

39 **A REVIEW OF EVIDENCE SUPPORTING CERTAIN  
DISABILITY RIGHTS CONCERNS ABOUT “END OF LIFE”  
ADVOCACY**

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10.1136/bmjspcare-2012-000250.39

Attendees will have the opportunity to learn more about disability rights issues from a plenary speakers and an additional presenter. Central topics, with actual examples, will be:

- Rush to judgment cases – “pull the plug” versus “wait and see”

- ▶ Elder abuse – health care decisions laws that may appoint abusers as surrogates
- ▶ Futile care policies – overruling an advance directive
- ▶ Organ procurement policies for upper spinal cord injured, neuromuscular disabilities
- ▶ Organ transplant eligibility for people with disabilities

Attendees will be able to consider research from medical literature which reveals “Things people with disabilities know that others spent millions to research about individuals and families”:

- ▶ People change their minds about what is acceptable as disease/condition progresses
- ▶ Family members don’t consistently or correctly predict individual choices
- ▶ Family members have conflicts of interest and project personal disappointments onto their family member
- ▶ Lack of adequate home and community-based services is a big problem

Attendees will be able to consider research from medical literature which reveals “Things people with disabilities know that others spent millions to research about health care providers”:

- ▶ Healthcare providers say things to influence/pressure individuals and families to withhold treatment
- ▶ Healthcare providers are not consistently accurate in predicting terminal status
- ▶ Healthcare providers devalue people with disabilities and serious health impairments

A constructive relationship between the disability and palliative care communities could be developed based on recognition that healthcare policies affecting people with disabilities must be formulated with people with disabilities “at the table.”