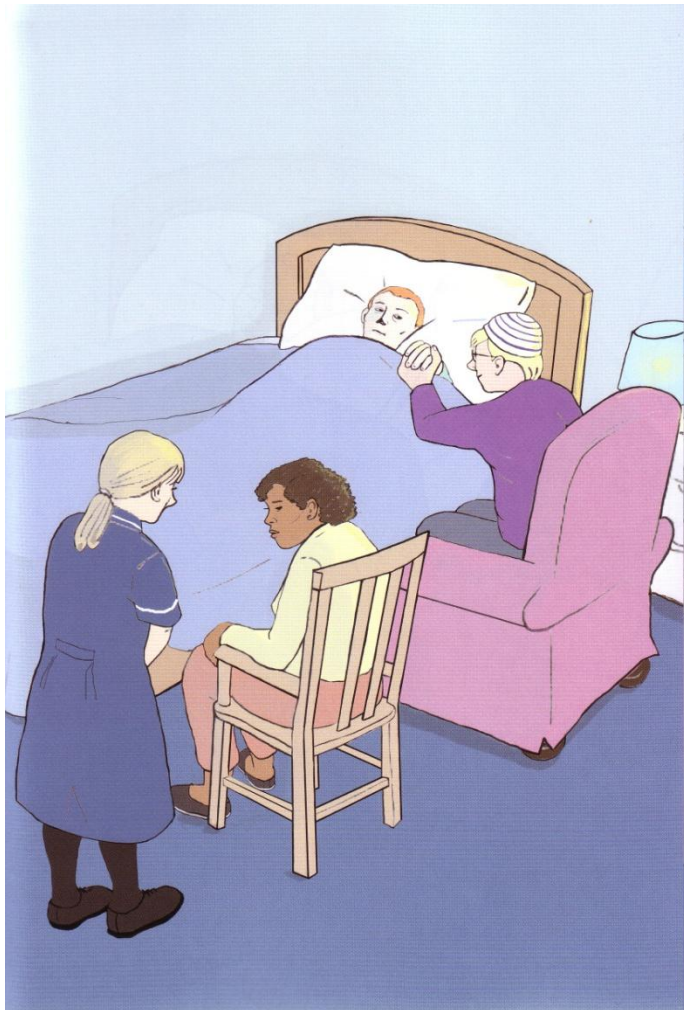


Supporting people with learning disabilities who are dying of cancer

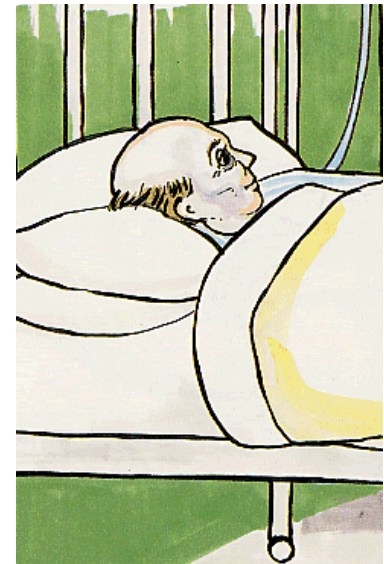
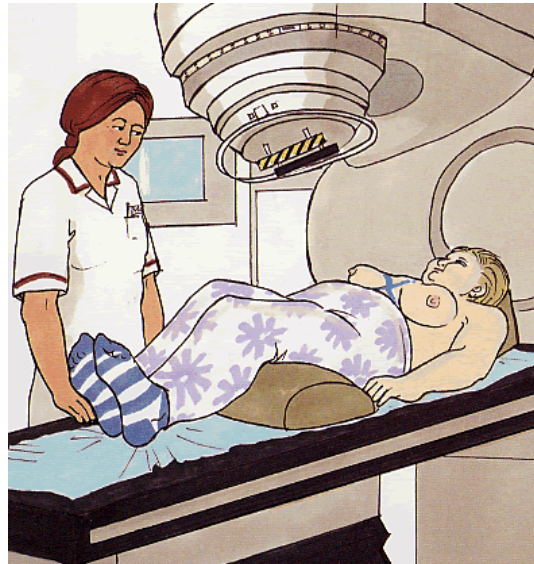


Dr Irene Tuffrey-Wijne



Aims and objectives

What is it like for people LD to have cancer?



The Veronica Project



In-depth qualitative study
(ethnography)

*Looking at the world through
people's eyes*

3 years (2005-2008)

Participants

13 adults with learning disabilities Cancer diagnosis

7 men, 6 women

Average age: **53** (*range 36-66*)

Degree of learning disability

Mild/moderate: 7

Severe/profound: 6

Living situation

Staffed residential care home: 7

Own flat without support: 3

Shared flat with support: 1

Parental home: 1

Family placement: 1



Participants

2 'cured'

Pauline and Amanda

11 died

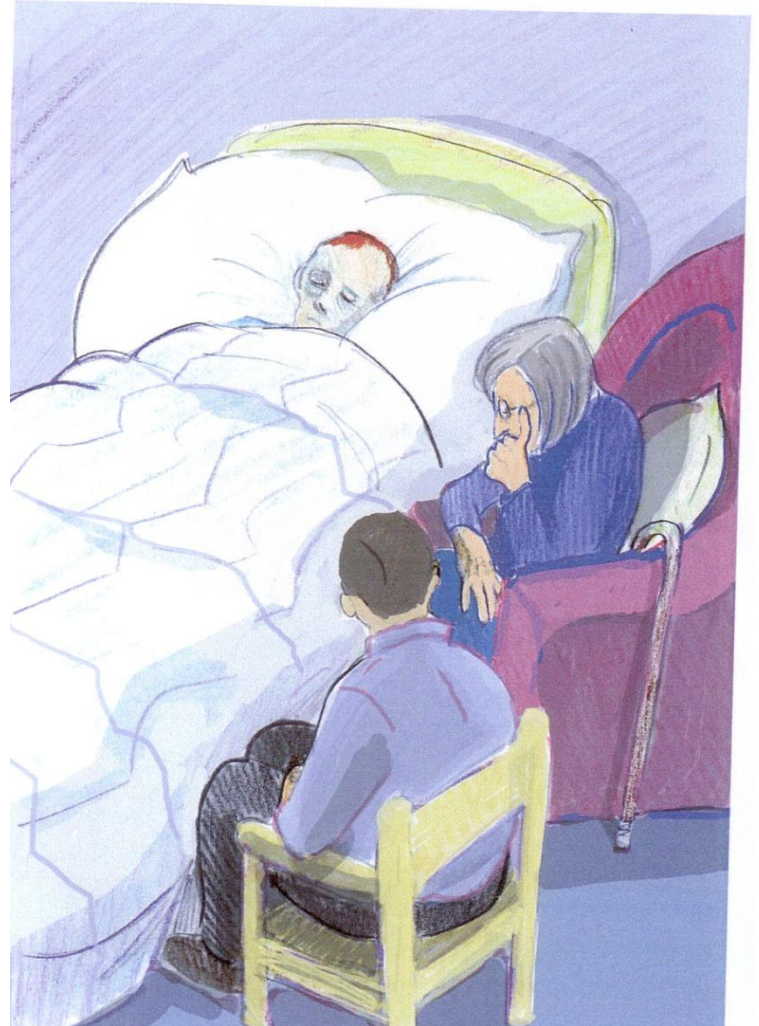
Residential care home *Pete, Nick*

Own flat *Vincent*

Hospice *Lily, Sally*

Hospital *Midas, Ursula, Ben*

Nursing home *John, Richard*



Methods

What I did

Data collection

Participant observation

Attending case reviews

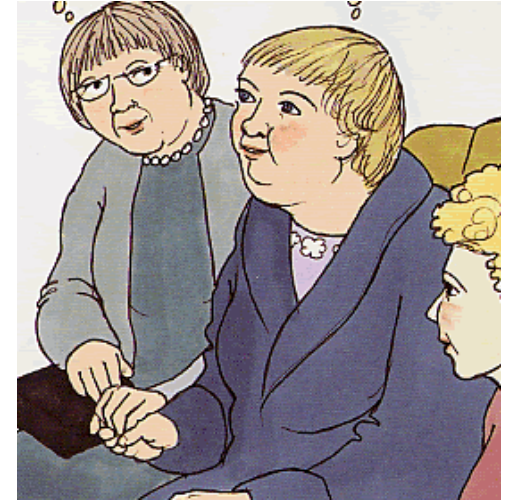
Reviewing case notes

Talking to family, carers and health staff

Etc

Field notes (*over 1,500 pages*)

Tape recording *Amanda and John*



Data analysis

How we made sense of it

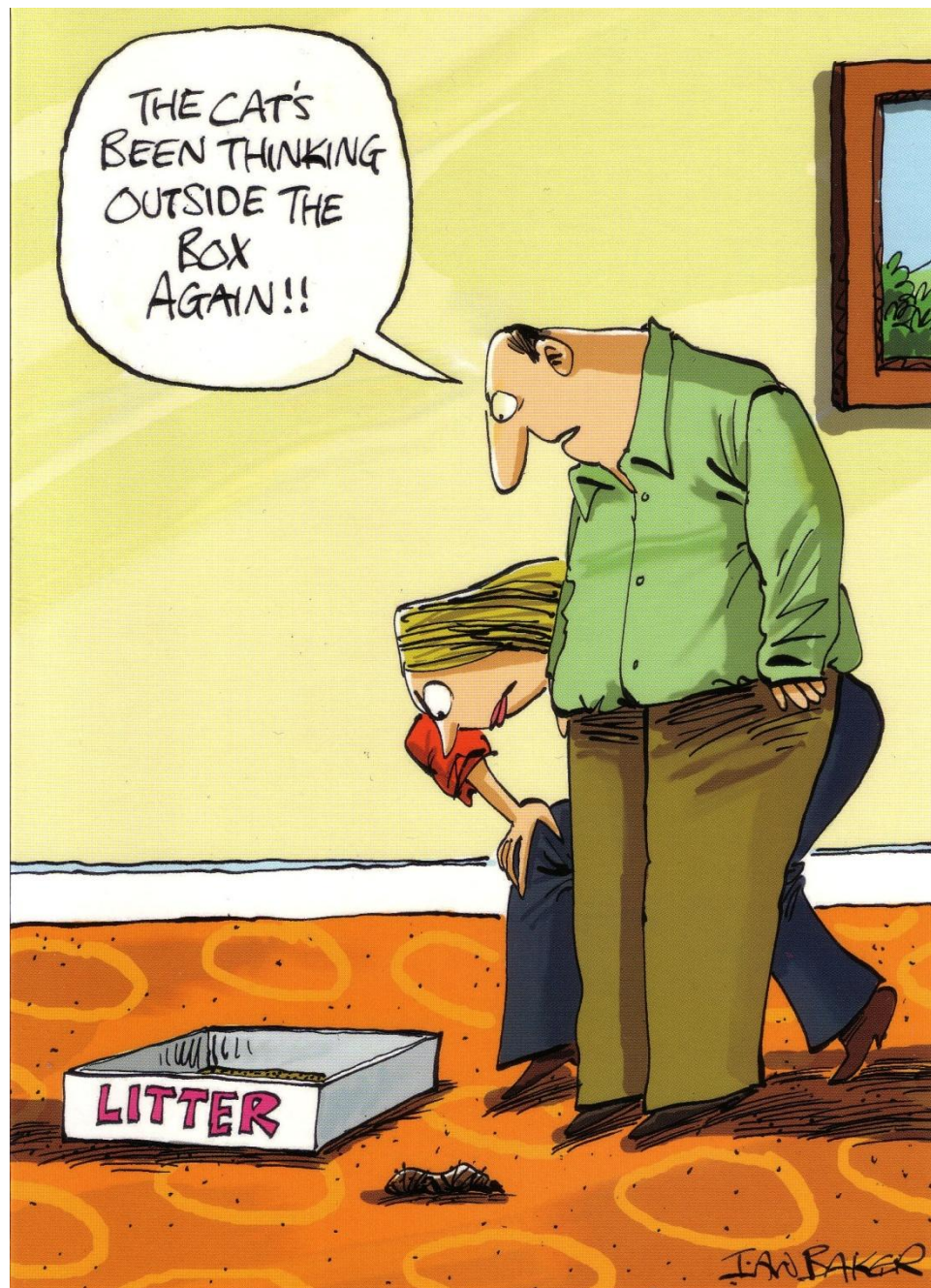
GROUNDNED THEORY

On-going discussions with colleagues

Feeding back some findings to
participants

Data read by colleagues





Findings

What is it like to live with a learning disability and cancer?

- 1. Dependent lives**
- 2. Deprived lives**
- 3. Understanding**
- 4. Importance of families**
- 5. Inexperienced carers**
- 6. Resilience**

What did people want and need?



To be diagnosed in good time

Diagnosis was delayed for at least 10 participants

- Not noticed
- Not complained
- Not believed

Some carers were:

- sensitive to changes in behaviour
- persistent with doctors



To receive treatment and care that is based on their own wishes, and on “best interest”

- Only 1 participant was helped to decide
- Very few “best interest” meetings
- Dependent on views of family & social care staff
- Suspicion of discriminatory practice by doctors

BUT

- Those who were helped to understand, coped better with treatments
- Best interest meetings led to more satisfied carers and better decisions

***Support worker of Marion
Severe learning disabilities
Breast cancer***



To be free of pain and other symptoms

- Timely input from palliative care services
- Carers must allow “pain experts” to act
- In difficult pain situations, hospice care was necessary



To have dignity

- Not being patronised
- To be spoken to and not ignored
- To be helped when help is needed; to be allowed to manage when help is not needed
- Looking and smelling nice



To have adequate equipment and space

- Can be problematic in “ordinary houses”
- Stairs!



To receive as much information as they want, in a way they can understand

- People wanted honesty without being overwhelmed
- Simple words, pictures

Amanda

Mild learning disabilities

Lymphoma (5 years ago)



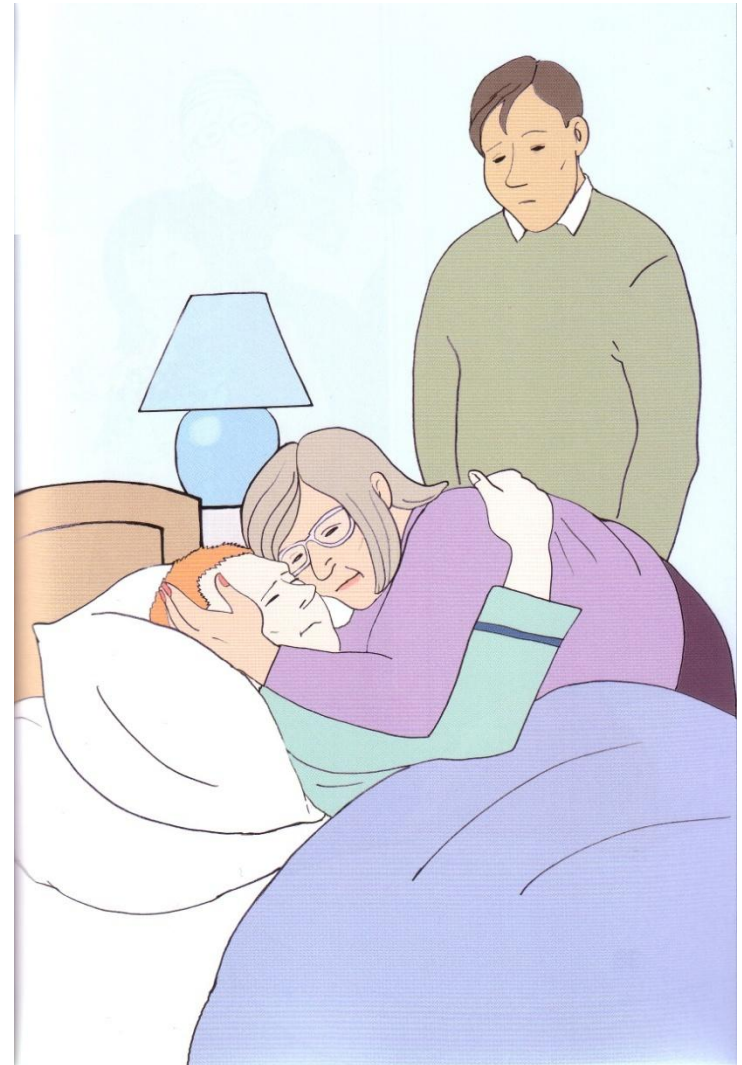
To have a degree of control over their lives

- **Dependence** and **Lack of control**: most striking findings
- Need to be involved in
 - Major decisions (*where to be cared for*)
 - Minor decisions (*what to do with your time,*



To have contact with their families

- Families **very** important (even if there has not been much contact)
- Paid carers often crucial in supporting this



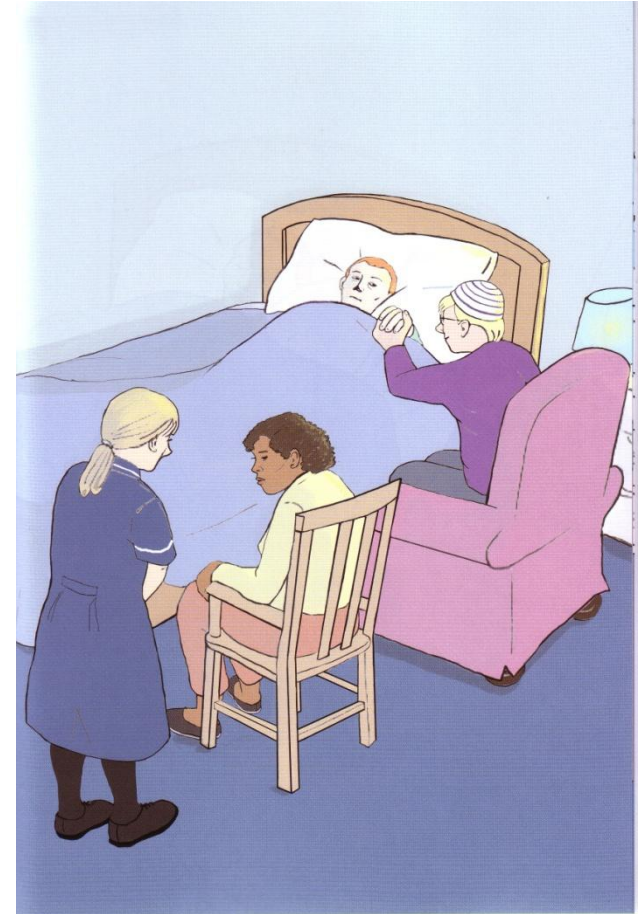
To have contact with their friends

- Friendships often limited
- Supervised friendships
- Dependent on carers



To have carers who are well supported

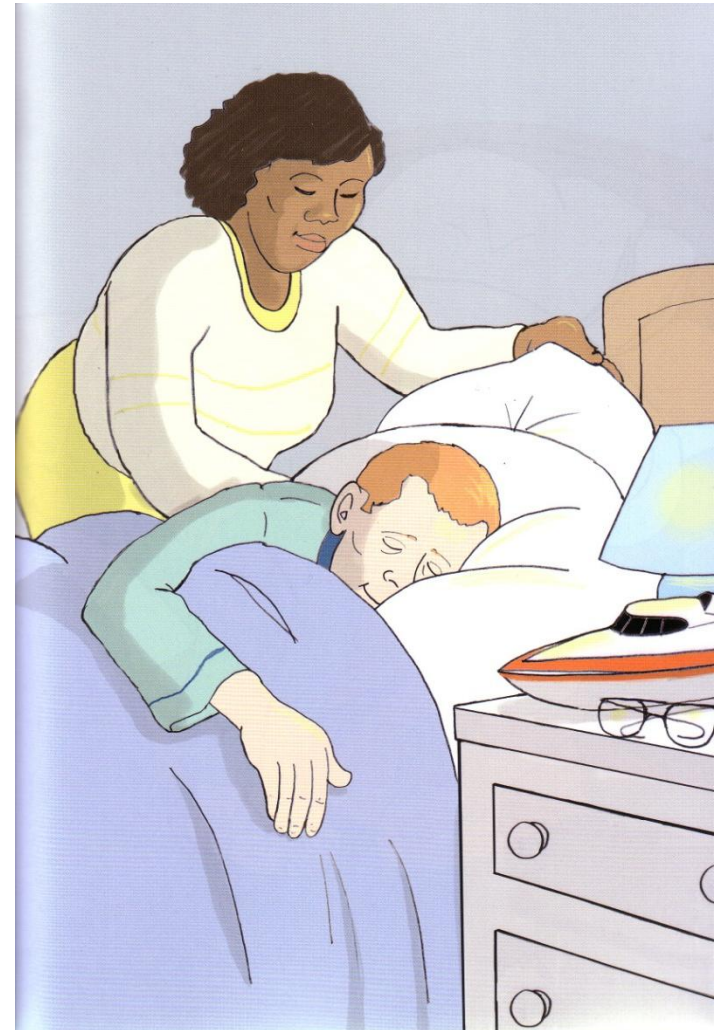
- **Practical** support
 - Extra staffing
 - Learning how to do caring tasks
- **Emotional** support
 - From managers and outside agencies



Well supported carers were better able to support the dying person

To have carers who love them

- Love mattered and made the illness bearable
- Paid carers' love and grief should be allowed
- Carers are vulnerable and need support



To be allowed to be sad as well as happy

This is me being sad.

Maybe you think I'm being happy in this picture.
Really I'm being sad but pretending I'm being happy.
I'm doing that because I think people won't
like me if I look sad.



From **Michael Rosen's Sad Book** by Michael Rosen & Quentin Blake, 2005

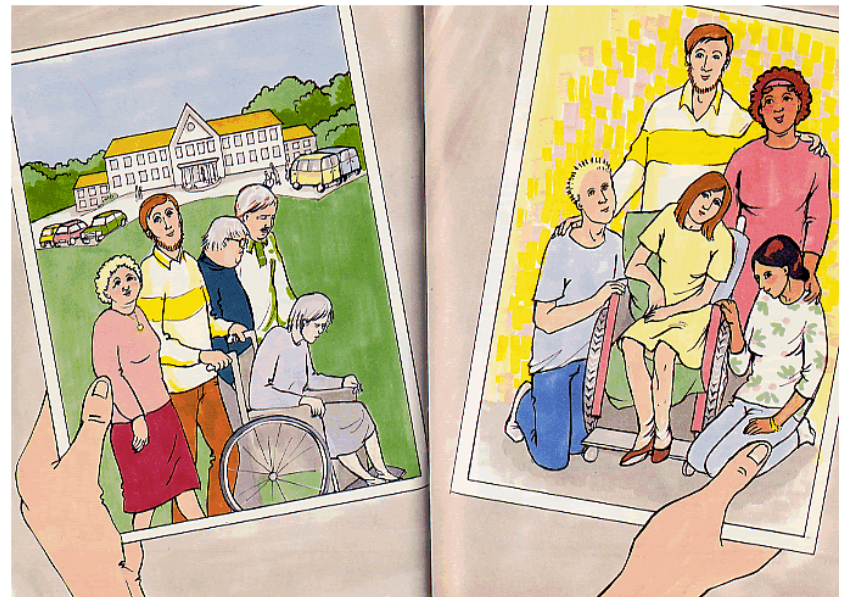
To “keep going” with what they enjoy



To be cared for, and to die, in a place where they feel safe and loved

- Understand the routines
- Know the carers
- Spend time with the people they love

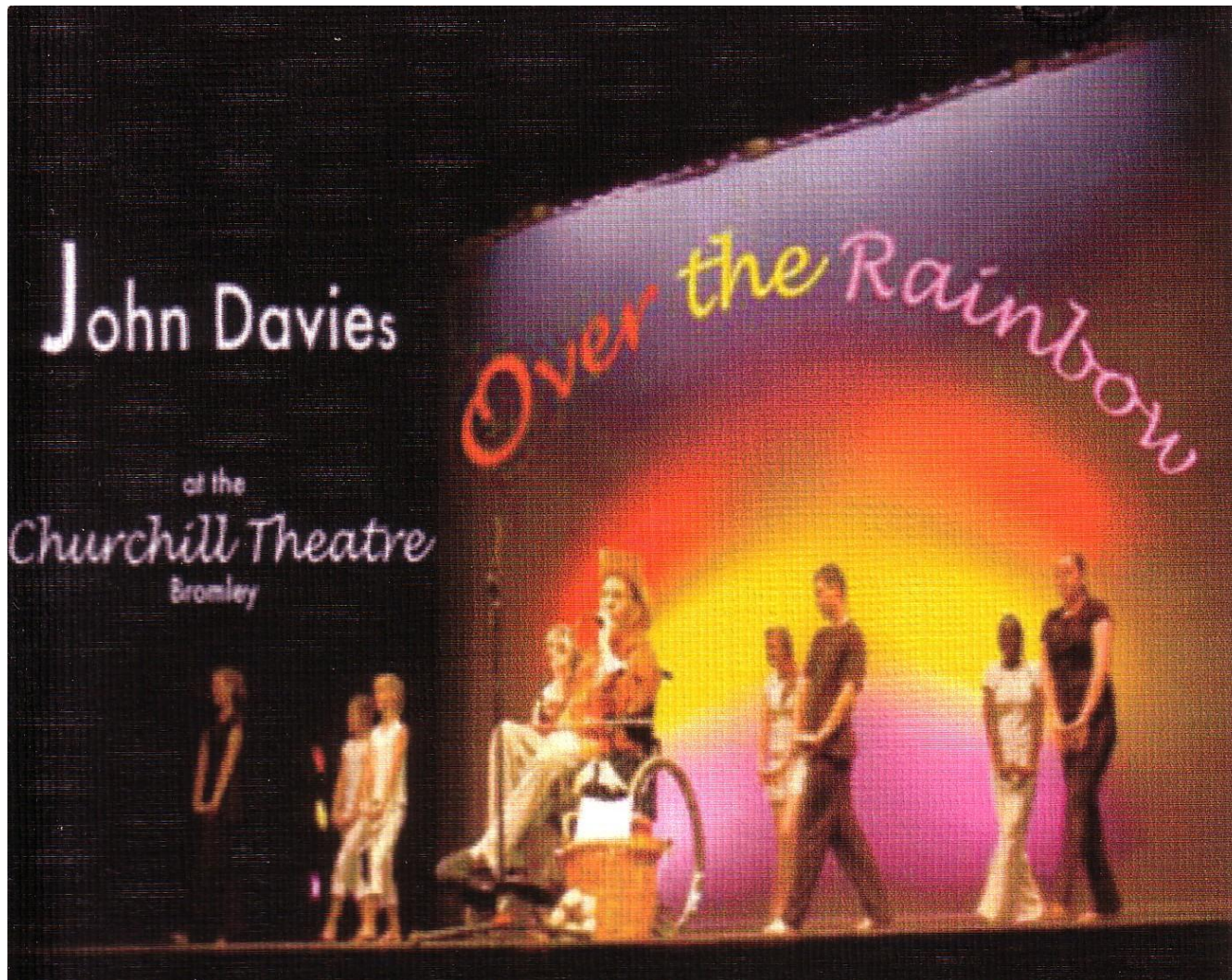
This was often **at home**, but not always!



To look back on their lives



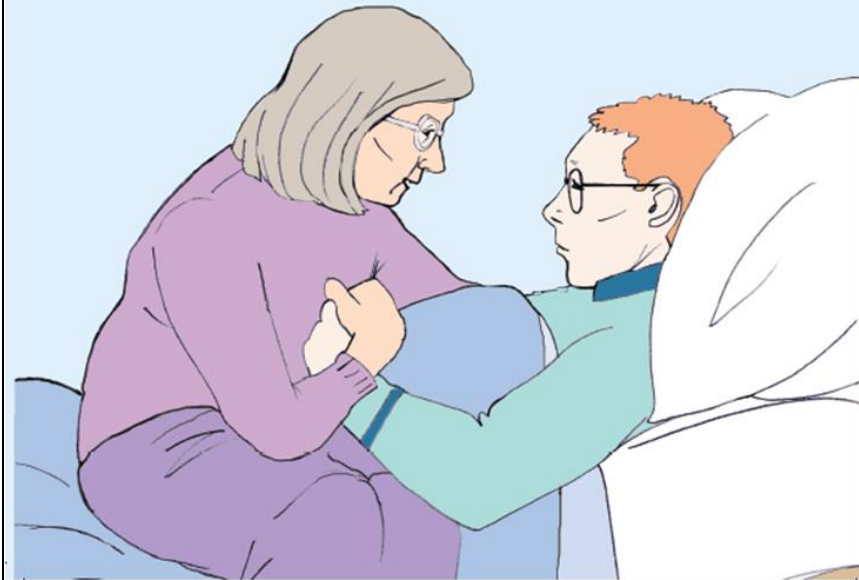
To leave a legacy



Am I Going to Die?

*One of the Books Beyond Words series for healthcare professionals,
parents and carers who support people with learning disabilities*

Sheila Hollins and Irene Tuffrey-Wijne
illustrated by Lisa Kopper



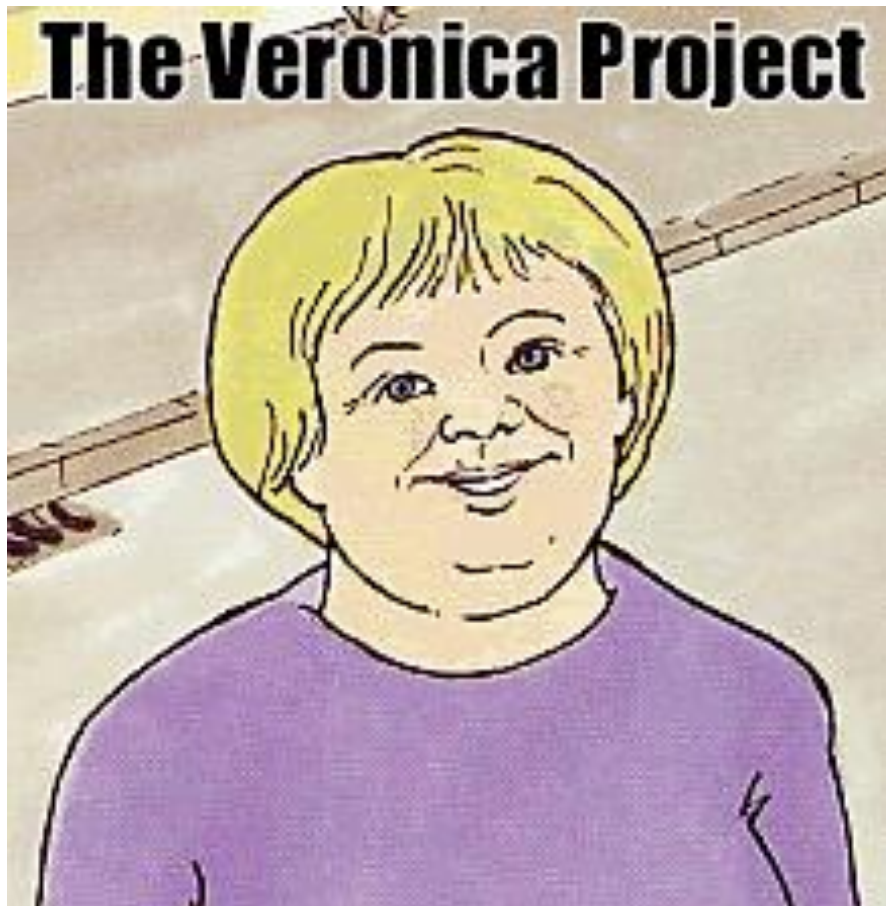


Living with Learning Disabilities, Dying with Cancer

Thirteen Personal Stories

Irene Tuffrey-Wijne

Jessica Kingsley Publishers
www.jkp.com



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Images for this presentation were taken from the
Books Beyond Words Series

www.rcpsych.ac.uk/publications/booksbeyondwords.aspx