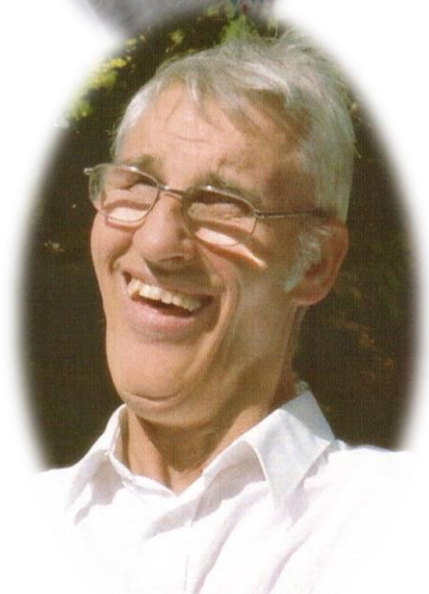


Best practice in delivering palliative care to people with learning disabilities

Irene Tuffrey-Wijne RN, PhD

*Associate Professor in
Intellectual Disability & Palliative care
Kingston University &
St George's University of London*



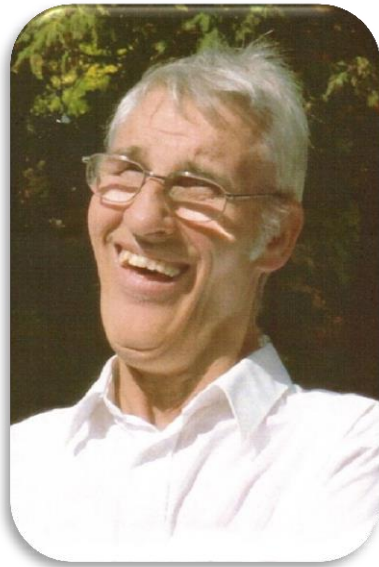
**Kingston
University**
London



St George's
University of London



Keith Lindsay
1949-1999



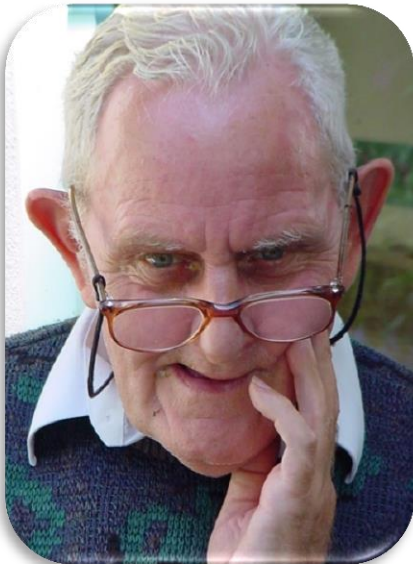
Brian Matthews
1945-2007



Doreen Wright
1936-2002



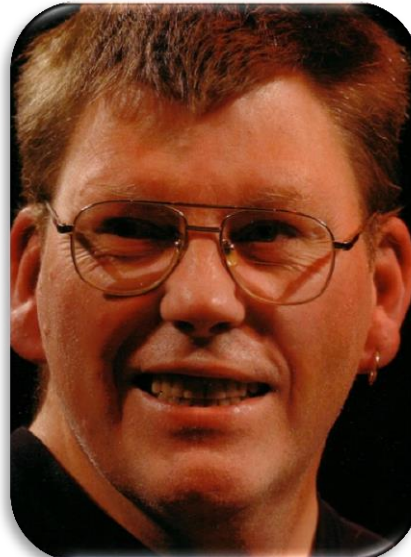
Philip Yates
1942-2003



John Roffey
1939-2005



Doris Maxwell
1933-2006

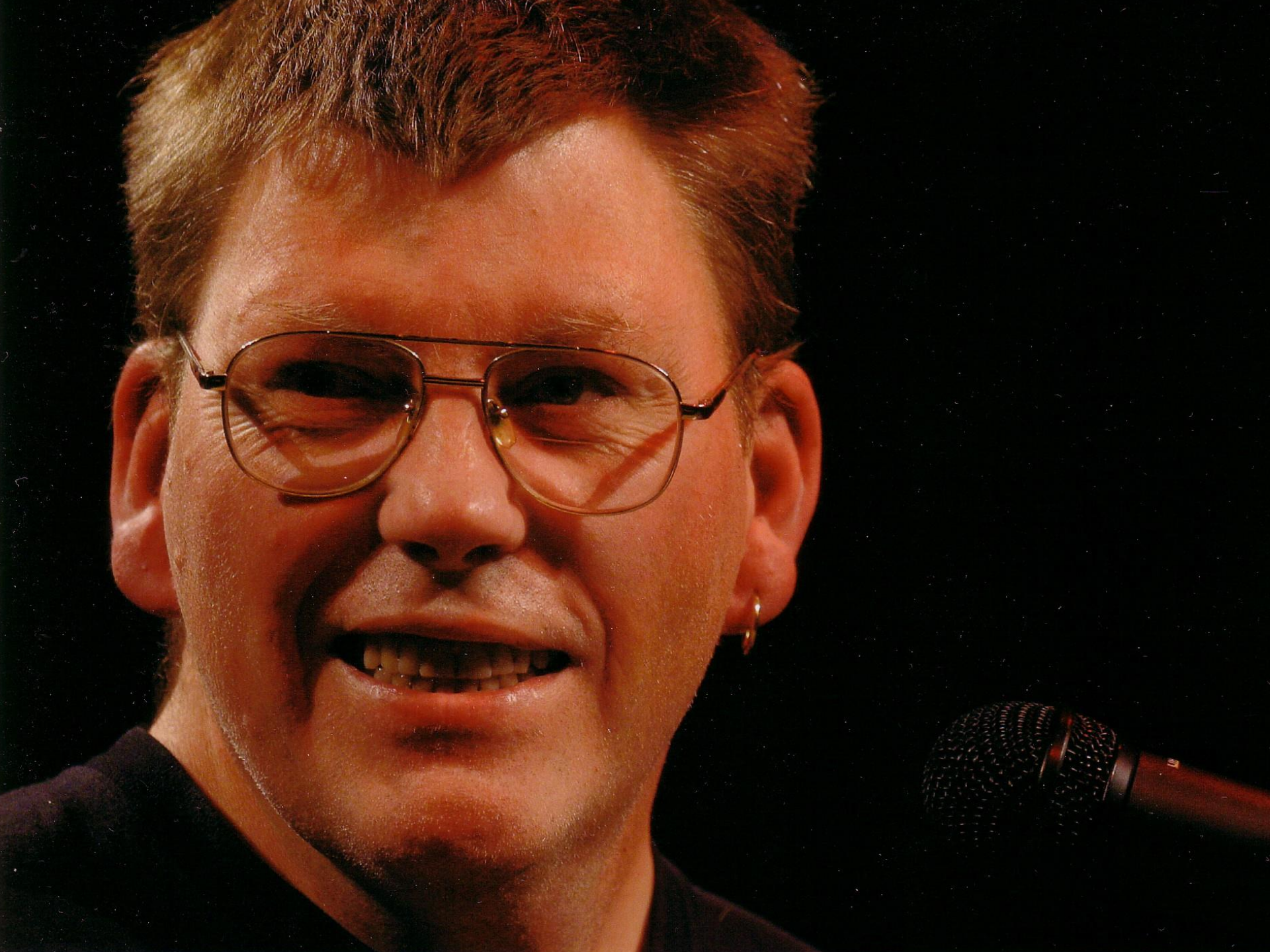


John Davies
1961-2006



Primrose Pollock
1935-2007





Someone to Talk to

WHAT KIND OF SUPPORT DO PEOPLE NEED?
FAMILY, PROFESSIONALS

"The hospice was very good because they were very supportive. They have counselling which I thought was really great. And I think it really helps. I think I would never have got over all of it completely if I didn't have counselling. (Female, age 48)

"I can't go to my brother and his family. You must be joking! That's why I like talking to my friend about it" (Female, 42)

CAN YOU UNDERSTAND CANCER?

NO JARGON PLEASE

They should have it in easier words, easy format for people with learning disabilities to understand more there are so many different types of cancer. If somebody can't hear or all the different parts of the human body to say "You get it here, there, there, and there" and point to it on a diagram like for people with learning disabilities non-verbal people can take all of it in and it makes sense to them. "There, there, there and there" then it's easier to understand because how are they to know otherwise?"

4 THEMES

PROTECTION

UNDERSTANDING

COPING with Cancer

SUPPORT

NEEDING BEING SUPPORTER

Someone to talk to about my feelings and worries



Two people sitting at a table. A woman on the left with short grey hair and glasses, wearing a floral patterned top, is smiling and holding a white mug with a black and white kitten on it. A man on the right with short grey hair and glasses, wearing a dark jacket over a striped shirt, is also smiling. They are surrounded by papers and documents on the table.

A woman on the right with short brown hair and glasses, wearing a light blue cardigan over a dark t-shirt, is smiling. She is sitting at a table with various items including a water bottle, a red can, a bag of snacks, and a clear plastic container. In front of her is a document titled "MY FAMILY TOLD ME" with the sub-heading "Protection and inclusion".

What is so special about people with learning disabilities who need palliative care?



Many palliative care needs are **no different** from those of the general population, BUT...

Unique issues and **disadvantages** make it more difficult to meet those needs



Communication

Insight and understanding

High incidence of mental health problems

Complex social circumstances

Eclectic range of family, friends, care staff and professionals

Mental capacity and decision making

Symptoms masked by unconventional behaviour

Multiple co-morbidities



Equal treatment
does not mean
the same treatment!



Provide
reasonable adjustments...



...or remove the barriers
(the source
of the inequity)

Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe

EAPC White Paper

European Association for Palliative Care (EAPC)
Taskforce on People with Intellectual Disabilities

APRIL 2015



GOOGLE:

- EAPC
- White Paper
- Intellectual Disabilities

Consensus norms

- To **provide guidance** on what good practice looks like, regardless of setting or national differences
- To describe **norms** that are relevant and achievable across Europe
- Norms are
“a consensus on quality goals that have to be aimed for...
if (or when) norms are achieved, high quality can be safely expected.”
EAPC White Paper on standards and norms for hospice and palliative care in Europe, 2009

Methods

Using DELPHI method to build consensus:

1. **Drafting the norms** by the Taskforce

13 norms, incl 52 statements

2. **Evaluating the norms** by an expert panel

Online survey: 80 experts from 15 European countries

3. **Modifications, decisions and recommendations** by the Taskforce

1 statement dropped

4. **Review and acceptance** by EAPC Board (*April 2015*)

6. End of life decision making

	Agree totally	Agree a little	Disagree a little	Disagree totally	Not sure/ don't know
End of life decision making can be complex, regardless of whether or not the person has disabilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with intellectual disabilities have a right to life, and a right to recognition of the value of their lives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal frameworks around capacity and decision making vary. Professionals should be aware of national and local laws and regulations, and these should be adhered to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with intellectual disabilities are assumed to have capacity to make decisions around their care and treatment, unless it is demonstrated otherwise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with intellectual disabilities should have all the necessary support, including advocacy, in order to maximise their involvement in end of life decision making.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please write any COMMENTS:

Categories for norms

1. Equity of access 98.7%
2. Communication 100%
3. Recognising the need for palliative care 100%
4. Assessment of total needs 98.6%
5. Symptom management 97.6%
6. End of life decision making 96.9%
7. Involving those who matter: family, friends and carers 97.1%
8. Collaboration 100%
9. Support for family and carers 99.2%
10. Preparing for death 93.8%
11. Bereavement support 94.0%
12. Education and training 99.4%
13. Developing and managing services 98.4%

The hurdles

What are intellectual disabilities?

An invisible population

What is palliative care?

How do we include ALL of Europe?



Prevalence:

1-3% of the population

5-15 million citizens of the EU

An invisible
population



HOW MANY exactly?

WHERE do they live?

WHERE do they die?

WHO supports them?

Not
visible



Not a
priority

Not a
problem

Palliative care

Supportive care

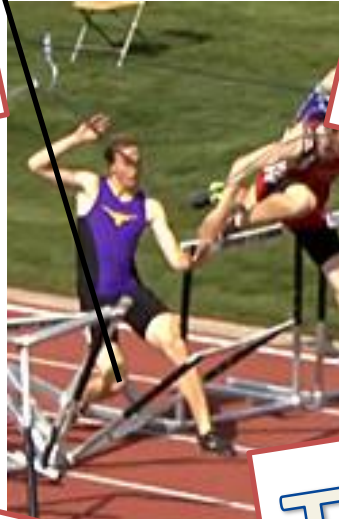
What is palliative care?

End of life care

Hospice care

Palliative medicine

Terminal care



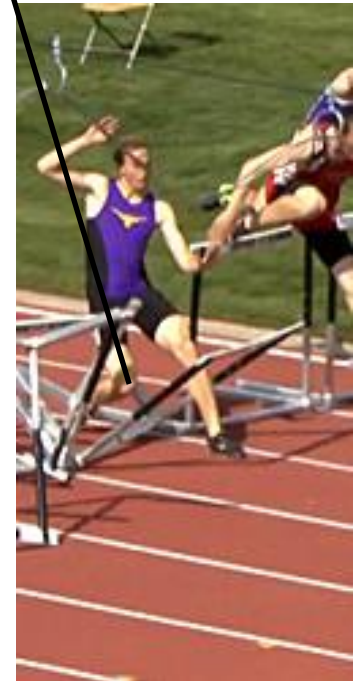
The EAPC definition of palliative care (1998)

Palliative care is the **active, total care** of people whose disease is not responsive to curative treatment.

Management of **pain, of other symptoms, and of social, psychological and spiritual problems** is paramount.

Palliative care is **interdisciplinary** in its approach and encompasses **the patient, the family and the community** in its scope.

What is palliative care?



White Paper: conclusions

Palliative care services should **actively reach out** to find the population of people with learning disabilities within their catchment areas



PCPLD Network
Positive Care for People with Learning Disabilities



Delivering high quality end of life care for people who have a learning disability

Resources and tips for commissioners,
service providers and health and social care staff

GOOGLE:

- NHS England
- End of life
- Learning disability





PCPLD Network

Palliative Care for People with Learning Disabilities

Change Text Size: A|A|A



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The Management Team



WELCOME to the PCPLD Network

We aim to raise awareness of the palliative care needs of people with learning disabilities, to share and promote 'best practice' and to enhance collaboration between all services providers, carers and people with a learning disability.

PCPLD Network 20th Anniversary Conference

London, 13th June 2018

Registration is now open. For details click [here](#)

Linda McEnhill Award 2018

Deadline for nominations extended to 31st January 2018. For details click [here](#)



ABOUT US

Find out about our aims, history and constitution

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**LINDA MCENHILL
AWARD**

Find out all about the award

[Learn More >](#)



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Click here for the latest news

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A SHOWCASE FOR EXCELLENCE IN PALLIATIVE CARE PROVISION FOR PEOPLE WITH LEARNING DISABILITIES

PCPLD NETWORK 20TH ANNIVERSARY CONFERENCE

13th June 2018
Euston, London

Keynote Speakers

Prof Bee Wee and Dr Jean O'Hara

NHS England National Clinical Directors for Palliative Care and for Learning Disability

Linda McEnhill and Dr Noëlle Blackman

Founders of the PCPLD Network

Dr Irene Tuffrey-Wijne

Associate Professor in Palliative Care and Intellectual Disability

Other confirmed speakers

Allison O'Donnell Prince & Princess of Wales Hospice, Glasgow

Melanie Davies Morrision Hospital, Swansea; Winner of RCN Nurse of the Year 2017

Dr Corinne Midgley Saint Francis Hospice, Romford

GRASSroots group of people with learning disabilities, London

Performance by people with learning disabilities from the **Baked Bean Theatre Company**

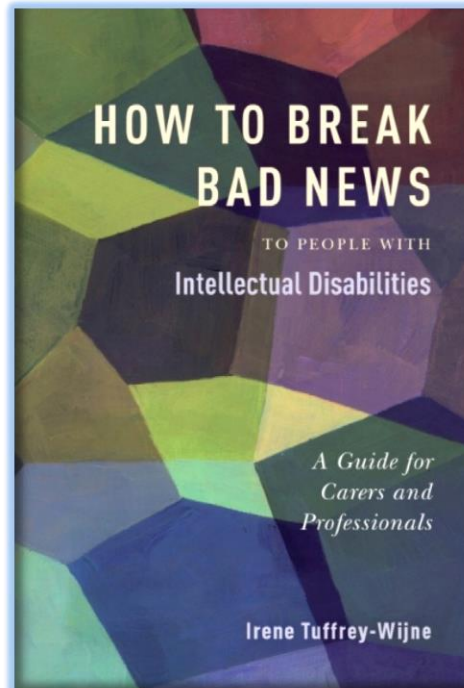
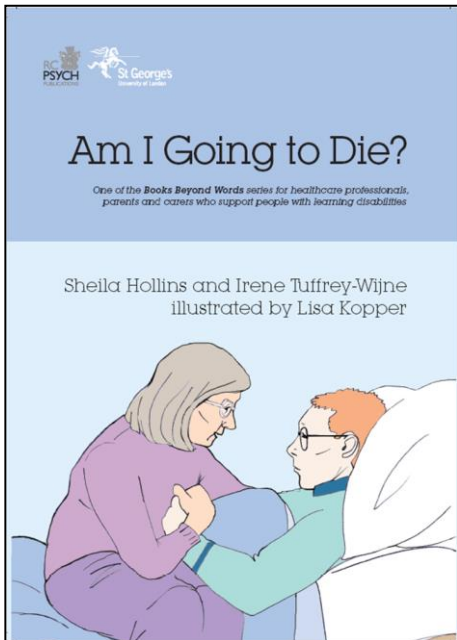
COST: £100 early bird (payment received before 31 March 2018) and £150 thereafter
Lunch and refreshments included.

Living with Learning Disabilities, Dying with Cancer

Thirteen Personal Stories

Irene Tuffrey-Wijne

Dr Irene Tuffrey-Wijne
I.Tuffrey-Wijne@sgul.kingston.ac.uk



www.breakingbadnews.org

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Home

Welcome

to the official website of Dr Irene Tuffrey-Wijne

This website contains information about my research and projects, and hosts my blog.

Address

Kingston University & St George's, University
of London
Faculty of Health, Social Care and Education
Cranmer Terrace



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A life-and-death decision 16th
December 2017

A home for life...? 12th
November 2017



John Davies

1961-2006