

# Palliative and End-of-Life Care for People with Learning Disabilities

## Resources and Websites

### Internet Resources/ Websites

[www.learningdisabilitycancer.nhs.uk](http://www.learningdisabilitycancer.nhs.uk)  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)  
[www.macmillan.org.uk](http://www.macmillan.org.uk)  
[www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)  
[www.rmhdni.gov.uk/equallivesreport.pdf](http://www.rmhdni.gov.uk/equallivesreport.pdf)  
[www.planetamber.com/resources/191.html](http://www.planetamber.com/resources/191.html)  
[www.ldresources.com](http://www.ldresources.com)  
[www.bild.org.uk](http://www.bild.org.uk)  
[www.cancerandyou.info](http://www.cancerandyou.info)  
[www.cancernorth.nhs.uk](http://www.cancernorth.nhs.uk)  
[www.cancerscreening.nhs.uk/publications/s52.html](http://www.cancerscreening.nhs.uk/publications/s52.html)  
[www.down-syndrome.org.uk](http://www.down-syndrome.org.uk)  
[www.cancerresource.co.uk](http://www.cancerresource.co.uk)  
[www.mencap.org.uk](http://www.mencap.org.uk)  
[www.easyhealth.org.uk](http://www.easyhealth.org.uk)  
[www.changepeople.co.uk](http://www.changepeople.co.uk)  
[www.dundee.ac.uk/pamis](http://www.dundee.ac.uk/pamis)  
[www.sclid.org.uk](http://www.sclid.org.uk)

### Other Resources

#### Books Beyond Words Series (£10 each)

'Am I going to die?'  
'Getting on with cancer'  
'When mum died'  
'When dad died'  
'When someone dies'  
'Going into hospital'  
'Going to out-patients'

[www.rcpsych.ac.uk/publications/booksbeyondwords](http://www.rcpsych.ac.uk/publications/booksbeyondwords)

Tel: 020 7235 2351 ext: 146

Living with cancer 1: What is cancer ?

Living with cancer 2: Someone I know has cancer. What does it mean for me?

Living with cancer 3: Colorectal (Bowel) cancer

Living with cancer 4: Skin cancer

Living with cancer 5: Breast cancer

Cancer of the Oesophagus

Email: [multimedia@fairadvice.org.uk](mailto:multimedia@fairadvice.org.uk)

[www.fairadvice.org.uk](http://www.fairadvice.org.uk)

Tel: 0131 662 1962

'Living with an illness that I will die from'. The puzzle of palliative care.

Palliative care and people with learning disabilities (2009)

Freely available from Dr. Sue Read: [s.c.read@nur.keele.ac.uk](mailto:s.c.read@nur.keele.ac.uk)

Living and Dying with Dignity

[www.mencap.org.uk/endoflifecare](http://www.mencap.org.uk/endoflifecare)

Tel: 01159 827 022

'An Ordinary Death'

The Foundation for People with Learning Disabilities (Feb 2003)

[www.fpld.org.uk/publications](http://www.fpld.org.uk/publications)

Disdat Pain Assessment Tool and Guide

[www.mencap.org.uk/resources](http://www.mencap.org.uk/resources) (Look under publications)

'Dying Matters'

The Foundation for People with Learning Disabilities March 2005- £25

Tel: 020 7803 1101

'The Hospital Communication Book'

Surrey Learning Disability Partnership (April 2008)

[www.mencap.org.uk](http://www.mencap.org.uk) (Look under professionals/health/tools)

'Let's Talk About Death'

Karen Watchman

[www.dsscotland.org.uk/publications/learning-disability](http://www.dsscotland.org.uk/publications/learning-disability)

Department of Health (2001) Seeking Consent: working with people with learning disabilities. London: DH

[www.dh.gov.uk](http://www.dh.gov.uk)

**Department of Health, Social Services and Public Safety (2003) Reference guide to consent for examination, treatment or care. Belfast: DHSSPS**  
[www.dhsspsni.gov.uk/consent-referenceguide](http://www.dhsspsni.gov.uk/consent-referenceguide)

**'Widening access to palliative care for people with learning disabilities. (£10 per copy)**  
**Publications, Help the Hospices, Hospice House, 34-44, Britannia Street, London. WC1X 9JG.**