best for them, not the patient.
- ▶ A leading neurologist recently admitted in a New York Times interview that it is "not uncommon" for physicians to ignore the appropriate "wait-and-see" period following a brain injury and urge families to withhold life-sustaining treatment. The disability community is concerned that, increasingly, people like Terrie are not surviving.