

Palliative care for people with intellectual disabilities: the EAPC White Paper in a nutshell

The European Association for Palliative Care (EAPC) has recently published a White Paper from its Taskforce on Palliative Care for People with Intellectual Disabilities. **Irene Tuffrey-Wijne** explains how it was put together, what it contains, and why it is pivotal in the care of people with intellectual disabilities at the end of life

This article gives an overview of the background, development and content of the White Paper on palliative care for people with intellectual disabilities in Europe recently published by the European Association for Palliative Care (EAPC).

The definition of intellectual disability encompasses three aspects:¹

- Impaired intelligence (making it more difficult to understand new or complex information and to learn new skills)
- Impaired adaptive functioning (a significantly reduced ability to cope independently)
- Early onset (before adulthood), with a lasting effect on development.

Intellectual disability affects around 1–3% of the population.² This is often a hidden population: people with intellectual disabilities are not always known to health- and social care services. Evidence suggests that they do not have the same access to palliative care services as people without intellectual disabilities, and concerns have been raised about the quality of care they receive towards the end of life.^{3–8}

While their palliative care needs may not be very different from those of the general population, people with intellectual disabilities often present with unique problems, challenges and disadvantageous circumstances that make meeting their needs more difficult.⁹ Their needs are often poorly understood and poorly met by professionals who are not used to treating or supporting someone with intellectual disabilities. Some of the unique challenges concerning people with intellectual disabilities are listed below.

- People with intellectual disabilities often

have difficulty in communicating physical problems, making it more difficult to recognise illness and treat symptoms.

- People with intellectual disabilities may have less insight into their illness and treatment, and find it more difficult to understand the consequences of their situation.
- Intellectual disability may affect the person's insight into their own mortality.
- Some people with intellectual disabilities have limitations in their mental capacity, which affects their ability to participate in decision-making.
- In that population, signs and symptoms of aging can occur at a younger age.
- Many people with intellectual disabilities have co-morbidities and use a range of medication (polypharmacy), making palliative care assessment and treatment more difficult.
- People with intellectual disabilities experience higher levels of behavioural or psychiatric problems.
- When family relationships end (for example, when elderly parents die), they are less likely to be replaced by new relationships.

Key points

- People with intellectual disabilities often present with unique problems, challenges and disadvantageous circumstances that make meeting their palliative care needs more difficult.
- The Taskforce on Palliative Care for People with Intellectual Disabilities of the European Association for Palliative Care (EAPC) has recently published a White Paper containing 13 norms and related statements, real-life examples and available resources.
- The EAPC White Paper represents a Europe-wide consensus on what should be aimed for in order to achieve good palliative care for people with intellectual disabilities.

- The social circumstances of many people with intellectual disabilities make the delivery of palliative care (and any decision-making processes) more complex; for example, there may be care staff involved as well as families.

The EAPC Taskforce

The EAPC Taskforce on Palliative Care for People with Intellectual Disabilities was created in 2012 in recognition of these challenges. The Taskforce consists of 12 professionals from seven European countries (see Box 1), all of whom have expertise in palliative care provision for people with intellectual disabilities, including clinical and academic expertise.

One of the aims of the Taskforce was to develop norms that could serve as guidance on good practice. Developing norms that would be relevant and achievable across Europe was complex, as the provision of both palliative care and intellectual disability services varies significantly between countries. The norms in the EAPC White Paper are, therefore, aspirational and represent a Europe-wide consensus on what should be aimed for in order to achieve good palliative care for people with intellectual disabilities, regardless of social and geographical settings or national and cultural differences.

Developing the norms: a four-step process

Developing the norms involved creating draft norms and building systematic consensus through the use of Delphi methods.

- Step 1: drafting of the norms by a core group of experts. The Taskforce discussed and

agreed 13 draft norms, setting out several statements for each one.

- Second step: evaluation by a panel of experts. Through an online survey, 80 experts from 15 European countries indicated their level of agreement with each of the statements relating to the 13 norms and provided additional feedback.
- Third step: modifications, decisions and recommendations. The Taskforce made minor modifications in light of the survey results and drafted the White Paper.
- Fourth step: review and acceptance. The EAPC Board of Directors reviewed and accepted the White Paper.

An article describing the methodology in more detail has been published in the journal *Palliative Medicine*.¹⁰ Box 2 lists the 13 norms and Box 3 gives an example of one norm with its related statements.

The White Paper

The White Paper is published on the EAPC website.¹¹ It contains the full set of norms, as well as the background to and rationale for each of them. Thirteen real-life examples are given to illustrate how a particular norm can be achieved in practice. These were selected from 88 examples received from 13 countries (the members of the expert panels had been invited to submit examples of good practice). The White Paper also highlights available resources; for example, the section on symptom management (see Box 3) signposts readers to the Disability Distress Assessment Tool (DisDAT) used for assessing distress in people with severe communication difficulties.^{12,13}

Challenges for the future

The Taskforce found that much of the identified good practice depends on the dedication of individual practitioners, rather than on effective organisations or policies. One of the challenges for the future, therefore, is to find ways to 'scale up' good practice and ensure it is embedded in services and systems.

Furthermore, professionals from countries that were under-represented in the survey (especially from Eastern and Southern Europe) indicated that either palliative care was not available to people with intellectual disabilities in their country, or that they simply did not know what happened to people with intellectual disabilities at the end

Box 1. Members of the EAPC Taskforce on Palliative Care for People with Intellectual Disabilities

- Irene Tuffrey-Wijne (chair), UK
- Leopold Curfs, Netherlands
- Anne Dusart, France
- Catherine Hoenger, Switzerland
- Linda McEnhill, UK
- Dorry McLaughlin, UK
- David Oliver, UK
- Sue Read, UK
- Karen Ryan, Ireland
- Daniel Satgé, France
- Benjamin Straßer, Germany
- Britt-Evy Westergård, Norway

1. Equity of access
2. Communication
3. Recognising the need for palliative care
4. Assessment of total needs
5. Symptom management
6. End-of-life decision-making
7. Involving those who matter: families, friends and carers
8. Collaboration
9. Support for families and carers
10. Preparing for death
11. Bereavement support
12. Education and training
13. Developing and managing services

Box 2. Overview of the norms in the White Paper

Box 3. Norm 5 (symptom management) and related statements

- 5a. Management of symptoms associated with the end of life is of the utmost importance
- 5b. Assessment of pain and other symptoms can be more difficult when people have intellectual disabilities. Symptoms may be masked or expressed in unconventional ways, for example through behavioural changes (including behaviour that may be seen as 'challenging') or withdrawal
- 5c. Professionals should be aware of the possibility of 'diagnostic overshadowing', where the symptoms of physical ill-health are attributed to the presence of intellectual disability, and therefore not treated or managed
- 5d. Those who care for a person with intellectual disabilities at the end of life (whether this is a professional, or untrained care staff, or families) should be supported in recognising symptoms, including pain
- 5e. Medical professionals should be aware that symptom management of people with intellectual disabilities may be more complex due to comorbidities
- 5f. Collaboration between those who know the person well and those who are experts in symptom management is crucial in ensuring adequate symptom management for people with intellectual disabilities

of life. This was one of the reasons why it was difficult to involve professionals from all European countries. This is an issue that requires further investigation, as it indicates that there may be significant inequalities between countries.

Recommendations

The White Paper collates the insights, experiences and expertise of a wide range of sources and countries. The Taskforce members believe that it can serve as a reference for developing and improving practice. The Taskforce's recommendations include that:

- Palliative care services actively reach out to find the population of people with intellectual disabilities in their areas
- There is an ongoing exchange of experiences, expertise and best practice on different levels: locally between palliative care and intellectual disability services; nationally between individuals and organisations involved in supporting people with intellectual disabilities at the end of life; and internationally within Europe
- Further research is conducted (the White Paper makes detailed suggestions).

The Taskforce was encouraged by the enthusiasm and commitment of professionals across Europe. The work has highlighted the importance of having a specific and ongoing focus on the palliative care needs of people with intellectual disabilities.

Declaration of interest

The author declares that there is no conflict of interest.

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