## A summary of resources to support palliative and end of life care for people with Learning Disabilities

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. www.ncpc.org.uk

NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement. www.dyingmatters.org

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Title and organisation	Information	Available from
We're living well but Dying Matters – Dying Matters	'We're living well but Dying Matters', produced by CHANGE for Dying Matters and the National End of Life Care Programme, is about including people	www.dyingmatters.org/page/were -living-well-dying-matters (There are lots of other resources
	with learning difficulties in discussions around death, dying and bereavement.	available here)
Routes to Success: People with Learning Disabilities – National end of life care programme	This publication aims to provide a practical guide which supports anyone caring for people with learning disabilities to ensure that those who may be in the last months of their life receive high quality end of life care. It may also be useful to health or social	http://www.endoflifecareforadults. nhs.uk/publications/route-to- success-people-with-learning- disabilities
	care professionals who come into contact with people with learning disabilities in clarifying what measures need to be taken to ensure that they can access appropriate care.	
Books Beyond Words: Am I going to die? St George's Hospital	John has a terminal illness. This book tells his story, dealing with both physical deterioration and the emotional aspects of dying in an honest and moving way. John is shown getting weaker and needing more help. He looks back at his life and makes choices about how to spend his time. The pictures highlight the importance of going on special outings, of remembering good times, and of saying proper goodbyes to family and friends. The final images show John dying at home.	http://www.booksbeyondwords.co .uk/node/7

Living and Dying with Dignity - An accessible DVD about End of Life Care Speakup	This accessible DVD has been produced by Speakup, a team of people with learning disabilities working in partnership with professional film makers and specialist End of Life Care nurses. The DVD shows people with learning disabilities talking about death and dying. It talks about the choices people have in End of Life Care and also encourages people to talk about them and make sure someone they know and trust knows what they are.	www.friendlyresources.org.uk. orders@friendlyresources.org.uk
End of life care University of Keele	A DVD featuring people with learning disabilities talking about dying, death and bereavement	Sue Read s.c.read@keele.ac.uk
Death by Indifference Mencap	As a result of receiving unequal healthcare, people with a learning disability are dying when their lives could be saved.	http://www.mencap.org.uk/campa igns/take-action/death- indifference
Living and Dying with dignity Mencap	The best practice guide to end of life care for people with a learning disability	http://www.mencap.org.uk/all- about-learning- disability/information- professionals/health/end-life-care
When I die	An easy read 'advance care planning' document	http://www.dyingmatters.org/page /people-learning-disabilities

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