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Living with Learning Disabilities, Dying with Cancer

Thirteen Personal Stories

Irene Tuffrey-Wijne

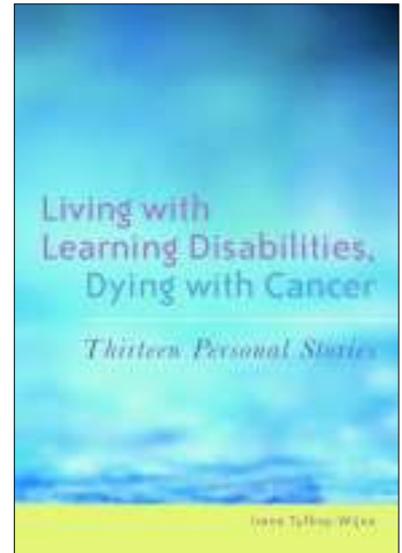
Sheila Hollins

October 2009 272pp ISBN: 9781849050272 pb £19.99

This book is a powerful and moving account of the experiences of 13 people with learning disabilities who were living with cancer. The author followed their lives as part of a 3-year research study, during which 10 people died. She spent extensive periods of time with them at their homes and day centres, in hospitals, hospices and nursing homes. In doing so, she gained a unique understanding of what it is like for individuals with learning disabilities to live with deteriorating health and how this may impact upon their families, friends and carers. How was each person's cancer diagnosed? How was their cancer and its implications explained to them? How much did they understand and how did they cope with treatment? What happened when they were dying? In answering these questions, the book exposes the suffering of people with learning disabilities at the end of their lives, but also their remarkable resilience and strength. In an optimistic final chapter, the author demonstrates how people with learning disabilities can best be supported at the end of life.

This book will be an invaluable resource for anyone involved in the care and support of people with learning disabilities who have cancer and who are dying, including health and social care professionals, families and friends.

Irene Tuffrey-Wijne qualified as a nurse in Amsterdam, and moved to the UK in 1985. She holds a first degree in Palliative Care Nursing and completed a PhD in the palliative care of people with learning disabilities at Maastricht University, The Netherlands. **Irene** has extensive clinical experience in the fields of both learning disabilities (as a support worker and home manager) and palliative care (as a clinical nurse specialist at a hospice). She now works as a Research Fellow at St George's University of London, leading a programme of research aimed at improving end of life care for people with learning disabilities. She is chair of the Network for Palliative Care of people with Learning Disabilities. **Irene** lives in London with her husband and three young children.



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