Best practice in delivering palliative care to people with learning disabilities

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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

Complex social circumstances

High incidence of mental health problems

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

EAPC ONLUS

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

End of life decision making can be complex, regardless of whether or not the person has disabilities.

People with intellectual disabilities have a right to life, and a right to recognition of the value of their lives.

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.

People with intellectual disabilities are assumed to have capacity to make decisions around their care and treatment, unless it is demonstrated otherwise.

People with intellectual disabilities should have all the necessary support, including advocacy, in order to maximise their involvement in end of life decision making.

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
What is palliative care?
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.

**The EAPC definition of palliative care (1998)**

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.
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
Working together

Palliative care services
Families
ID services

The person’s story is at the heart of everything

Individual "champions" Organisational commitment

Commitment
PCPLD Network
Palliative Care for People with Learning Disabilities

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.
A SHOWCASE FOR EXCELLENCE IN PALLIATIVE CARE PROVISION FOR PEOPLE WITH LEARNING DISABILITIES
PCPLD NETWORK 20TH ANNIVERSARY CONFERENCE

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 Morriston 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.

13th June 2018
Euston, London
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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.

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Irene’s recent blog posts
A life-and-death decision 16th December 2017
A home for life…? 12th November 2017