

## Resource List for Supporting People with Learning Disabilities and Dementia

### Packs

1. **Supporting People with Learning Disabilities and dementia – £55**

<https://www.pavpub.com/supporting-people-with-learning-disabilities-and-dementia-training-pack>



Supporting People with Learning Disabilities and Dementia, a training pack for support staff and allied healthcare professionals (based on the Supporting Derek film and guide).

2. **Down's Syndrome and dementia- a resource for carers and support staff - £20**  
**Karen Dodd, Vicky Turk and Michelle Christmas**

<https://www.bild.org.uk/product/downs-syndrome-and-dementia-resource-pack/>

A resource book for family carers, staff and other professional to help them care more effectively for people with Down's Syndrome and dementia.

This book focuses on practical day to day issues, including; supporting the person with Down's syndrome to maintain skills and independence in every way and for as long as possible.

This book has been revised to take into account further developments both in working with people with learning disabilities in general and specific developments for people who develop dementia.



3. **Dementia Workbook - £15.45**  
**Karen Dodd, Diana Kerr and Scott Fern**

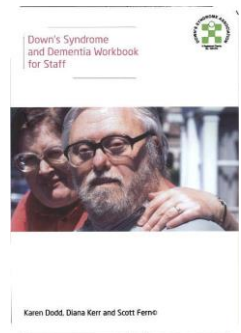
### For a better life

<http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/for-professionals/1091-downs-syndrome-and-dementia-workbook.html>

This brand new user-friendly workbook will appeal to health and social care staff supporting individuals with Down's syndrome and dementia.

Supporting someone with dementia can be a bewildering and difficult time for staff that are often unsure what needs to be put in place and who to approach for resources. Staff often feel they need more information about the condition but are unsure where to look.

The Dementia Workbook will support and guide staff throughout the course of the condition starting at the early point when dementia is suspected and there is a need to make a referral for assessment through to the late stages and death. Record sheets, information text and action points are provided to cover every aspect of dementia. Staff should use this book as a record and action plan for each person with the condition and in return the book will help guide staff through the complexities of supporting some with Down's syndrome who has dementia.



## Accessible dementia booklets

### BILD books

<https://www.bild.org.uk/shop/>

- 'About Dementia' - £8.00
- 'The journey of life' - £10.00
- 'About my friend' - £12.00

A series of three easy-to-read booklets for people with learning disabilities who want to understand dementia.

They will be particularly helpful for people who have a friend or family member with dementia, or who are worried about developing dementia themselves.

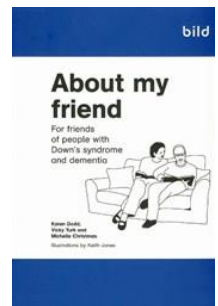
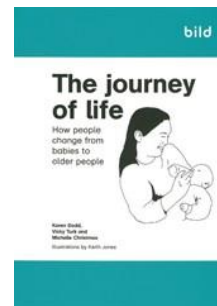
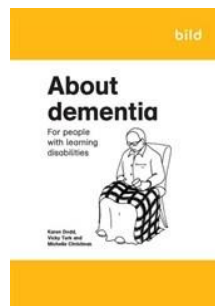
'*About dementia*' is designed to help more able people with learning disabilities who want to understand and talk about dementia.

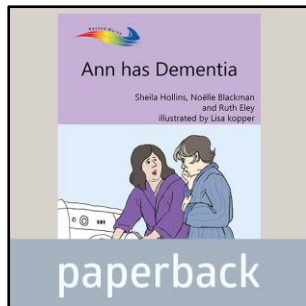
'*The journey of life*' will be useful for helping people with learning disabilities understand the human life cycle.

'*About my friend*' looks at what happens when a friend develops dementia.

### Books Beyond Words – Ann has dementia

<https://booksbeyondwords.co.uk/bookshop/paperbacks/ann-has-dementia>





This is a story told in pictures about Ann, who is diagnosed with dementia. We see her GP and her supporter trying to provide the right care for Ann in the early days of her dementia until she becomes so confused that she has to move into residential care.

If you know someone with an intellectual or learning disability who has dementia, or who has a family member or friend with dementia, you can use the pictures in this book to help them understand what dementia is and how the person with dementia can be supported.

### Jenny's Diary

<https://www.learningdisabilityanddementia.org/jennys-diary.html>



Jenny's Diary is a free to download booklet and a set of postcards. It is aimed at supporting conversations about dementia with people who have a learning (intellectual) disability. Conversations about dementia are never easy. All dementia strategies in the UK state that everyone is entitled to know of their diagnosis, not only as a human rights issue but as part of developing appropriate and individualised post diagnostic support

### DVDS

The DVDs detailed below are available from the Down Syndrome Association ([www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk))

#### 1. **Fighting for Andrew** – £15.00

<http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/families/adults-18/1085-downs-syndrome-and-dementia-fighting-for-andrew.html>

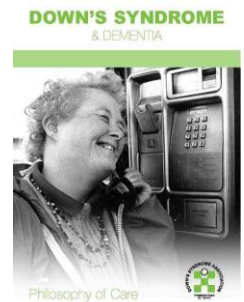
'Fighting for Andrew' powerfully illustrates both a sister's dedication to her brother and a gold standard of care for someone with Down's syndrome and dementia.



## 2. **Philosophy of Care** - £15.00

<http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/families/adults-18/1087-downs-syndrome-and-dementia-philosophy-of-care.html>

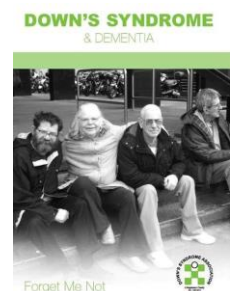
'Philosophy of care' helps carers to understand the experience of dementia and explains the principles that need to underpin care to provide the best quality of life.



## 3. **Forget me not** - £15.00

<http://www.downs-syndrome.org.uk/shop/publications/medical-and-health/families/adults-18/1086-downs-syndrome-and-dementia-forget-me-not.html>

'Forget me not' is a drama written and performed by the GOLD group (Growing Older with Learning Disabilities) who have been together since 1998. Based upon their experiences of two members who developed dementia, they have been inspired to produce this play which illustrates the importance of friendship and supporting peers.



## Other Publications

### 1. **Happy Eating**– £29.95

Surrey and Borders Partnership NHS Foundation Trust

<http://www.pavpub.com/p-570-happy-eating.aspx>

This resource aims to ensure the highest quality care in eating and drinking for people with dementia, making it an enjoyable and stress free experience for them by using a person-centred approach.



### 2. **A Good Death Guide 1**– £9.95

Surrey and Borders Partnership NHS Foundation Trust

<http://www.pavpub.com/p-569-a-good-death-guide-1.aspx>

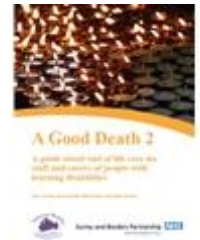
This easy read resource can be used by staff and carers with people with learning disabilities to help them understand about end of life choices, dying and death.



3. **A Good Death Guide 2**– £9.95  
Surrey and Borders Partnership NHS Foundation Trust

<http://www.pavpub.com/p-568-a-good-death-guide-2.aspx>

This resource will give staff and carers of people with learning disabilities basic information on providing end of life care to people with learning disabilities.



4. **A Good Death Guide 3** – £9.95  
Surrey and Borders Partnership NHS Foundation Trust

<http://www.pavpub.com/p-567-a-good-death-guide-3.aspx>

This value for money resource offers basic information to staff working with people with learning disabilities in palliative and acute settings.



## Books

1. British Psychological Society (2015) Dementia and People with Learning Disabilities. Guidance on the assessment, diagnosis, intervention and support of people with learning disabilities who develop dementia. British Psychological Society, Leicester.
2. Buijssen H (2005) The Simplicity of Dementia. Jessica Kingsley Publishers. London.
3. Dodd, K (2003) Supporting people with Down's Syndrome and dementia. Tizard Learning Disability Review 8 (4) 14-18
4. Fray M (2000) Caring for Kathleen. BILD
5. Joseph Rowntree Foundation (2006) Pain management for older people with learning difficulties and dementia. Findings. York: JRF
6. Kerr, D. (1997) Down's Syndrome and Dementia: A Practitioner's Guide
7. Kerr D (2007) Understanding Learning Disability and Dementia: Developing Effective Interventions. Jessica Kingsley Publishers. London
8. Kerr, D. & Wilkinson, H. (2005) In the Know. Implementing Good Practice. Brighton: Pavilion Publishing
9. Wilkinson, H., Kerr, D., Cunningham, C. & Rae, C. (2004) Home for Good? Preparing to support people with a learning disability in a residential setting when they develop dementia. York: JRF publications.
10. Watchman K (Ed) Intellectual Disabilities and dementia: research into practice. Jessica Kingsley Publishers: London

11. Dodd K. (2017) Commentary on 'Estimating the number of people with Down's syndrome in Scotland and the cohort at elevated risk of early onset dementia'. *Tizard Learning Disability Review* 22 (3) 172 – 176.
12. Dodd K, (2015) Care considerations for dementia in people with Down's syndrome – a Management Perspective. *Neurodegenerative Disease Management* 5(4) 293-304.