The experiences of disabled people at the end of life

Marie Curie has worked with Disability Rights UK to ask disabled people in the UK and their carers how well they have been cared for and supported at the end of life.

Accessing information
- 53% said they were not given information about end of life care in a format they could understand.

Adjustments for disability
- 48% said adjustments for their disability were not put in place.

Staff knowledge
- 40% of those using assistive technology (e.g., hoists, communication aids) said the people supporting them did not know how to use it.

Making the transition to end of life care
- 67% did not find moving to end of life care straightforward.
- 58% did not have continuity of care: the same person or people caring for them throughout.

Place of death
- 80% said they wanted to die at home.
- 45% said they did not expect to die in their preferred place.

Source: Survey carried out by Disability Rights UK between March and June 2014

mariecurie.org.uk/policy