

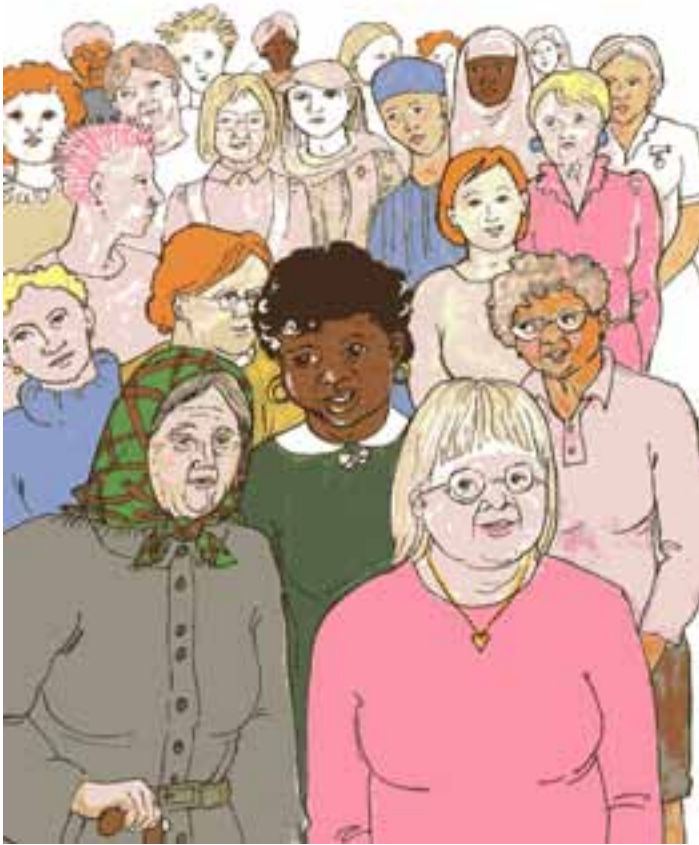
Bridging the gap

Palliative care
for people with
learning disabilities

Dr Irene Tuffrey-Wijne



Learning disabilities



1. Significantly reduced ability to understand new or complex information, to learn new skills
2. Reduced ability to cope independently
3. Started before adulthood, with a lasting effect on development

2.5% of the UK population

Most of these have MILD learning disabilities

Higher incidence in inner-city areas

Degrees of learning disabilities

from the ICD-10 definition of “mental retardation”

Mild (IQ 50-69)

- Some learning difficulties in school
- Many adults will be able to
 - work
 - maintain good social relationships
 - contribute to society

Moderate (IQ 35-49)

- Marked developmental delays in childhood
- Most can learn to develop
 - some degree of independence in self-care
 - adequate communication and academic skills
- Adults will need varying degrees of support to live and work in the community

Degrees of learning disabilities

from the ICD-10 definition of “mental retardation”

Severe (IQ 20-34)

- Continuous need of support.

Profound (IQ below 20)

- Results in severe limitation in
 - self-care
 - continence
 - mobility
 - communication

Mortality in people with learning disabilities

- Increasing life expectancy
- Down's Syndrome: life expectancy doubled in past 20 years (*Yang et al, 2002*)
- Increased risk of life-limiting illness
- Disease profile of those with MILD intellectual disabilities now similar to general population

Example: Alzheimer's Disease in people with Down's Syndrome



40-49 years	9.4%
50-59 years	36.1%
60-69 years	54.5%

(Prasher 1995)

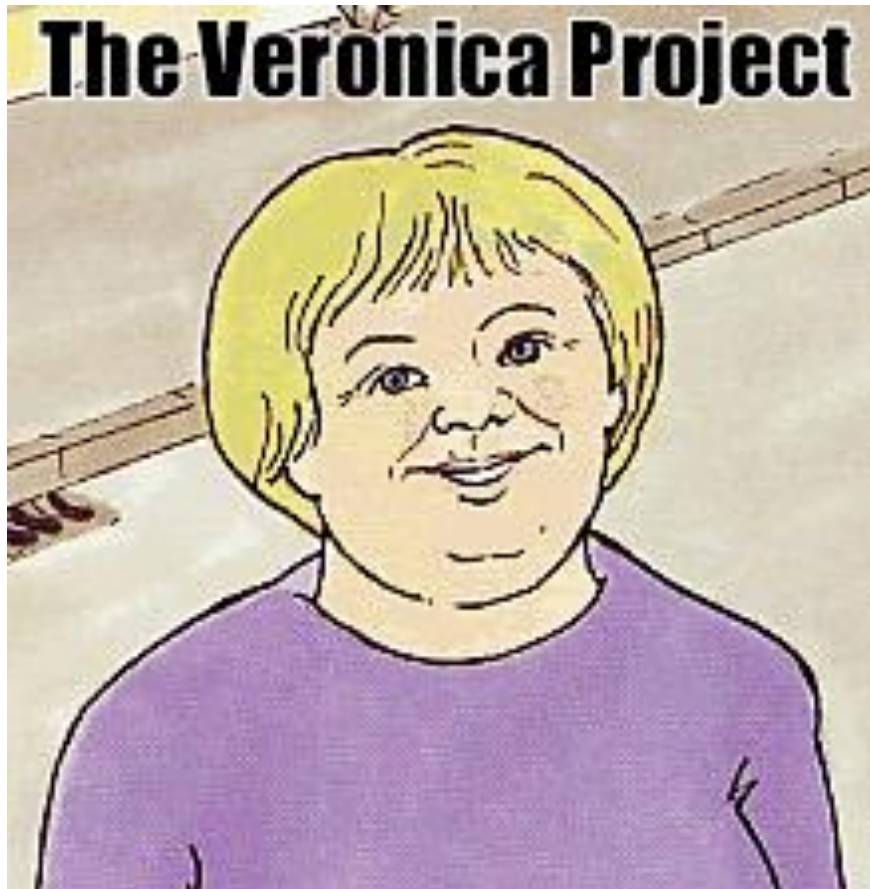
Mortality

in people with learning disabilities

- Primary causes of death:
 - respiratory disease
 - cardiovascular disease
- Cancer deaths
 - 8-16%
- Increased risk of:
 - gastro-intestinal cancers
 - leukemia, lymphoma and testicular cancer in Down's Syndrome (but lower risk of all other common tumours)

(Hogg & Tuffrey-Wijne 2008)

The experiences of people with learning disabilities who have cancer: an ethnographic study



Aims and objectives

What is it like for people LD to have cancer?



What is 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

1 still terminally ill

Richard

10 died

Residential care home

Pete, Nick

Own flat *Vincent*

Hospice *Lily, Sally*

Hospital *Midas, Ursula, Ben*

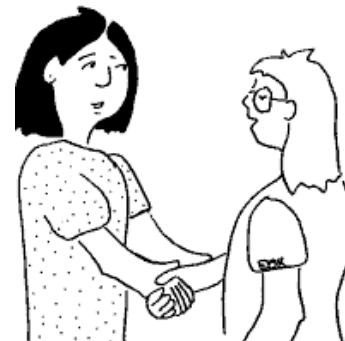
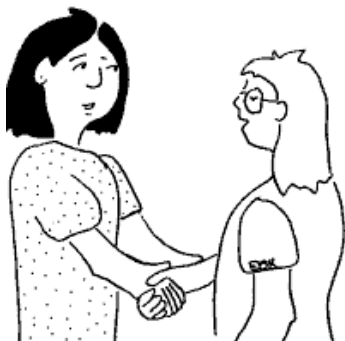
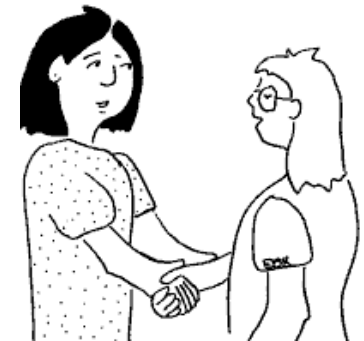
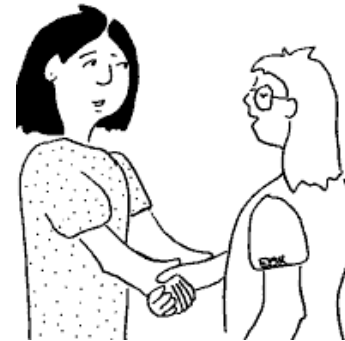
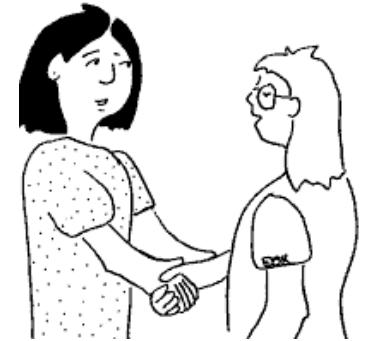
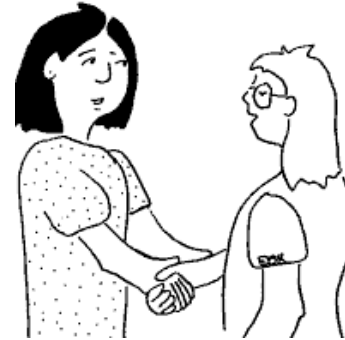
Nursing home *John, Marion*



Participants

Length of involvement
1 day – 2 years

Total data collection
150+ visits
250+ hours



Data collection

What I did

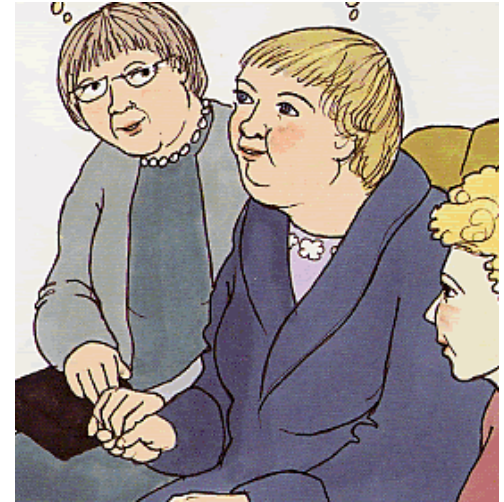
Participant observation

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*



Ethical issues

Ethical approval

Consent

Anonymity

Observation of sub-optimal care

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**

Dependent lives

Lack of control

Decisions about:

Where you live

What you eat

Who your friends are

What you do during the day

Etc

Independence was hard-won and precarious.

Dependent lives

The need for someone to help

Need someone else to help you
to make use of the health
system



Diagnosis

Delayed for at least 10 participants

- Not noticed
- Not complained
- Not believed

Treatment

1 participant was helped to decide

Dependent on views of family & social care staff

Suspicion of discriminatory practice by doctors



„If the doctors said that there was a 50/50 chance of the treatments working, then I would say: forget it. Just let her be happy.“

Support worker of Marion (63), Severe learning disabilities, Breast cancer



Deprived lives

Bullying and abuse

Experienced by all 13 people

On-going experience of being 'un-important'



Ursula and her carer

Severe learning disabilities

Breast cancer



Deprived lives

Lack of meaningful relationships

„Families“ are **parents** and **siblings**

Some had **no real friends**

Many **related mostly to staff**,
rather than peers

Lack of sexual identity



Loneliness



“I get really lonely here. I worry or I panic.

Sometimes I sit here and there is something on TV that makes me panic, like when they talk about cancer. Then I ring people up, and they ask me „what“s wrong“, so I tell them that I am having pain. I“m not in pain really, I am just lonely and worried. But I can“t keep ringing people up, can I? I can“t keep ringing *[my sister]* every five minutes just because I am lonely. She has her own life to live.”

Vincent (47), Mild learning disabilities, Lung cancer

Everyone is jolly



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

Understanding

To tell or not to tell?

„I wouldn't want to be told myself“

„Why upset him, he is happy as he is“

„Her mum knows her best“

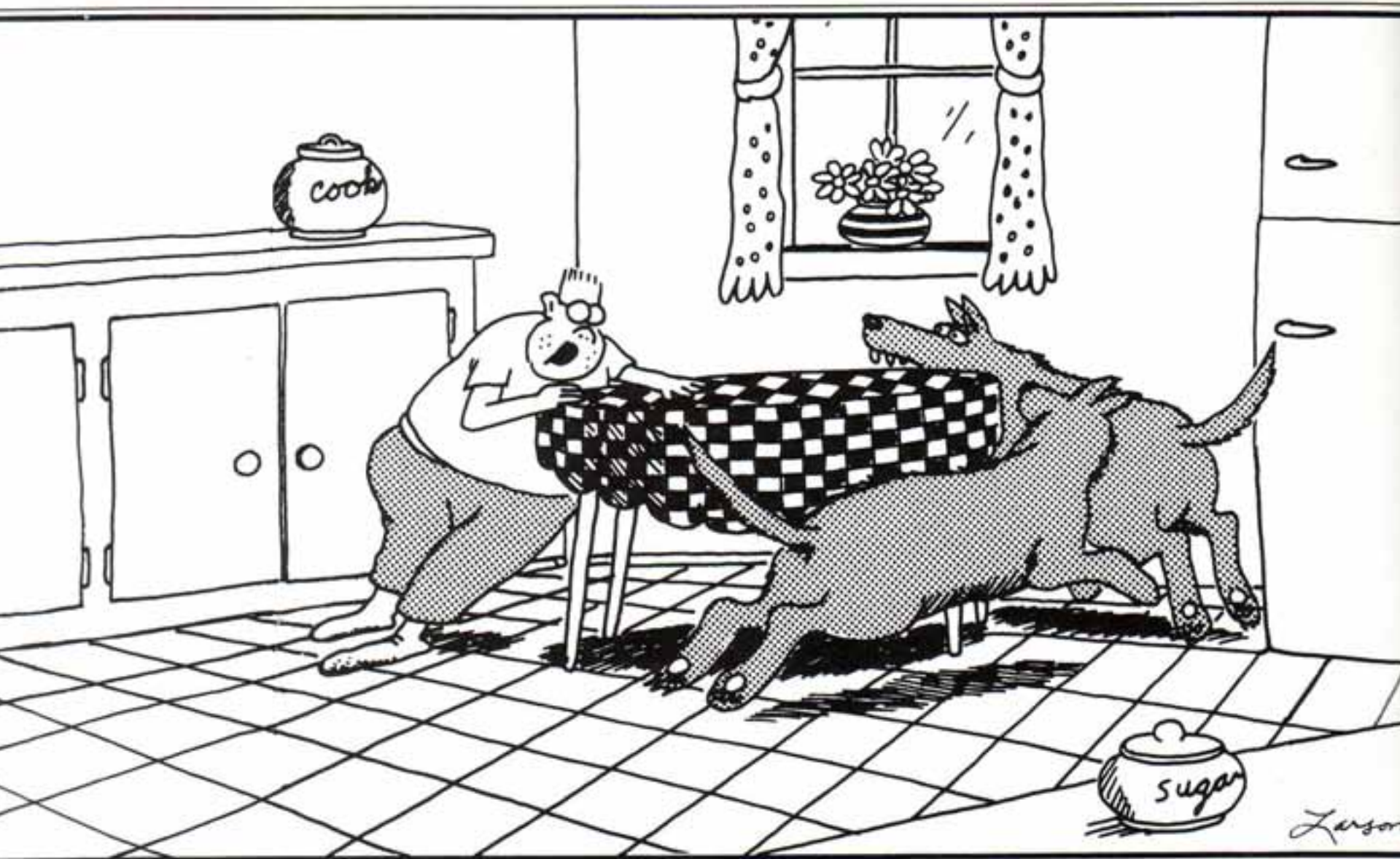
being told ≠ understanding



“What doctors and nurses and other people should know is that it is really important people are told about their cancer. If they are not told, how can they understand it? They need to know! But they should tell people in a way that they can understand. They should say: „You“ve got something growing inside you, and we want to get rid of it, because if we don“t, you are going to die.“And it is important to explain exactly what is going to happen.”

Amanda (36), *Mild learning disabilities,*
Lymphoma (5 years ago)





Luposliphobia: The fear of being pursued by timber wolves around a kitchen table while wearing socks on a newly waxed floor.

Understanding

How did people cope with knowledge?

‘What you don’t know can’t hurt you’

Able to ‘take each day as it comes’

Those who weren’t told, seemed to work out eventually that they were dying



Year 1

„I’ve got a little bit of cancer. That’s not going to go away. It’s only small. I won’t die of it.“

Year 2

„I am quite worried, actually. I am losing weight.“

Year 3

„Cancer never goes away. It makes you weaker. It happened to my dad, he died of cancer, he got weaker and weaker and then suddenly he died“

„Do you think that will happen to you, too?“

„Yes, I think it will. Because that is what happens.“

Richard, mild LD and lung cancer

Inexperienced carers

Hospital staff

Ignorance around LD

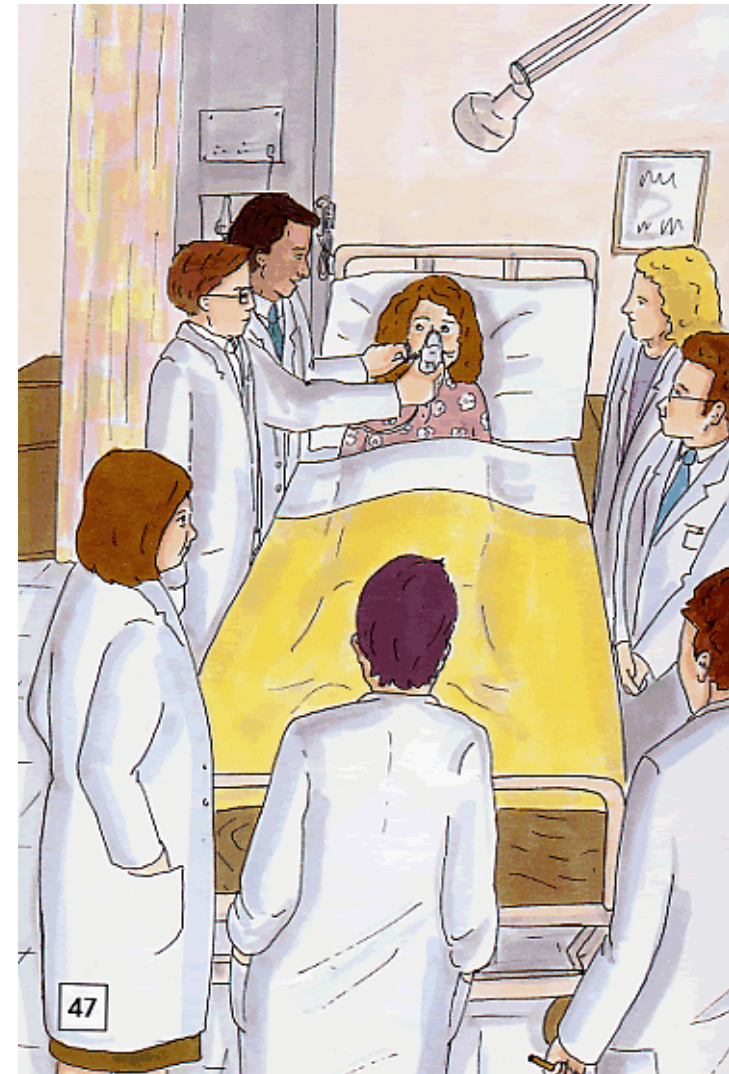
Often ignoring people's individuality

Lack of communication skills

Lack of skills in assessing capacity

(Too) much reliance on families and paid carers

Quality of care dependent on individual team members



Inexperienced carers

Social care staff

Didn't know much about cancer and dying

Frightened

Close emotional involvement

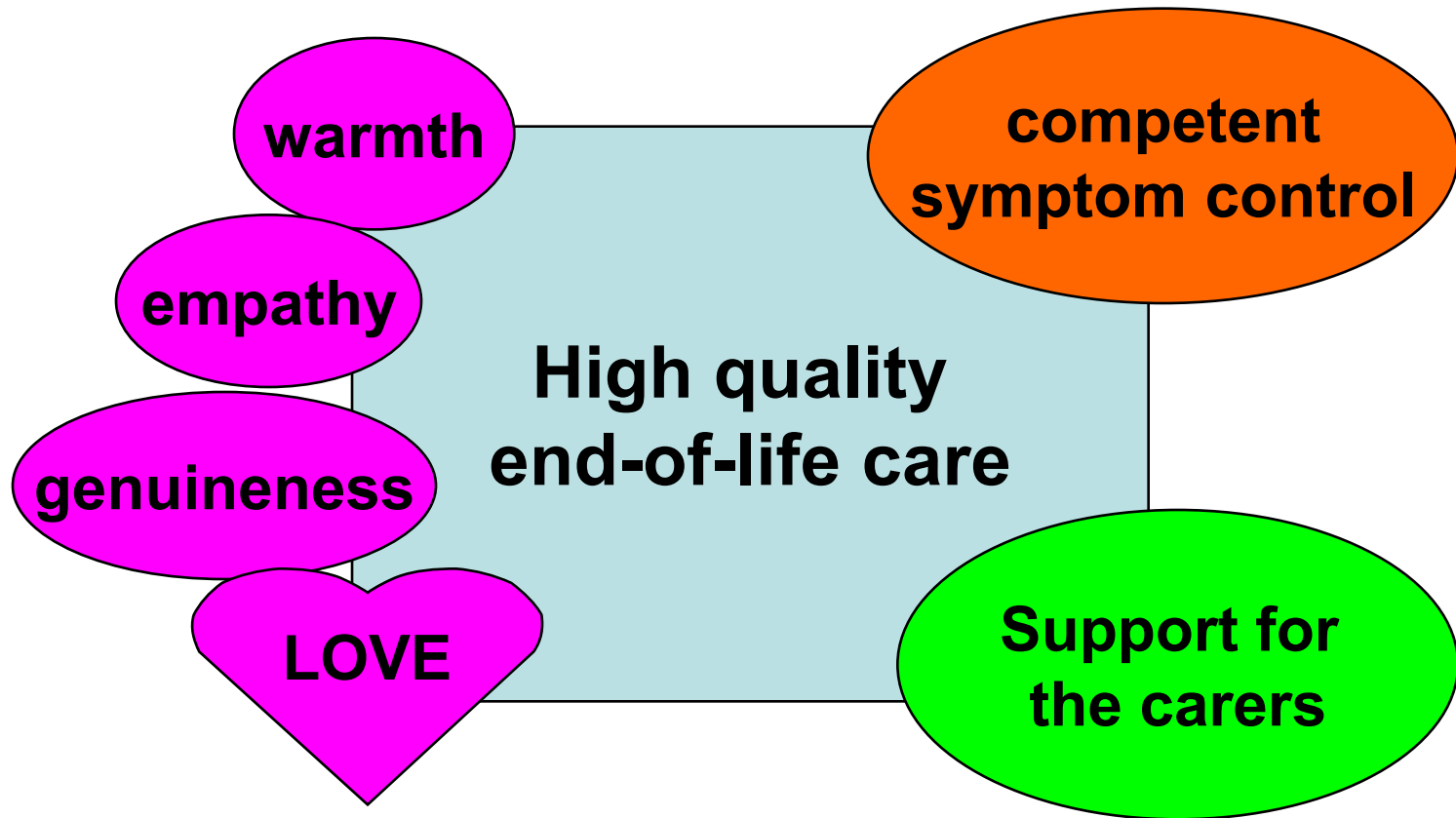
Need outside support

Practical and emotional



Importance of **genuine** carers





Keep singing!



The most important question...

What matters most to this person?



Who can really listen?

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



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

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



Living with
Learning Disabilities,
Dying with Cancer

Thirteen Personal Stories

Irene Tuffrey-Wijne

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