

# 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

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Authors

**Irene Tuffrey-Wijne<sup>a</sup>** and **Dorry McLaughlin**

on behalf of

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

### Taskforce members

**Dr Irene Tuffrey-Wijne** (chair)

Associate Professor in Nursing *Kingston University & St George's University of London, UK*

**Prof Dr Leopold Curfs**

Director *Gouverneur Kremers Centre, Maastricht University, The Netherlands*

**Anne Dusart**

Psychologist and Sociologist *Centre Régional d'Études, Dijon, France*

**Catherine Hoenger**

Project Manager *Service the la Santé Publique, Lausanne, Switzerland*

**Linda McEnhill**

Family Support Manager *The Prince & Princess of Wales Hospice, Glasgow, UK*

**Dr Dorry McLaughlin**

Lecturer in Palliative Care and Chronic Illness *Queen's University Belfast, UK*

**Dr David Oliver**

Consultant in Palliative Medicine *Wisdom Hospice, Rochester, UK*

**Prof Sue Read**

Professor of Learning Disability Nursing *Keele University, UK*

**Dr Karen Ryan**

Consultant in Palliative Medicine *Mater Misericordiae University Hospital, Dublin, Rep. Ireland*

**Dr Daniel Satgé**

Medical Pathologist and Philosophy *Oncodefi, Montpellier, France*

**Benjamin Straßer**

Social Worker *Caritas of the Diocese of Munich and Freising, Munich, Germany*

**Britt-Evy Westergaard**

Research Fellow *Norwegian National Advisory Unit on Ageing and Health, Tønsberg, Norway*

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<sup>a</sup> Contact email [I.Tuffrey-Wijne@sgul.kingston.ac.uk](mailto:I.Tuffrey-Wijne@sgul.kingston.ac.uk)

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# EXECUTIVE SUMMARY

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## Introduction

People with intellectual disabilities<sup>b</sup> make up an estimated 1-3% of the population. They are increasingly living into old age, with an associated increase in the need for palliative care provision; however, many do not currently have equitable access to palliative care services. Whilst their palliative care needs may be no different from those of the general population, they often present with unique issues, challenges and circumstances that make it more difficult to meet those needs. Therefore, they need focused consideration.

There are complexities in describing norms that are relevant and achievable across Europe, as there are huge variations in the provision of both palliative care services and intellectual disability services. This White Paper aims to provide guidance on what good practice looks like, regardless of social and geographical setting or national and cultural differences. The norms are aspirational, presenting a European-wide consensus on quality goals that have to be aimed for in order to achieve good palliative care for people with intellectual disabilities.

## The Taskforce and its methods

The White Paper was prepared by a taskforce of 12 known European experts in the field, bringing academic and clinical expertise around palliative care provision for people with intellectual disabilities.

The process involved generating draft norms and building systematic consensus through the use of Delphi methods in four rounds:

1. **Drafting the norms by a core group of experts:** the Taskforce discussed and agreed 13 draft norms.
2. **Evaluation of draft norms by an expert panel:** through an online survey, 80 experts from 15 European countries indicated their level of agreement with each of the statements within the 13 norms and provided additional written feedback.
3. **Modifications, decisions and recommendations:** the Taskforce made some minor modifications in light of the survey results and drafted the White Paper.

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<sup>b</sup> For a definition of *intellectual disabilities* see page 16

4. **Review and acceptance:** the EAPC Board of Directors reviewed and accepted the White Paper.

In addition, the expert panel was invited to submit best practice examples; 88 such examples were received from 13 European countries.

### *Limitations*

Most of the input into the Taskforce came from Northern Europe. Despite our best efforts, it was particularly difficult to gather survey responses and examples from certain parts of Europe. Palliative care professionals from under-represented countries typically commented that they had never come across a patient with intellectual disabilities. Many intellectual disability professionals thought that in their country, palliative care was not available to people with intellectual disabilities.

These findings are, of course, anecdotal, but they indicate that across Europe, there may be serious inequalities with respect to palliative care provision to people with intellectual disabilities that need to be investigated further, and addressed.

## Conclusions and recommendations

Across Europe, it appears that good practice is often dependent on **the commitment of dedicated individuals**, rather than on good policies, systems or guidelines. Sometimes, excellence seems to be achieved *despite* the system, rather than because of it.

The problem is exacerbated by a **lack of population data** about people with intellectual disabilities, which means that this is a largely invisible population with hidden needs. There is a risk that their needs are therefore not seen as a priority, or even as a problem.

However, experience from some European countries demonstrates that with sufficient attention to the needs of people with intellectual disability, and with the passion of dedicated staff, change can be achieved within systems, structures, national guidelines and funding streams. **Sharing best practice is an important part of that process.**

‘Getting it right’ for people with intellectual disabilities has huge advantages for palliative care services (or any other mainstream services). Those who are able to provide good care for patients with this level of complexity and challenges, are likely to be able to

provide good care for *all* their patients – including those presenting with other challenges, such as patients with dementia or mental health problems. The skills needed to meet the norms in this White Paper are transferable. The way in which palliative care is provided for people with intellectual disabilities could thus be a benchmark for all service provision.

The following would make a significant contribution to ensuring that people with intellectual disabilities across Europe have their palliative care needs met:

- **Palliative care services actively reaching** out to *find* the population of people with intellectual disabilities within their catchment areas.
- **On-going exchange** of experiences and expertise on a range of 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
  - Internationally within Europe
- **International exchange of expertise** could be achieved through:
  - An on-going, regularly updated online multi-language resource, signposting relevant literature, resources, contacts etc.
  - A dedicated person or team who can act as a “point of contact” for palliative care provision to people with intellectual disabilities in Europe.
- **Further research.** The main areas in need of investigation are:
  - What are the issues around **end of life decision making** for people with intellectual disabilities across Europe?
  - “Mapping”: What is **the current state of affairs** around palliative care provision for people with intellectual disabilities in Europe, and how does this compare to the general population?
  - What are the **challenges in providing high quality palliative care** for people with intellectual disabilities across Europe?
  - **Developing outcome measures** for palliative care of people with intellectual disabilities.

An overview of the consensus norms is provided on the next pages.

## Overview of consensus norms: Palliative care for people with intellectual disabilities in Europe

### 1. Equity of access

- 1a** People with intellectual disabilities should have equity of access to the palliative care services and supports that are available in their country.
- 1b** Services and professionals who support people with intellectual disabilities in their daily lives should ensure that they have equal access to available palliative care services when they need them, by referring them to such services.
- 1c** Ensuring equity of access may mean making changes to the services provided. Palliative care services should make the necessary adjustments to enable people with intellectual disabilities to access their services and support.

### 2. Communication

- 2a** People with intellectual disabilities may have a range of specific communication needs. The communication needs of people with intellectual disabilities should be recognised and taken into consideration.
- 2b** Professionals and formal carers have a responsibility to strive to understand the communication of people with intellectual disabilities, and to seek the necessary training for this.
- 2c** People with intellectual disabilities should be supported to communicate their needs in the best possible way, whether verbal or non-verbal.

### 3. Recognising the need for palliative care

- 3a** All health and social care professionals caring for people with intellectual disabilities must be able to recognise when palliative care is needed, whether the person is in the family home, in an institutional setting or in single or shared homes in the community. They must be alert to the signs and symptoms of serious illness, end of life and the dying phase.
- 3b** When a need for palliative care is identified for an individual, a person-centred plan should be put into place to instigate palliative care support.

### 4. Assessment of total needs

- 4a** The needs of people with intellectual disabilities at the end of life include physical, emotional, social and spiritual needs, similar to those of the rest of the population.
- 4b** All physical, psychological, social and spiritual needs should be assessed, documented, addressed, evaluated and reviewed.
- 4c** People with intellectual disabilities may have additional and special palliative care needs as a result of their impairment. This should also be recognised and addressed.
- 4d** People with intellectual disabilities should have equity of access to support for those needs. This includes access to appropriately tailored counselling services, and support in maintaining social links, including links with friends (who may have special support needs themselves).



## 5. Symptom management

- 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 which 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.

## 6. End of life decision making

- 6a** End of life decision making is complex, regardless of whether or not the person has disabilities.
- 6b** People with intellectual disabilities have a right to life, and a right to recognition of the value of their lives.
- 6c** 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.

- 6d** People with intellectual disabilities should be assumed to have capacity to make decisions around their care and treatment, unless it is demonstrated otherwise.
- 6e** People with intellectual disabilities should have all the necessary support, including advocacy, in order to enable their involvement in end of life decision making.

## 7. Involving those who matter: families, friends and carers

- 7a** The important relationships ('significant others') of people with intellectual disabilities should be identified. This could include family, partners, friends, carers (including paid care staff) and others. People with intellectual disabilities should be involved in identifying these significant others.
- 7b** Significant others should be encouraged, if they wish, to be as involved as possible at the end of life.
- 7c** The person's closest carer(s) are likely to know him/her best. For many (but not all) people with intellectual disabilities, this is their family, who have often been their carers for many years or decades. Professionals should respect and involve the carers as expert care partners.
- 7d** For people with intellectual disabilities, family bonds may be crucially important at the end of life. This may be the case even where these bonds have been broken through lack of contact.
- 7e** Family bonds that are important to the person with intellectual disabilities should be recognised and respected by professionals and care staff.
- 7f** The person's wishes around involving their families at the end of life should be sought and respected.

## 8. Collaboration

- 8a** Collaboration between services is key to successful provision of palliative care to people with intellectual disabilities.
- 8b** Anyone (and any services) with expertise to offer at the end of life should be identified as early as possible in the care pathway, and involved if there is a need. This can include professional service networks, paid care staff, informal (family) carers and spiritual leaders.
- 8c** It is of crucial importance that people with intellectual disabilities have access to medical and nursing professionals, including support and advice from palliative care experts if needed.
- 8d** All these individuals and services should collaborate with each other and share their expertise when required for the benefit of the person with intellectual disabilities.

## 9. Support for families and carers

- 9a** Families and carers (including paid/professional care staff) are often deeply affected when someone with intellectual disabilities reaches the end of life. They should be supported in their caring role.
- 9b** Many people with intellectual disabilities, including those with severe and profound intellectual disabilities, are at the centre of their family's and carer's life. The death of someone with intellectual disabilities is often a significant and difficult loss for those around them.
- 9c** Families should have recognition and support for their loss.
- 9d** Professional carers may not be expected to grieve, but have often formed deep attachments to the people they support. They, too, should be supported in their loss, including training on self-care for those working with people who are dying.

## 10. Preparing for death

- 10a** Opportunities should be provided to involve people with intellectual disabilities in advance care planning, where appropriate and desired. This includes discussions and recording of choices regarding preferences for end of life care, funeral wishes and wills.
- 10b** Such discussions could take place as early as is appropriate. They could take place before the need for palliative care arises.
- 10c** Once the need for palliative care has been identified, carers and professionals should put into place a care plan, anticipating future holistic needs for treatment and care. The wishes of the person with intellectual disabilities should be incorporated in this plan.
- 10d** Where families are not routinely responsible for funeral arrangements, professionals and care services should recognise the role of the family in organising the funeral, and provide the family with the necessary support to do so.

## 11. Bereavement support

- 11a** People with intellectual disabilities experience loss and grief, just like the rest of the population (although they may express it differently).
- 11b** People with intellectual disabilities are at a higher risk of complicated grief than the rest of the population. Those who support and care for them should be alert to the possibility of complicated grief reactions.
- 11c** Those who support and care for people with intellectual disabilities should also be aware of any available mainstream and specialist bereavement support services to which they can refer people with intellectual disabilities, if necessary.
- 11d** People with intellectual disabilities should be offered the opportunity and necessary support to attend funerals.

## 12. Education and training

- 12a *Staff training:*** Carers and professionals involved in supporting people with intellectual disabilities at the end of life should be trained in order to deal with their specific needs. This includes training on death, dying and palliative care for staff working in intellectual disabilities services, and training on intellectual disabilities for staff working in palliative care services.
- 12b *Death education for people with intellectual disabilities:*** Throughout their lives, people with intellectual disabilities should not be protected from information and discussions about illness, death and dying. This could, for example, include sessions at Day Centres or special education facilities, as well as discussions at home. Families and carers should be given help and support in encouraging such discussions.

## 13. Developing and managing services

- 13a** Policy makers should prioritise equitable palliative care for people with intellectual disabilities.
- 13b** Policy makers should commit adequate resources to the provision of palliative care for people with intellectual disabilities.
- 13c** Organisations providing care services for people with intellectual disabilities should plan for the provision of palliative care for them.
- 13d** Organisations providing palliative care services should plan for the inclusion of people with intellectual disabilities among their case load. This includes planning for adequate space, equipment, staffing and the provision of expertise.

# INTRODUCTION

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This White Paper was prepared by the European Association of Palliative Care (EAPC) Taskforce on Intellectual Disabilities. The Taskforce was set up in 2012, bringing together known experts in the field in order to produce consensus norms for best practice that would be applicable and acceptable across Europe.

The work was undertaken in recognition of the fact that people with intellectual disabilities are increasingly living into old age,<sup>1</sup> with an associated increase in the need for palliative care provision; however, many do not currently have equitable access to palliative care services.<sup>2</sup> While many of their palliative care needs are no different from those of the general population, they often present with unique issues and challenges that need focused consideration.

The Taskforce acknowledges the complexities in describing European-wide norms, as there are huge variations in the provision of both palliative care services<sup>3</sup> and intellectual disability services.<sup>4</sup> The White Paper aims to provide guidance on what good practice looks like, regardless of social and geographical setting or national and cultural differences.

## Why norms?

Norms represent ‘a consensus on quality goals that have to be aimed for (aspirational norms). If (or when) norms are achieved, high quality can be safely expected.’<sup>5</sup> (p.278-9)

The concept of ‘norms’ was chosen, rather than ‘standards’ which would imply a minimum level below which care should not fall. The Taskforce agreed that as the availability and nature of both palliative care services and intellectual disability services varies enormously in different European countries, it would not be appropriate or even possible to set European-wide standards for the palliative care of people with intellectual disabilities. There might be a danger, for example, that in some regions or countries where palliative care is unavailable, even for the general population, ‘standards’ for palliative care of people with intellectual disabilities would be dismissed as being unachievable and therefore irrelevant.

## Scope

- This document focuses on **the provision of palliative care services for adults with intellectual disabilities (age 18 and over) who are in need of such services**. The needs of children (with or without intellectual disabilities) require a particular and additional focus<sup>6</sup> and are outside the scope of this White Paper.
- It covers **people across the entire spectrum of intellectual disabilities** (ranging from mild to profound). It must be noted that some of the norms may not be applicable to some people with intellectual disabilities (for example: not all people with intellectual disabilities, especially those with mild intellectual disabilities, have communication difficulties or need the support of a carer). People with mild intellectual disabilities in particular may not have been identified as such and are therefore largely 'invisible' within health and social care services.
- It covers **palliative care provided in a range of settings**, including the family home, independent living arrangements, residential settings for people with intellectual disabilities, nursing homes, acute hospitals and specialist palliative care settings.
- It covers **care provided by family and others with social links to the person with intellectual disabilities, paid care staff, professionals in health and social care settings, and expert palliative care professionals**.

# BACKGROUND

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## Rationale

### *The right to palliative care*

The EAPC believes that access to palliative care is a human right.<sup>7</sup> All people should have a right to receive high-quality care during advanced illness and to a dignified death free from pain and in accordance with their spiritual and religious needs.

However, many people lack the palliative care that they require.<sup>8</sup> This is compounded when people have disabilities. Disability initiates numerous global human rights issue and yet many people with disabilities lack equitable access to quality healthcare.<sup>9,10</sup> It is, therefore, not surprising that there are international concerns about the quality of palliative care available to people with intellectual disabilities.

The Taskforce believes that people with intellectual disabilities have an equal right to holistic care.

### *Why are people with intellectual disabilities at a disadvantage?*

It is not always easy to apply existing guidelines for good palliative care to people with intellectual disabilities. While many of their palliative care needs are no different from those of the general population, they often present with unique issues, challenges and disadvantageous circumstances that make it more difficult to meet those needs.<sup>11</sup> For example:

- Communication difficulties affect all aspects of palliative care provision.
- 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.
- The presence of intellectual disability may affect the person's insight into his or her own mortality.
- Some people with intellectual disabilities have limitations in their mental capacity, affecting their ability to participate in decision making.



- Signs and symptoms of ageing can occur at a younger age.
- Many people with intellectual disabilities have co-morbidities and use a range of medication (multi-pharmacy), making palliative care assessment and treatment more difficult.
- When family relationships end (for example, when elderly parents die), they are less likely to be replaced by new relationships.
- 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.
- There are higher levels of behavioural or psychiatric problems among the population of people with intellectual disabilities.

Focused attention and specific guidance is necessary, therefore, to ensure that people with intellectual disabilities receive good palliative care when they need it. Services and support may need to be adjusted in order to meet the individualised needs of people with intellectual disabilities. Care and support should also be available to them during their experiences of serious illness that affect family and friends, and in bereavement.

## Definitions

### Intellectual disabilities

#### *Definition*

Despite varying definitions and inclusion criteria, there is international consensus that intellectual disability is present when the following **three criteria** are present:<sup>12,13</sup>

- (1) **a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)**
- (2) **a significantly reduced ability to cope independently, expressed in conceptual, social, and practical adaptive skills (impaired adaptive functioning)**
- (3) **early onset (before adulthood), with a lasting effect on development**

Other terms have been used synonymously with ‘intellectual disability’, for example, ‘learning disability’ (UK), and ‘mental retardation’ and ‘mental handicap’, although these latter terms are increasingly thought of as pejorative and therefore disregarded.

People with intellectual disabilities are not a homogeneous group. Each person is different and individual. ‘Intellectual disability’ covers a wide range of abilities and disabilities, skills and limitations. The WHO ICD-10 Classification of Mental and Behaviour Disorders takes into account the criterion of intelligence quotient (IQ), as well as evidence of social impairment and limitation in daily activities and self-care skills. It classifies intellectual disability as mild, moderate, severe or profound. Those with mild intellectual disabilities (IQ 50-69) may be able to function within society with a good degree of independence. Those with moderate intellectual disabilities (IQ 35-49) will be able to achieve some independence with intermittent support, whilst those with severe (IQ 20-34) and profound (IQ below 20) intellectual disabilities will need 24 hour support. Some people with intellectual disabilities, especially those at the severe and profound end of the spectrum, also have significant physical impairments which may be life-limiting.

There is a growing trend to regard disability, including intellectual disability, not simply as a medical or biological concept, but rather as a problem of the person’s functioning within their environment. It allows for the impact of the environment and other contextual factors on the functioning of an individual or a population to be considered when defining disability.<sup>14</sup> This is an important development, especially in a European context. It means that in defining intellectual disability, additional factors must be taken into account, such as the community environment typical of the individual’s peers and culture. Consideration should also be given to linguistic diversity and cultural differences in the way people communicate, move, and behave.

Furthermore, it is important to remember that limitations in individuals often coexist with strengths, and that the focus should be on what people can do (with support if necessary), rather than on what they cannot do.<sup>13,15</sup> For example, one in-depth study found that people with intellectual disabilities were remarkably resilient in the face of declining health and impending death, and this resilience seemed to stem from their experience of living with disabilities.<sup>16</sup>

The challenges of developing norms around palliative care for people with intellectual disabilities that could be accepted by countries across Europe became clear during early discussions among Taskforce members, where it emerged that members from different countries included or excluded different groups of people from the definition of ‘intellectual disabilities’. Whilst some members assumed that the entire spectrum of

‘intellectual disabilities’ would be covered by the norms (including mild intellectual disabilities), others thought that only those with severe or profound intellectual disabilities fell within the scope of the project. The issue also emerged in the responses to our European survey. One respondent wrote: ‘People with intellectual disabilities are not *all* as dependent as they are being depicted in this questionnaire’ – despite the fact that the above definition was given to everyone involved in developing the consensus norms.

### Prevalence

There is a general lack of statistical information on the prevalence of intellectual disability. Even when statistics are kept, there is little or no standardisation between countries, due to a variety of terms and definitions.<sup>17</sup> Prevalence figures vary due to the use of different criteria, methods and age groups used in surveys. This makes it difficult to provide an overview of the scale of the problem. It is generally thought that an estimated 1-3% of the population have intellectual disabilities.<sup>18</sup> It is estimated that between five million and 15 million citizens of the European Union have intellectual disabilities.<sup>19</sup> People with mild intellectual disabilities account for around 85% of the total population of people with intellectual disabilities.<sup>15</sup> Countries with lower income tend to have higher rates of mild to moderate intellectual disability, reflecting the impact of poverty and deprivation which hinders the development of vulnerable children.<sup>17</sup>

There are further challenges. Many people with intellectual disabilities do not access specialist services (if these are available), making this a largely hidden population. This problem is most pronounced for people with mild and moderate intellectual disabilities, whose disabilities may not be recorded or supported.

### Palliative care

Across Europe, there are many commonly used terms to denote palliative care, hampering the international comparisons and the development of international standards. These include ‘hospice care’, ‘end of life care’, ‘comfort care’ and ‘supportive care’. In line with other EAPC Task Forces and the recommendations set out in the EAPC White Paper on standards and norms for hospice and palliative care in Europe<sup>5</sup>, this White Paper uses the EAPC definition of 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. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the**

**patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.”<sup>20</sup>**

Although some confusion and discrepancy remains around the interpretation of the term ‘palliative care’, other terms are even more confusing internationally. For example, in the UK (and, more widely, in North America) the term ‘end-of life-care’ has been used synonymously with palliative care, with end of life understood as an extended period of one to two years (although it can be longer) during which the patient/family and health professionals become aware of the life-limiting nature of their illness. Such an interpretation of terminology is challenging when people have intellectual disabilities and may have had extremely complex health needs from early childhood. However, end-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life.<sup>5</sup>

There are overlaps in the philosophies of palliative care services and intellectual disability services. Whilst palliative care services aim to support someone to live fully what is left of life, intellectual disability services aim to support someone to live fully with a disability.

However, there can be a clash of cultures when intellectual disability services are prevailed upon to provide care for people who are dying. An on-going focus on ‘living’ and a culture of enabling people to have full and meaningful lives may prevent such services from acknowledging the need for palliative care.<sup>21</sup> The acknowledgement that people with intellectual disabilities will need support in their dying may be particularly emotive within the cultural and historical context of Europe, which includes the systematic murder of people with intellectual disabilities during World War II.<sup>22</sup>

## Comparisons between European countries

Whilst it would be extremely helpful and valuable to be able to contextualise this White Paper through an overview of important national characteristics in terms of palliative care provision as well as the nature of support for people with intellectual disabilities, this is not straightforward or even possible.

In a European context, the diversity in palliative care service development and delivery in different countries, along with varying definitions of palliative care, is challenging. It means that there are serious limitations and constraints when compiling an overview of palliative care in Europe, although the *EAPC Atlas of Palliative Care in Europe* goes some way to address this.<sup>23</sup>

The challenge is deepened by European-wide variations in definitions and service structure models for intellectual disability. The process of deinstitutionalisation, the state of community based service provision and the reliance on families to support people with intellectual disabilities varies enormously. In Sweden, for example, institutional services for people with intellectual disabilities are no longer permitted and all care is provided in small scale community settings, whereas in Greece and Spain, most care is still provided by families or in institutional settings.<sup>4</sup> The World Health Organisation asserts that the situation for people with intellectual disabilities may be particularly challenging in eastern parts of the European Region where there has been considerable economic and social distress, in some countries exacerbated by war and conflict. This may lead to partial breakdown of societal structures:

“Overall, the quality of and access to health, education and social services has deteriorated, which has been particularly hard on vulnerable population groups with little or no voice.”<sup>17</sup> (p.5)

It has also been noted that

“people with severe and profound intellectual disabilities generally have least access to new models of services, so that there is to some extent a two-tier system of services in which people with the greatest needs receive care in the poorest settings”<sup>4</sup> (p.9).

The huge variations in general support as well as specific expertise around palliative care for people with intellectual disabilities became obvious when the Taskforce received feedback from experts across Europe. Here are some divergent examples.

### *Netherlands*

In the Netherlands, many people with intellectual disabilities live in semi-institutional settings, where a service provider may support several thousand people in small, residential community settings across a large region.

“The Netherlands has a health care system where there are trained physicians specialised in intellectual disability (ID). Some of these ID physicians are now being trained through a national palliative care training programme for family physicians and nursing home physicians... This means that the Netherlands now has such ID physicians specialised in palliative care. Within this professional group, national guidelines have been developed for palliative care and for end-of-life decision making for people with intellectual disabilities.”<sup>c</sup>

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<sup>c</sup> Report by Dr Annemieke Wagemans (Intellectual Disability Physician; Medical Director of a large provider of intellectual disability services) (*personal communication*)

### *Croatia and Bosnia Herzegovina*

Experts in Eastern European countries reported a lack of provision, services or expertise.

“Currently, Croatia does not have organised palliative care, although an action plan for obtaining palliative care is in the process of implementation. With regards to adults with intellectual disabilities, they are placed in institutions for people with intellectual disabilities, or in institutions for psychiatric patients, or they are under parental care with no professionals involved.”<sup>d</sup>

“Overall, palliative care for people with intellectual disabilities is not specifically addressed in current regulations.”<sup>e</sup>

### *Italy*

Experts in Italy<sup>f</sup> reported that following de-institutionalisation in the late 20<sup>th</sup> century, people with intellectual disabilities in Italy are no longer supported in professionally supervised living situations. There has been very little investment in community-based projects. This means that people with intellectual disabilities rely on their families for living and support throughout their lives. There is, however, little or no professional, social or financial support available to families who are faced with a terminally ill relative who has intellectual disabilities. Palliative care organisations have little or no experience of providing care for people with intellectual disabilities. Despite legislation which states that vulnerable people (including people with intellectual disabilities) should be protected, there is a lack of state-funded provision for people with intellectual disabilities who do not have families to look after them. There are charitable organisations that provide care and support. There is a general lack of information and knowledge in Italy about the fate of people with intellectual disabilities at the end of life.

This means that whilst in some countries, those supporting people with intellectual disabilities (whether they are families or professional carers) can call upon expert help when there are palliative care needs, in other countries there is no such help available, and much depends on the preparedness, skill and willingness of people within non-expert care structures. Clearly, this has an impact not only on who provides direct palliative care to people with intellectual disabilities, but also on who is responsible for funding, training staff and supporting carers.

<sup>d</sup> Report by Dr Ljiljana Igrić (Head of PhD Programme Disability Studies, University of Zagreb)

<sup>e</sup> Report by Melita Murko (*personal communication*)

<sup>f</sup> Verbal reports by Dr Fabrizio Fea (Neurologist; Medical Director at a rehabilitation centre); Raffaella Dobrina (Palliative Care Nurse); Dr Raffaella Antonione (Palliative Care Physician) (*personal communication*)

One key finding of the Taskforce, therefore, was the importance of the following inter-related questions:

- **Where** are people with intellectual disabilities cared for at the end of life?
- **Who** provides their care?
- **How** will those care providers (including both families and professionals) obtain the necessary expertise and support?

The answers to these questions are largely unknown, but they will determine, to a significant degree, how easy or difficult it is to achieve the norms described in this White Paper.

## Death and people with intellectual disabilities

### *Age at death*

Issues around adequate palliative care provision for people with intellectual disabilities has gained prominence over the past decade. This population is living longer than before, partly due to reduced childhood mortality.<sup>24</sup> With their increased longevity, more people with intellectual disability are at risk of developing advanced progressive disease and will require palliative care.<sup>25</sup>

Even so, the average age of death for people with intellectual disabilities remains below that of the general population. A government inquiry into the deaths of 247 people with intellectual disabilities in England found that the median age at death was 64, which was 16 years younger than the general population. The age at death decreased with increasing severity of intellectual disabilities. In other words, those with the most profound intellectual disabilities were most likely to die younger.<sup>26</sup> Other studies have similar findings.<sup>27,28</sup>

Whilst the reasons for earlier death may include factors linked to the intellectual disability itself (for example, people with Down Syndrome have a shorter-than-average life expectancy<sup>24 29 30</sup>), there is a growing body of evidence that inequalities in healthcare provision for people with intellectual disabilities can lead to premature death.<sup>9, 32, 32</sup>

### *Cause of death*

Studies have repeatedly found that the leading causes of death in people with intellectual disabilities are **respiratory disease** and **heart and circulatory disorders**, followed by **cancer**.<sup>26,28,33,34</sup>

Deaths due to **respiratory disease** are thought to be mainly due to pneumonia and aspiration, normally associated with gastro-oesophageal reflux disorder (CORD), problems with swallowing, feeding and posture.<sup>35</sup>

**Heart disease** is an area of concern for people with Down Syndrome as there is a high incidence of aortic insufficiency, mitral valve disorder, cardiac septal defects, Tetralogy of Fallot and ductus arteriosus. People with intellectual disabilities are at risk of cardiovascular disease (such as hypertension, cerebral vascular accident or vascular dementia) as part of the ageing process.<sup>36</sup>

**Cancer** is the second most common cause of death in Europe, accounting for 20% of all deaths.<sup>37</sup> There are no European-wide statistics for cancer in people with intellectual disabilities. In England and Wales, cancer accounts for 29% of deaths among the general population<sup>38</sup>, and 20% of deaths among people with intellectual disabilities.<sup>26</sup> In terms of cancer profile of people with intellectual disabilities, there is an excess of digestive tract malignancies.<sup>39-41</sup> People with Down syndrome have a particular tumor profile with an important increased risk of leukemia, a less important risk of germ cell tumors and a lower risk of many, but not all solid tumors, particularly breast cancer and neural cancer.<sup>42,43</sup>

There are also higher rates of **dementia** in the population of people with intellectual disabilities<sup>44</sup> and a higher incidence of Alzheimer's Disease associated with Down Syndrome.<sup>45</sup> A Swedish study found that dementia was a main or contributing cause of death in 30% of older people with Down Syndrome.<sup>46</sup> The genetic link between Down Syndrome and dementia is thought to be due to the presence of the third chromosome 21 which is associated with the production of the beta-amyloid protein which has been found in the brain of people with Alzheimer's dementia.<sup>47</sup>



# THE TASKFORCE AND GROUP OF EXPERTS

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## The Taskforce

The issues around palliative care for people with intellectual disabilities have been highlighted by a small but growing group of experts. Since the start of this century, they have met to share and discuss their work at specialist international conferences within the fields of both palliative care and intellectual disabilities – in particular, through the EAPC and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). This is still, however, an area in which few professionals have specialised, with most expertise located in north-western Europe, and in particular in the UK.

Through networking by key experts, the EAPC Taskforce on Intellectual Disabilities was formed in 2012. It consisted of 12 professionals from seven European countries (see title page). All had considerable expertise in palliative care provision for people with intellectual disabilities, including both academic and clinical expertise. The Taskforce was chaired by Dr Irene Tuffrey-Wijne, Associate Professor at Kingston University & St. George's University of London.

The aim of the Taskforce was not only to develop European-wide norms for palliative care, but also to provide guidance on what good practice looks like across Europe, regardless of setting or national difference. As part of that process, the Taskforce gathered examples of good practice from across Europe that could act as an inspiration for others, including countries where access to good palliative care was difficult, or where the availability of support for people with intellectual disabilities was limited.

## The Group of Experts

In order to test draft norms and gather a wide range of examples, a 'Group of Experts' was identified through the networks of the Taskforce. This group consisted of 34 professionals in 18 countries (see *Appendix*) who had expertise in the field of palliative care, the field of intellectual disability, or both. A specific effort was made to enlist experts from as many countries as possible, in particular in Eastern and Southern Europe.

# METHODS

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## Using Delphi methods to build consensus norms

The process involved generating draft norms and building systematic consensus through the use of Delphi methods in four rounds.

### Round 1: Drafting norms by a core group of experts (the Taskforce)

A sub-group of five Taskforce members met in person several times to discuss and develop draft norms. A number of documents were studied and used as a starting point. These included the EAPC White Paper on standards and norms for hospice and palliative care in Europe<sup>5</sup>, as well as range of regional and national guidelines for the provision of palliative care for people with intellectual disabilities. Much of the early discussions centred around the ways in which norms for people with intellectual disabilities differed from those for the general population, and ways in which national guidelines might be applicable (or not) in a European context. However, there was immediate general consensus among the Taskforce sub-group about the core issues around palliative care provision for people with intellectual disabilities. These led to the definition of 13 categories for the resulting norms (see Box 1). The first draft of the norms was sent to all Taskforce members and, following two rounds of comments and amendments, agreed. It contained 52 statements within the 13 categories.

#### Box 1 Categories for norms

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: family, friends and carers
8. Collaboration
9. Support for family and carers
10. Preparing for death
11. Bereavement support
12. Education and training
13. Developing and managing services

## Round 2: Evaluation of draft norms by an expert panel, using an online survey

The resulting draft norms were incorporated in an electronic survey and piloted within the Taskforce. It was then sent to the Group of Experts. The group was asked to respond, and also to email the survey to colleagues with experience in either field (and preferably in both).

For each of the 52 statement, respondents were asked: “How much do you agree that the following statement should be part of the norms?” They could indicate their level of agreement using the following scale: ‘agree totally’, ‘agree a little’, ‘disagree a little’, ‘disagree totally’, and ‘not sure/don’t know’. They were also invited to provide additional feedback on each item through a free text box, especially if they disagreed with an item.

A total of 80 usable questionnaires were returned from 15 European countries (see Box 2). The over-representation of certain countries is due to the efforts and national networks of Taskforce members from those countries.

The plan had been to modify the draft norms in light of the survey results, and conduct further rounds of the online survey. However, there was very strong consensus among survey respondents, with none of the items scoring less than 86% of agreement (respondents scoring the item “agree a little” or “agree totally”). The vast majority of these were ranked “agree totally”. The Taskforce therefore agreed that a second round of the survey was not needed.

## Round 3: Modifications, decisions and recommendations by the Taskforce

All survey response scores, including all feedback comments, were collated and distributed among the Taskforce, highlighting in particular any items with a ‘disagree’ response. These were carefully considered, leading to several items being modified and emailed to all Taskforce members. The modifications were accepted where at least 10 of the 12 expert Taskforce members agreed. One item was deleted because of a lack of

### Box 2 Survey respondents, by nationality

Belgium	2
Bosnia and Herzegovina	3
Czech Republic	1
Denmark	1
France	4
Germany	8
Ireland (Rep)	12
Italy	4
Netherlands	8
Norway	24
Poland	2
Sweden	1
Switzerland	4
UK	3
Ukraine	2
unknown	1
<b>Total</b>	<b>80</b>

consensus among the Taskforce members following the feedback from the expert panel; several Taskforce members thought that on reflection, this item was related to a more general need for attitudinal change within society and therefore fell outside the scope of this White Paper (see Box 3).

Overall, and including the Taskforce members, the recommended norms were developed with the strong consensus of 92 experts in 15 European countries.

**Box 3**  
**Deleted norm**

**12c** Public education: General education and information available to the public should be aimed at leaving future generations less afraid of people with intellectual disabilities, and less afraid of dying.

### Round 4: Review and acceptance by the EAPC Board of Directors

The draft White Paper was submitted to the EAPC Board of Directors, reviewed, and approved in April 2015.

### Best practice examples

A further aim of the Taskforce was to identify and publish examples of good and promising practice across Europe in relation to palliative care provision (or aspects of palliative care provision) for people with intellectual disabilities. Such examples were invited from both the Taskforce and the Group of Experts (see Box 4).

The first versions of the call for examples asked for ‘Examples of Good Practice’. On piloting, it emerged that not all members of the Group of Experts were aware of what constitutes good practice. One member commented:

“I think you have good practice in England, but I don’t think we have good practice in our country.”

In the belief that there are elements of good practice to be found across Europe, the Taskforce decided, therefore, simply to invite examples of “what is happening in your country” with regards to palliative care for people with intellectual disabilities. We would then be able to extract the “good” aspects of care, in comparing them with the emerging norms.

A total of 88 examples were received from 13 European countries (see Box 5), ranging from case studies to policy documents (see Box 6). A further two examples were received from New Zealand; they were excluded from this paper.

The names in all examples quoted in this White Paper are pseudonyms.

**Box 4**  
**Call for examples (extract)**

**Do you know about someone with intellectual disabilities who is going to die, or who is dying, or who has died? If so, we want to hear from you!**

We need to hear what is happening in your country. We are looking for YOUR examples of what happens when people with intellectual disabilities need care at the end of their life. Who is giving them care and support? What works well? What are your problems? Please tell us!

**Box 5**  
**Examples received, by country**

Belgium	2
Bosnia and Herzegovina	3
Croatia	3
France	5
Germany	23
Italy	1
Norway	11
Netherlands	4
Poland	2
Rep. Ireland	2
Sweden	3
Switzerland	11
UK	18
<b>Total</b>	<b>88</b>

**Box 6**  
**Types of examples received**

Case studies	54
Service developments	13
Policy documents	5
Resource developments	5
Training initiatives	5
Description of (lack of) services	4
Research	1
Poems	1
<b>Total</b>	<b>88</b>

## Challenges and limitations

### Finding experts from across Europe

Collecting information through a relatively small number of invited ‘experts’ runs the risk that the data provided by these key persons could become slightly exaggerated.<sup>48</sup>

The survey responses and examples received are skewed towards Northern Europe, with respondents from Norway and Ireland particularly over-represented.

It is worth noting that despite our best efforts, it was particularly difficult to gather survey responses and examples from certain parts of Europe, especially countries in Southern Europe. These efforts included speaking to delegates from those countries at international conferences, including the EAPC congress and its equivalent in the field of intellectual disabilities, the IASSIDD congress. Palliative care professionals from under-represented countries typically commented that they had never come across a patient with intellectual disabilities and had no idea who they were or where they lived. Many intellectual disability professionals commented that in their country, palliative care just was not available to people with intellectual disabilities.

These findings are, of course, anecdotal, but they indicate that across Europe, there may indeed be serious inequalities with respect to palliative care provision to people with intellectual disabilities that need to be investigated further, and addressed.

### Dedicated individuals vs. the system

One expert from Eastern Europe made the following observation:

“The trouble with countries in transition is that our social and health care systems got seriously shaken and have been undergoing reforms for almost 20 years now. Consequently, when good things happen it is almost always thanks to some extraordinary individuals and their genuine commitment rather than the system. I think it is important to keep this in mind when assessing the situation in this region, because otherwise those good examples could “cover up” the failures of the mainstream services.”

The Taskforce believes that the dependence on dedicated individuals is, unfortunately, not restricted to Eastern European countries and is a very important area of concern.

There may be a perception, for example, that people with intellectual disabilities in the UK receive consistently good palliative care, due to the many excellent developments and initiatives in that country, including national guidelines. However, there, too, good practice is often due to inspirational staff going beyond the call of duty, and many people with intellectual disabilities still do not access the care they need. An independent inquiry into access to healthcare for people with intellectual disabilities in England, commissioned by the government following allegations of discriminatory practice leading to unnecessary deaths, found that

“good practice is thinly spread... witnesses went so far as to say that no good practice exists in this area without the strenuous effort from energetic, passionate local staff prepared to fight continuously against the odds”<sup>9</sup> (p.34)

## The possibility for excellence

This White Paper presents guidelines for best practice that are accepted across Europe. The examples demonstrate how some services or individuals manage to meet some of those standards, sometimes *despite* the social and health care systems.

This, hopefully, will show others in similar situations what can be achieved and what should be aimed for. It can be used for advocacy and lobbying governments with regards to policy and practice development. Experience from some Northern European countries demonstrates that with sufficient attention for the needs of people with intellectual disability, and with the passion of dedicated staff, change can be achieved within systems, structures, national guidelines and funding streams.

### **Sharing best practice is an important part of that process.**

We hope that this White Paper will encourage and empower National Associations and key stakeholders in Europe to make the changes required in their own countries.

# THE CONSENSUS NORMS

This sections sets out each of the consensus norms in 13 categories, as follows:

## Rationale, including background information and literature

### The Norm

### Example

#### Illustrative practice examples

Some examples of good practice are described alongside the relevant norm (although in most cases, they straddle several norms). The examples received exemplified some of the challenges in achieving high quality palliative care for people with intellectual disabilities, as the following quote from Bosnia Herzegovina illustrates:

“Our clients are mainly old people with dementia and people with intellectual disabilities who have no home and are in need of care. Our centre provides adequate accommodation (rooms with two or three beds), sufficient medical staff and other professionals trained to work with people with special needs. Additionally, there are several private homes for the elderly in our town, where older people with intellectual disabilities can also be admitted. Overall, there are many problems remaining to be solved, including regulatory insufficiencies and financial constraints. Of particular concern is the fact that the number of people with intellectual disabilities coming under the care of social welfare centres has been steadily increasing over the past ten years, thereby placing greater demands for institutional care.”

### Resources

Resources relevant to the norm are added at the end of each section. They may be relevant to a range of norms, so readers are advised to check all the **Resources** boxes when looking for further information.



# 1. EQUITY OF ACCESS

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Despite equality- and anti-discrimination legislation, there is consistent evidence that people with intellectual disabilities have poor access to palliative care services in comparison with the rest of the population. They may not be referred to palliative care services in the first place. When they are referred, palliative care services may not be sufficiently adapted to meet their specific needs.

People with intellectual disabilities have many special health and social care needs that need to be addressed, and they often face barriers in relation to accessing services which may be taken for granted by other members of the population.<sup>49</sup> Such barriers can arise from several sources:<sup>50,51</sup>

- People with intellectual disabilities may be less able to recognise the importance of health screening, to recognise the signs and symptoms of ill health, or to draw this to the attention of others. This is, in part, due to the intellectual disability itself, and in part due to communication difficulties.
- The knowledge, beliefs and attitudes of clinicians and carers can create barriers to accessing services. This may be due to lack of training, causing professionals to attribute changed or unusual behavioural patterns to the intellectual disability itself, rather than due to discomfort or illness which may need explored and treated.<sup>52</sup> The latter has been described as ‘diagnostic overshadowing’.

Many of the barriers which inhibit equity of health care access for people with intellectual disabilities in general are also present when they require palliative care. The tendency for people with intellectual disability to be diagnosed late in their disease trajectory due to lack of screening or ‘diagnostic overshadowing’ may mean that those who are referred to palliative care services are referred at the end stage of the disease process. This may reinforce the myth and barrier of hospice and palliative care services being only about death and dying and the last days of life, rather than their more positive role of helping people to cope, adapt and live fully what is left of life, from the diagnosis of an advanced disease.

There is evidence from several European countries that the numbers of people with intellectual disabilities are under-represented in hospice and palliative care services.<sup>26,53–55</sup> A comprehensive review of deaths of people with intellectual disabilities in England found they had less access to palliative care services and received less opioid analgesia in their final illness compared with the general population. Their care at

the time of these deaths shows that there has been little planning and that there was an uncoordinated and poorly managed approach.<sup>26</sup>

The importance of making ‘reasonable adjustments’ to healthcare services, in order to make them accessible to people with disabilities, has not only been highlighted but enshrined in law in some countries.<sup>56</sup> Reasonable adjustments include removing physical barriers to accessing services, but importantly also include changing the ways in which services are delivered and ensuring that policies, procedures and staff training work equally well for people with intellectual disabilities.<sup>57</sup> To enable palliative care to be delivered to people with intellectual disabilities in a meaningful and accessible way requires health and social care professionals to recognise this population’s additional needs. Reasonable adjustments could include, for example:

- Giving information that is accessible and tailored to the person’s communication needs
- Giving people more time
- Listening to, and involving, family and other carers
- Providing training for staff about the needs of people with intellectual disabilities who require palliative care

## Norm 1: Equity of access

- 1a People with intellectual disabilities should have equity of access to the palliative care services and supports that are available in their country.**
- 1b Services and professionals who support people with intellectual disabilities in their daily lives should ensure that they have equal access to available palliative care services when they need them, by referring them to such services.**
- 1c Ensuring equity of access may mean making changes to the services provided. Palliative care services should make the necessary adjustments to enable people with intellectual disabilities to access their services and support.**

## Resources

### The Palliative Care for People with Learning Disabilities Network

The PCPLD Network was founded in England in 1998. It started as a National Network, and although it is still predominantly UK organisation, it has since attracted members from across the globe.

Its aims are to:

- Raise awareness of the palliative care needs of people with intellectual disabilities
- Share and promote 'best practice'
- Enhance collaboration between all service providers, carers and people with intellectual disabilities

It does this by:

- Offering opportunities for networking, collaboration and exchange of ideas
- Recognising and sharing best practice through an annual award
- Hosting learning events and supporting training opportunities

<http://www.pcpld.org/>

### Information and resources about palliative care for people with intellectual disabilities in the Netherlands

'Agora' is a national organisation providing information and support on all aspects of palliative care, including existing networks. Its website lists extensive information and resources about supporting people with intellectual disabilities, including guidelines for professionals, and an educative film for people with intellectual disabilities.

<http://www.palliatief.nl/Themas/Verstandelijkebeperking.aspx>

### Best practice guides

Best practice guides for professionals include:

- The Route to Success in End of Life Care- Achieving quality for People with Learning Disabilities (National End of Life Care Programme, 2011) **(UK)** <http://www.nhs.uk/resource-search/publications/eolc-rtg-learning-disabilities.aspx>
- Widening access to palliative care for people with learning disabilities: guidance and resources for professionals (McEnhill / Help the Hospices, 2012) **(UK)**  
[file:///C:/Users/User/Downloads/HTH\\_Learning\\_Disabilities\\_Doc\\_Singles\\_06\\_LR.pdf](file:///C:/Users/User/Downloads/HTH_Learning_Disabilities_Doc_Singles_06_LR.pdf)
- 'Living and Dying with Dignity' (Read and Morris, 2008) **(UK)** <https://www.mencap.org.uk/about-learning-disability/information-professionals/health/end-life-care>
- Making a Difference Together: a Health Toolkit (Keele University, 2014) **(UK)** <http://aldhc.co.uk/wttk>
- Wegwijzer palliatieve zorg voor mensen met een verstandelijke beperking (Agora 2011) **(Netherlands)** <http://www.venvn.nl/LinkClick.aspx?fileticket=5pXPsU6Mn6o%3D&tabid=1513>

### Books

A number of books on aspects of palliative care include a chapter on intellectual disabilities (and books on intellectual disability may include chapters on palliative care). There are, however, also several books available that focus exclusively on the range of issues around palliative care provision for people with intellectual disabilities. These are edited books, with experts in the field contributing chapters.

**UK: Palliative care for people with learning disabilities.** Edited by S.Read (2006). London: Quay Books

**USA: End-of-life care for children and adults with intellectual and developmental disabilities.** Edited by S. Friedman and D. Helm (2010). Washington: American Association on Intellectual and Developmental Disabilities

**Germany: Palliative Care für Menschen mit geistiger Behinderung: Interdisziplinäre Perspektiven für die Begleitung am Lebensende.** Edited by R. Bruhn and B.Straßer (2014). Stuttgart: Kohlhammer

## 2. COMMUNICATION

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Problems with communication are often given as a significant reason why palliative care provision for people with intellectual disabilities is more difficult. Communication problems affect a range of issues pertinent to optimal palliative care provision, including assessment of pain and other symptoms, emotional support, truth disclosure, or consent to care and treatment. People with intellectual disabilities may have difficulties with making themselves understood, particularly (but not only) if they do not use verbal communication. They may also have difficulties in understanding verbal communication. This can be challenging for professionals who typically rely on using verbal communication with their patients.<sup>58</sup>

The Taskforce agreed that the following are important in ensuring good communication with people with intellectual disabilities:

- Recognising the fact that many people with intellectual disabilities need more time to understand information, cannot manage too much information at once and need repetition of information.
- Supplementing verbal and written information with clear words and pictures to promote understanding.
- Tailoring communication styles to the specific needs of the individual with intellectual disability.
- Helping people with intellectual disabilities to understand their situation as much as they want to, in a way that is suited to their communication needs.

Mainstream health care services often fail to meet the specific informational needs of people with intellectual disabilities who have cancer or are in need of palliative care.<sup>53,59</sup><sup>60</sup> <sup>61</sup> It is important for people approaching the end of life, and for their professional and family carers and friends, to have access to appropriate sources of information in a format that is understandable, as this can reduce anxiety, increase preparedness for events and compliance and enable people to cope more effectively.<sup>62</sup> Furthermore, without information that can be easily understood, people with intellectual disabilities are prevented from making informed decisions and choices about their care and treatment.<sup>63</sup>

There is a growing number of accessible resources to support communication with people with intellectual disabilities at the end of life, many of them available online (see Resources). There are hardly any research studies in this area that include people with severe and profound intellectual disabilities as research participants<sup>64</sup>, but studies have found consistently that people with mild and moderate intellectual disabilities are able to talk about death and dying and have insight into what the support needs are at the end of someone's life.<sup>65-68 69 70</sup> These support needs include 'talking about the illness' and having access to information about illness, treatment and prognosis.

Whilst many people with intellectual disabilities are protected from knowledge about the palliative nature of their illness, the literature suggests that they should be more included in conversations around death and dying. Their perception and emotional capacities are often underestimated.<sup>16,71 66-68</sup>

## Norm 2: Communication

- 2a People with intellectual disabilities may have a range of specific communication needs. The communication needs of people with intellectual disabilities should be recognised and taken into consideration.**
- 2b Professionals and formal carers have a responsibility to strive to understand the communication of people with intellectual disabilities, and to seek the necessary training for this.**
- 2c People with intellectual disabilities should be supported to communicate their needs in the best possible way, whether verbal or non-verbal.**

### Example

#### Communicating beyond words: Explaining difficult concepts (England)

A 59 year old man with severe intellectual disabilities was diagnosed with stomach cancer and referred to the palliative care team three years later. His elderly mother had already said that she didn't want him to die at home. The team started building a relationship with him by inviting him to attend hospice day care one day per week. It took

several months before he started to interact with the staff and the other patients, although he enjoyed the lunches. Eventually the staff asked him to assist them by pushing the linen trolley when they replaced the bedding and towels in the hospice rooms. This was a deliberate ploy to help familiarize him with the whole hospice and he seemed content to help. At this stage his family didn't think he understood what the hospice was – he probably thought it was just another day care centre, slightly nicer than the one he used to attend. Two years later, when he had an acute episode of pain, he was admitted to the hospice ward for a week to get his symptoms under control. Patrick had become so familiar with the ward and with the staff that he settled quickly. He had several further admissions for respite care before finally spending his last few weeks of life in the hospice.

*(Real-life example taken from “How to break bad news to people with intellectual disabilities”, Tuffrey-Wijne 2013)*

## Resources

### Signposting resources

The following websites signpost examples of good practice and accessible information for people with intellectual disabilities on death, dying and bereavement (English language)

**PCPLD Network** <http://www.pcpld.org/links-and-resources/>  
**Easy Health** <http://www.easyhealth.org.uk>

### Books Beyond Words

The Books Beyond Words series is aimed at people who find it easier to understand pictures than words. The pictures are used to tell stories that engage and empower people to ask questions and tell their own stories. The series includes titles on death, dying and bereavement.

<http://www.booksbeyondwords.co.uk/>

### How to break bad news to people with intellectual disabilities

A website providing unique and flexible guidelines that can be used by practitioners, families and carers to ease the process of breaking bad news to people with intellectual disabilities. The guidelines are adaptable to individual communication ability and level of understanding. A comprehensive book by Dr Tuffrey-Wijne (who developed the guidelines) is also available, in English and in Dutch.

<http://www.breakingbadnews.org>

### Easy-read information on cancer and palliative care

Pictorial information, plus guidance for carers and professionals, available free of charge (whilst stock lasts) <http://be.macmillan.org.uk/be/s-428-accessible-information.aspx>

**Picture book for people with intellectual disabilities about palliative care** (in Dutch)

Accompanied by a workbook and a guide for carers and professionals. Belgium. See:

<http://www.maklu.be/MakluEnGarant/BookDetails.aspx?id=9789044130492>

**picTTalk app**

A communication resource for use on tablet computers, including a number of pictograms, developed to facilitate stories and conversations, helping people to have a voice in what's happening in their lives – including issues around death and dying. Freely available to download from iTunes and Google Play.



### 3. RECOGNISING THE NEED FOR PALLIATIVE CARE

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People with intellectual disabilities may have poor access to palliative care services as there is a lack of recognition by those that support them that palliative care may be needed. The background and training of care and support staff for people with intellectual disabilities varies across countries; such staff may not be trained in healthcare, and may miss signs and symptoms of serious illness.

It is important to identify which people will benefit from palliative care - seeking to identify, as accurately as possible, which people are entering the last year of life, and when the focus of care needs to change to take account of disease progression. Diagnosing those at the end of life can be very difficult to do.

A number of triggers have been used to identify those in need of palliative care<sup>72</sup>:

1. Ask yourself the '*Surprise Question*': 'Would you be surprised if this person were to die in the next 6-12 months?'
2. Are there *general indicators* of decline and increasing need? (such as, for example, decreasing activity, general physical decline, progressive weight loss, repeated hospital admissions)
3. Are there *specific clinical indicators* related to a particular life-limiting condition such as cancer, organ failure, dementia, frailty/co-morbidities?

However, identifying the need for palliative care through prognostication may be particularly difficult for people with intellectual disabilities. Many have physical and congenital conditions, co-morbidities and associated complications, such as epilepsy and degenerative mobility problems.<sup>73 26</sup> Some have very complex health needs throughout their lives, from birth or early childhood. It can be a challenge to recognise when the ongoing management of their health problems needs to become end of life care.

It is especially important for this group not to rely too heavily on prognostic indicators, but to use 'rainy day thinking' – hoping for the best but preparing for the worst. This is more related to anticipating and meeting likely needs, planning ahead, rather than focusing on trying to predict likely timescales. In order to identify those who are in need of pro-active palliative care, the focus should be on a pragmatic, even instinctive

prediction of the rate and course of decline.<sup>72</sup> Furthermore, it is important to review this on a regular basis for each person.

### Norm 3: Recognising the need for palliative care

- 3a All health and social care professionals caring for people with intellectual disabilities must be able to recognise when palliative care is needed, whether the person is in the family home, in an institutional setting or in single or shared homes in the community. They must be alert to the signs and symptoms of serious illness, end of life and the dying phase.**
- 3b When a need for palliative care is identified for an individual, a person-centred plan should be put into place to instigate palliative care support.**

## Example

### Anticipating the palliative care needs of a woman with Down syndrome and dementia (England)

Patsy Healy lived in a nursing home for eight people with intellectual disabilities, where the staff had no experience of palliative care. When she developed dementia, they signed up to a national training programme for care homes, run by the Gold Standards Framework. It is aimed at building confidence and experience, using up-to-date evidence of best practice. (<http://www.goldstandardsframework.org.uk>)

This helped the team to assess Patsy’s palliative care needs, symptoms and preferences, and plan her care accordingly in Patsy’s final years, months, weeks and days of life. It enabled Patsy to have a comfortable few years and a peaceful death, with involvement of all relevant outside professionals (her family doctor, the district nurse, the palliative care specialist community team) as well as her family.

This experience helped the nursing home to give greater thought to the potential palliative care needs of all their residents, to optimise their quality of life, and to support each other as well as the residents' families. Their care for Patsy won the Linda McEnhill Award for outstanding palliative care for people with intellectual disabilities (<http://www.pcpld.org/linda-mcenhill-award/>), which has since inspired other care homes for people with intellectual disabilities to follow their example.

*The full story can be found here: <http://www.pcpld.org/real-life-stories/caring-for-patsy/>*

## 4. ASSESSMENT OF TOTAL NEEDS

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Like anyone else with palliative care needs, people with intellectual disabilities require a multidisciplinary assessment of their physical, social, spiritual and emotional needs. Their high level of co-morbidities<sup>26</sup>, complex care needs and communication difficulties make this even more important. It is important to have an appreciation of the many complex factors that can contribute to suffering on a person's journey towards their death.<sup>74</sup>

The emotional, social and spiritual needs of people with intellectual disabilities may be overlooked for a variety of reasons, including unconventional ways of expressing such needs, assumptions made that such needs are less relevant than they are for the general population, and assumptions made about the (lack of) emotional capacities of people with intellectual disabilities. The life experience of people with intellectual disabilities, including possible experiences of isolation, loss and societal rejection, may have a significant impact on their experience of the last phase of life. People with intellectual disabilities often have a life-long experience of not being included and not being involved in decision making, sometimes lacking the experience of making even the most basic of choices. Many have experience of not having their needs understood or addressed. This affects their experience at the end of life.<sup>16</sup>

The concept of 'Total Pain', coined by Dame Cicely Saunders<sup>75</sup> to indicate the psychological, social, emotional and spiritual components that are part of the encompassing nature of the pain experience, has been well accepted in the palliative care community<sup>76</sup> and is of great relevance when caring for someone with intellectual disabilities.

There is evidence that spirituality plays a significant role in the lives of people with intellectual disabilities<sup>77</sup> and, therefore, they may need to be facilitated in expressing their spiritual needs at the end of life, like anyone else. The humanness of someone with an intellectual disability should be understood and respected.

Relevant points in holistic assessment are:

- Pain in the person with an intellectual disability at the end of their life is equally as subjective, multi-dimensional and complex in nature as it is for other people and may present itself in many different ways.

- Challenging behaviour in someone with an intellectual disability can sometimes be a way of communicating pain.<sup>36</sup>
- People with intellectual disabilities are likely to experience more episodes of pain due to co-morbidities such as contractures, sensory or motor impairments and postural problems (eg: associated with gastro-oesophageal reflux).<sup>36</sup>
- Sufficient time should be allocated for assessment with the person with intellectual disability to establish a relationship, to gain their trust and enable them to digest new information whether verbally or visually.<sup>78</sup>
- Simple and straightforward questions about pain and other symptoms should be used, remembering that the person may need more time to make responses.
- It is important to determine the person's receptive and expressive communication abilities, interpret their behaviour and changes in behaviour, and identify ways that the person normally expresses pain or discomfort from other symptoms. In order to do this, it is essential to work collaboratively with family carers, professional carers or those who matter to the person and have previous knowledge of them.<sup>36,78</sup> (see also Norm 8: *collaboration*)
- There is growing evidence that specific tools such as the Disability Assessment and Distress Tool' (DisDat) are an effective means of providing a picture of the language of distress used by people with intellectual disabilities who have severe communication difficulties.<sup>79</sup> Each person has their own vocabulary, and the cause of distress can be highly individual, as what may be seen as a minor issue for one person can be major for another. For example, what seems like an expression of severe pain could, in fact, be an expression of distress at changed routines. Identification of the distress is only the beginning of the assessment; the cause of this distress still needs to be determined and can often be no more than an 'educated guess' (see also Norm 5, *Symptom management*)
- Self-awareness is needed in relation to the professional's own personal beliefs that could affect pain assessment and subsequent treatment of pain in the person with an intellectual disability.<sup>80</sup>

## Norm 4: Assessment of total needs

- 4a** The needs of people with intellectual disabilities at the end of life include physical, emotional, social and spiritual needs, similar to those of the rest of the population.
- 4b** All physical, psychological, social and spiritual needs should be assessed, documented, addressed, evaluated and reviewed.
- 4c** People with intellectual disabilities may have additional and special palliative care needs as a result of their impairment. This should also be recognised and addressed.
- 4d** People with intellectual disabilities should have equity of access to support for those needs. This includes access to appropriately tailored counselling services, and support in maintaining social links, including links with friends (who may have special support needs themselves).

### Example

#### Becoming familiar with institutions that support people with intellectual disabilities (FRANCE)

Marie, a 40 year old woman with intellectual disabilities, who lived in a residential care home run by a religious voluntary association, was dying of cancer. The home manager called in the support of an outside volunteer “doula”, skilled in providing support for people at the end of life. This volunteer was apprehensive, as she was not used to working with people with intellectual disabilities. At the home manager’s request, she worked with the staff team (as well as with Marie), helping them understand how to “be” with Marie. Providing support for both a team and the patient was new to the volunteer’s organisation. Marie was surrounded by loving care and support. She received excellent nursing care. She was helped to make choices around her care, with her activities scheduled around her physical fatigue. She renewed contact with

her family. The staff made her a book with photos, drawings and short texts to remind her of her friendships and help her maintain them. Because this was a new situation for both the home care team and the outside volunteer, it took time to build up a good level of understanding and support. After Marie's death, the care home sought the volunteer's support for another team facing the final illness of a resident. The volunteer reflected how much easier it was this time round, as she had gained an understanding of how the institution works.

## Resources

### **DisDAT assessment tool for distress**

Experts in both intellectual disability services and palliative care services collaborated to develop the Disability Distress Assessment Tool (DisDAT), a method of recording a baseline of signs and behaviours when content, against which changes can be monitored when the person is distressed. It is particularly useful for people who don't use speech to communicate. Changes in the person's normal 'content' behaviours may indicate a physical, social, emotional or other problem, which will need further investigation. The DisDAT tool provides guidance on developing a hypothesis about the cause of the problem, which can then be tested.

<http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx>

## 5. SYMPTOM MANAGEMENT

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The rationale for Norm 5 echoes that of Norm 4: *assessment of total needs*.

Management of pain and other symptoms is crucial, but this can be difficult when people have intellectual disabilities. The belief that people with intellectual disabilities feel less pain than the general population still exists, perhaps due to the fact that they may express pain and other symptoms in unconventional ways, which may be seen as inherent in the intellectual disability itself, rather than a sign of ill-health ('diagnostic overshadowing'<sup>51</sup>). Pain is often not recognised, validated or treated in people with intellectual disabilities, which can mean delay in diagnosis, detection and treatment of serious medical conditions.<sup>81</sup> The ability of people with intellectual disabilities to self-report their pain, or other symptoms, is often limited and much more research is needed to understand and inform pain and symptom assessment with this population.

Where possible, people with intellectual disabilities should be active partners in pain and symptom assessment and decisions taken about their management. However, some people with severe and profound intellectual disabilities may be unable to recognise or articulate their pain or distress and will use other non-verbal or behavioural indicators to communicate this.<sup>82</sup> Those who know the person well and understand their way of communicating need to be involved and included in the team; they can act as 'interpreters'.

Difficulties with assessing the effects of symptom management strategies may deter professionals from instigating appropriate treatments, including medication regimes; this may mean that pain and other distressing symptoms are left under-treated. It is important to treat symptoms, including administration of opioids for likely pain, even when a patient is unable to indicate whether or not pain is indeed present. When a patient appears to be in distress, professionals should treat or manage the most likely cause. The result should then be monitored; if the distress does not resolve, further assessment and intervention for a further possible cause should be considered (the 'educated guess': see *DisDAT* assessment tool, above).

Due to the wide range of chronic medical conditions experienced by people with intellectual disabilities, and subsequent multiple medications, there is a risk of drug interactions which can make pain and symptom management complex.<sup>83</sup> The core principles of pain and symptom management in palliative care<sup>76,84</sup> need to be applied according to individual need:



1. *Evaluate* – for each symptom, try to establish whether the cause is the disease itself, the treatment of the disease, debility or another condition; any underlying pathological reason for the symptom; the impact of the symptom on the person’s life;
2. *Explain* the possible reasons for the symptom and the treatment options with the person and those who matter to them (accessible information may need to be used);
3. *Manage* the symptom (considering both pharmacological and non-pharmacological treatments, including complementary therapies, emotional and spiritual support, the use of life stories and reminiscence therapy, relaxation exercises etc. If the cause is not clear (possibly because the person cannot use words to explain the symptom), base the symptom management on an ‘educated guess’.
4. *Monitor* the symptom through continual review;
5. *Pay attention to detail*: do not make assumptions.

## Norm 5: Symptom management

- 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 which 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.**

## Resources

**DisDAT, an assessment tool for distress in people with severe communication difficulties**  
See Norm 4

**Guidelines on pain and symptom management**

can be accessed at the following websites:

<http://www.palliativedrugs.com>

<http://www.pallcare.info> (click on Palliative Care Guidelines)

**Guidelines and Audit Implementation Network (2011)**

General palliative care guidelines for the management of pain at the end of life in adults. (Includes a section on Intellectual Disability). Belfast: GAIN Office.

<http://www.gain-ni.org>

**Evidence-based EAPC guidelines on use of opioid analgesics in the treatment of cancer pain**

can be accessed at the following website:

<http://www.eapcnet.eu/Themes/Clinicalcare/EAPCOpioidGuidelines2012.aspx>

## 6. END OF LIFE DECISION MAKING

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Issues around end of life decision making include Advance Care Planning, Do Not Attempt Resuscitation orders and euthanasia, as well as decisions around the instigation or withholding of potentially curative treatments. These issues are covered by different laws across European countries, which should guide decision making.

It is important that all end of life decisions are based on the premise that the lives of people with intellectual disabilities are as important as the lives of people in the general population. There is evidence that medical decision making is sometimes based on misguided assumptions about the quality of life of people with intellectual disabilities, their ability to comply and cope with treatments, or their ability to consent to treatment and be involved in the decision making process. This can lead to people with intellectual disabilities not receiving potentially lifesaving treatment.<sup>9,32,85,86</sup>

People with intellectual disabilities have a right to be facilitated in making choices about care and treatment, where possible. There should be no assumptions about their capacity to make decisions due to the label 'intellectual disability'.<sup>87</sup> It is important to remember that people's capacity needs to be assessed for each situation; it is quite possible for someone to have the capacity to decide on one aspect of care or treatment at one particular moment in time, but lack capacity on another occasion.

A systematic mixed methods study review found evidence that many people in the general population are not involved in end-of-life care decision making as much as they desire to be and conversations about potential options in treatment do not often take place.<sup>88</sup> People with intellectual disabilities are particularly vulnerable and can be excluded from conversations that they may be able to have which could help to plan the palliative and end-of-life care that they wish to receive. For some, it may be that there is no carer with prior knowledge of them and how they best communicate.<sup>89</sup>

A retrospective study in the Netherlands looked at decision making in end of life care for 335 people with intellectual disabilities. It found that treatment documentation lacked evidence to show that people with intellectual disabilities were consulted about their views in relation to decisions taken.<sup>85</sup> More research is needed to explore the decision making processes used at end of life with people with intellectual disabilities.<sup>90</sup>

The difficulties for health care professionals who have limited experience of working with people with intellectual disabilities is exemplified in this quote from a consultant

physician, taken from an English study into the safety of people with intellectual disabilities in hospital.<sup>86</sup> (p. 98)

“The patient had cancer and needed surgery. I didn’t realise that he didn’t have the capacity to say “no” to the operation. He didn’t want the operation, and I just thought that was that. But the intellectual disability nurse came along and asked him, “What do you think will happen if you don’t have the operation?” and he really didn’t know. He didn’t have the capacity. So it became a best interest decision, and we decided to do the operation.”

## Norm 6: End of life decision making

- 6a End of life decision making is complex, regardless of whether or not the person has disabilities.**
- 6b People with intellectual disabilities have a right to life, and a right to recognition of the value of their lives.**
- 6c 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.**
- 6d People with intellectual disabilities should be assumed to have capacity to make decisions around their care and treatment, unless it is demonstrated otherwise.**
- 6e People with intellectual disabilities should have all the necessary support, including advocacy, in order to enable their involvement in end of life decision making.**

## Helping someone decide about life-saving treatment (England)

A hospital liaison nurse for intellectual disability explained:

‘There wasn’t much time to decide whether or not Jennifer should have bowel surgery that would leave her with a colostomy. Without the surgery, she would die, but her family and the medical team weren’t sure whether she would cope with the surgery and the colostomy. They didn’t think that she had the capacity to be involved in the decision and were planning a ‘best interest’ meeting. But I wanted to try, because I thought that with the right support, we could get Jennifer to the point of understanding and making a decision. I find that people with intellectual disabilities often surprise us with their abilities. It took an intensive week of explaining everything in all sorts of different ways. We talked, drew pictures and made models. I took her to the hospital where she could meet a patient who was willing to show Jennifer her colostomy and talked about the operation. The nurses on the ward really helped with this too. In the end, Jennifer decided that she would like to have the operation. And so far, she is coping well with her colostomy. I think it was very useful to think about what bits of information Jennifer needed to understand in order to make the decision, how we could help her understand as quickly as possible, and how we could support her in coping with the knowledge.’

*Real-life example taken from “How to break bad news to people with intellectual disabilities”, Tuffrey-Wijne 2013*

## 7. INVOLVING THOSE WHO MATTER: FAMILIES, FRIENDS AND CARERS

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In many European countries, the majority of people with intellectual disabilities live with their families, including elderly parents. Where people with intellectual disabilities live depends to a great extent on the practice and service provision within their country, which varies significantly across Europe. They may have been separated from their families and institutionalised at an early age; they may have lived with and depended on their families all their lives; or they may have lived fairly independent lives with various levels of support.

Many people with intellectual disabilities have had little power over the choice of their living arrangements, and may have experienced moves that included the loss of bonds with family or friends. In addition, for many people with intellectual disabilities it is much more difficult to create new bonds, including new family bonds, as their life progresses. People in the general population often rely on the support of partners and children when they develop a serious illness, but an in-depth study of people with intellectual disabilities who died of cancer in England (median age 55) showed that they didn't benefit from such networks; their family bonds consisted mostly of siblings and elderly parents.<sup>16</sup>

People with intellectual disabilities often need support in maintaining contact with friends or family (such as help with organising visits or phone calls). When they experience serious illness with an associated loss of skills and abilities, this need for support intensifies.

Studies that have included the voices of people with intellectual disabilities themselves, ascertaining their views on support at the end of life, have shown how important it is for them to have familiar people around, especially family, friends and familiar carers.<sup>26,65,68</sup> Furthermore, it has been shown that a lack of carer involvement leads to poorer outcomes for people with intellectual disabilities.<sup>9,26,86</sup>

Family members, friends and carers can bring crucial knowledge about the person with an intellectual disability. They often know what matters to that person and what their methods of communication are. It is important that wherever possible, palliative care services include family members, friends and carers as part of the team.

## Norm 7: Involving those who matter: families, friends and carers

- 7a** The important relationships ('significant others') of people with intellectual disabilities should be identified. This could include family, partners, friends, carers (including paid care staff) and others. People with intellectual disabilities should be involved in identifying these significant others.
- 7b** Significant others should be encouraged, if they wish, to be as involved as possible at the end of life.
- 7c** The person's closest carer(s) are likely to know him/her best. For many (but not all) people with intellectual disabilities, this is their family, who have often been their carers for many years or decades. Professionals should respect and involve the carers as expert care partners.
- 7d** For people with intellectual disabilities, family bonds may be crucially important at the end of life. This may be the case even where these bonds have been broken through lack of contact.
- 7e** Family bonds that are important to the person with intellectual disabilities should be recognised and respected by professionals and care staff.
- 7f** The person's wishes around involving their families at the end of life should be sought and respected.

### Example

#### Involving family and friends in an institution (Croatia)

Marta, a woman with mild intellectual disabilities, had lived in an institution for people with intellectual disabilities since she was 14 years old. She was well liked, sociable and had good communication. Around her 50<sup>th</sup> birthday, she was diagnosed with metastatic liver cancer. It was her choice to remain at the centre where she shared a room with four other residents. She had maintained a good relationship with her family, especially her mother. Her mother became closely involved in her care,

## Example

and along with the staff, received special training in end-of-life care. The staff at the centre talked to Marta's roommates about her illness and impending death, and encouraged them to keep in touch whilst Marta was in hospital. Throughout her illness, she was helped to keep in touch with these friends. There was excellent collaboration between everyone involved, in particular between the staff and the family, with further support provided by the family doctor. Family, staff and friends were all involved in Marta's funeral.

### **The family stays with a woman with intellectual disabilities in an institution (France)**

Hélène was in her late 40s and had profound intellectual disabilities. She lived in an institution where care was provided by nurses. When she was diagnosed with incurable cancer, her sister, who lived with her own family but always maintained strong links with Hélène, decided that she wanted to spend as much time as possible with Hélène. She moved into Hélène's room for the remaining six months of her life. The situation was not straightforward for the institution, who had to find a way of accommodating two people in a small room and provide extra meals, and whose staff sometimes felt challenged by the presence of family 'looking on'. However, they realised how important it was to support the strong family involvement (which also included Hélène's mother) and found ways of making this work. The nurses were further supported by a palliative care team. Hélène's sister was deeply grateful to the staff, reflecting afterwards how she felt comforted not only by their friendship but also by their attention to her own anxieties, fears and tears.

## Example

### **A woman with Down Syndrome moves into her mother's care home (Croatia)**

A 75 year old woman, whose health was deteriorating, refused to be admitted to a care home without her 45 year old daughter Denisa who had Down Syndrome. The care home's managing committee suggested that Denisa was sent to a home for psychiatric patients instead, but the



home's doctor managed to persuade the committee that such separation would cause huge problems for both mother and daughter.

The home did not have a palliative care unit or access to psychological services. They had never supported a person with Down Syndrome before. However, the arrangement of Denisa living with her mother in a double-bedroom suite was a huge success. She befriended the nurses.

Denisa's mother died four years later. Denisa was helped to prepare for the death; her mother reassured her that when she was gone, Denisa's favourite nurses would continue to take care of her. After the death, Denisa moved in with a younger disabled woman. They quickly became good friends. Denisa lived in the home until her death five years later.

Her doctor later reflected: "In my opinion, Denisa was provided for in the best way possible, considering our situation. All persons involved had a true desire to provide the best for her, with no expert knowledge of palliative care and no engagement from the interdisciplinary palliative care team. Today, we are aware that some procedures should have been different and more complete... still, we are very proud that we took her on and remained with her until the end – this was the first case of that kind for us."

## 8. COLLABORATION

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Partnership and collaboration between professionals and services enables quality health and social care outcomes.<sup>62,91 92</sup> Within palliative care services, professionals have long been working collaboratively with other services in order to support patients and families in the best possible way.

In reviewing the literature related to palliative care for people with intellectual disabilities, the most consistent finding is the importance of collaboration between services (in particular, but not exclusively, between palliative care services and intellectual disability services). Such collaboration is key to the provision of high quality palliative care for this population, and essential in ensuring that they have the opportunity to die well.<sup>55,82,93–96</sup> Winners of the Linda McEnhill award (an annual award for excellence in palliative care provision for people with intellectual disabilities, given by the PCPLD Network) invariably demonstrate such collaborative working (<http://www.pcpld.org/linda-mcenhill-award/>).

Setting up such collaboration may involve a concerted effort, in particular if professionals are not aware of each other's existence or range of services and expertise. Whilst intellectual disability professionals may have high levels of expertise in supporting the person and his/her highly individual needs (including basic health care needs), it is unlikely that they have sufficient expertise in recognising and addressing the full range of palliative care needs, which are likely to be complex. Palliative care services are likely to need access to the expertise of intellectual disability services in order to interpret and address the individual's palliative care needs. Depending on national service provision, such collaboration may take the form of exchanging information and individual advice.

Although both palliative care and intellectual disability services may recognise the need for partnership working, and may have a willingness to do so, studies have shown that this is not enough to make it happen effectively.<sup>55,95</sup> A best practice model, which was developed to guide and promote partnership practice between intellectual disability and palliative care services,<sup>97</sup> illustrates that developing a relationship built on mutual trust and respect for each other's knowledge base and skills can enable a more robust assessment of the holistic needs of people with intellectual disabilities. This can ensure better outcomes for this population, such as continuity of care and dying peacefully in their place of care with people familiar to them.

Collaborative working should not be restricted to professional services, but should include family carers and people with intellectual disabilities themselves; in fact, people with intellectual disabilities should be at the centre of partnerships at all times.<sup>68</sup>

## Norm 8: Collaboration

- 8a Collaboration between services is key to successful provision of palliative care to people with intellectual disabilities.**
- 8b Anyone (and any services) with expertise to offer at the end of life should be identified as early as possible in the care pathway, and involved if there is a need. This can include professional service networks, paid care staff, informal (family) carers and spiritual leaders.**
- 8c It is of crucial importance that people with intellectual disabilities have access to medical and nursing professionals, including support and advice from palliative care experts if needed.**
- 8d All these individuals and services should collaborate with each other and share their expertise when required for the benefit of the person with intellectual disabilities.**

### Example

#### Calling on the palliative care experts (Norway)

Staff in a residential care facility perceived that one of their clients, an elderly lady with mild intellectual disabilities, had severe stomach pain. She lacked verbal communication skills and had difficulty expressing her pain. Following poor cooperation from the general practitioner (and no improvement after switching to another general practitioner), the team contacted the Resource Unit in the municipality. This is a mobile team with expertise in palliative care, which provides services to the general population. A nurse and general practitioner from the mobile palliative care team did a home visit and instigated a care and treatment plan. They took charge of the medical situation. The palliative care nurses

visited several times a day, supervising the home staff on how to care for the woman. After her death, they also provided follow-up support for the home staff.

Since then, the residential facility has experienced several more deaths. Staff have realised the importance of training, good practice and cooperation, ensuring that their clients have access to palliative care expertise.

## 9. SUPPORT FOR FAMILIES AND CARERS

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The central role of family carers in palliative care was highlighted by an EAPC Taskforce in 2010.<sup>98,99</sup> Their caring role can bring considerable physical, psychological, emotional, social and financial challenges which they are largely unprepared for. Family carers are often ageing, may have co-morbidities themselves, and may have co-dependent relationships with the person they care for. They need considerable and sensitive support, a recognition of their expertise in relation to the cared-for person, and a regular assessment of their needs.<sup>100</sup>

All these issues are compounded for carers of people with intellectual disabilities, whose situation and caring role can be much more complex.

The grief of families and carers is sometimes ‘disenfranchised’ (where the relationship is not recognised, the loss is not recognised or the mourner is not recognised).<sup>101</sup> The presence of a person with intellectual disabilities within families can have a significant impact on roles and relationships; for example, parents or siblings who have been long-standing carers will experience a huge life changes when the person with intellectual disabilities is no longer there. Emotional bonds, and the sense of loss when they are broken, are often profound. Carers (and especially parents) of people with profound and multiple disabilities, for whom they will have provided intensive physical and emotional care over many years, can experience their deaths as a painful physical loss of part of themselves.<sup>102,103</sup> However, families may be given the message that the death of their relative is ‘for the best’ or even a blessing.<sup>103,104</sup>

Professional carers may not be recognised as ‘mourners’, even if they have formed strong attachments with the person with intellectual disabilities. The death of a client of resident with intellectual disabilities can have a complex physical and emotional dimension for staff that is seldom recognised.<sup>105</sup> It is important that the grief of all those who loved and supported the person with intellectual disabilities is recognised and validated, including not only family carers but also paid care staff.<sup>16</sup>

## Norm 9: Support for families and carers

- 9a Families and carers (including paid/professional care staff) are often deeply affected when someone with intellectual disabilities reaches the end of life. They should be supported in their caring role.**
- 9b Many people with intellectual disabilities, including those with severe and profound intellectual disabilities, are at the centre of their family's and carer's life. The death of someone with intellectual disabilities is often a significant and difficult loss for those around them.**
- 9c Families should have recognition and support for their loss.**
- 9d Professional carers may not be expected to grieve, but have often formed deep attachments to the people they support. They, too, should be supported in their loss, including training on self-care for those working with people who are dying.**

### Example

#### Support for the support worker (England)

Keith was in his 50s, who had mild intellectual disabilities, had lived alone in his own flat for ten years. When his health began to deteriorate, a support worker was appointed to work with him for two hours, three times a week. Keith was diagnosed with lung cancer and eventually died at home, as was his wish. His support worker had already attended a bereavement course which had equipped her to manage her own feelings about Keith's death. In addition, she was offered individual counselling by her employing organisation.<sup>9</sup>

<sup>9</sup> This example, sent to the Taskforce by the CIPOLD team (Confidential Inquiry into Premature Deaths of People with Learning Disabilities), was published: see <sup>134</sup>

## RESOURCES

### Supporting bereaved families

An award winning learning resource pack, including a unit about supporting bereaved parents and carers of people with profound intellectual disabilities:

**Young H, Garrad B, Lambe L. (2014) *Bereavement and loss: supporting bereaved people with profound and multiple learning disabilities and their parents*. Dundee: PAMIS**

Available through the PAMIS website: <http://www.pamis.org.uk/>

## 10. PREPARING FOR DEATH

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There is a growing emphasis on advance care planning as an integral part of providing choice for people around how and where they are cared for at the end of life. This is a process of discussion between the patient and the professionals involved in their care. It clarifies what the person's wishes are in the event of their deterioration, especially if they lose the capacity to make decisions or to communicate their wishes to others. With the person's permission, all those involved in their care should be made aware of the patient's wishes and advance decisions.

People with intellectual disabilities are often protected from knowledge about death, including their own.<sup>63,71</sup> This excludes them from the opportunity to prepare themselves for the future, and be involved in care planning, if they so wish. They will not be able to participate in decision making around type and place of care and treatment, nor in discussions around funeral wishes and making a will. A culture of openness and inclusion, where people with intellectual disabilities are given opportunities to think and talk about death-related issues throughout the life cycle, can be an important foundation for helping them prepare for their own final illness and death. Planning and preparing for the end of life is not a one-off event, but should be revisited regularly.

People with intellectual disabilities may wish to engage with what is happening at the end of their life and should be given the same opportunities to talk about their death as anyone else. This will require an understanding of how the person with intellectual disability communicates and facilitating them to take part in conversations about death and dying. It will also require professionals to adapt their communication by giving time to the person with intellectual disability and using accessible information as appropriate to enable communication to and from the person. There are now a number of tools and resources available to support advance care planning for people with intellectual disabilities (*see Resources*).

### Norm 10: Preparing for death

**10a Opportunities should be provided to involve people with intellectual disabilities in advance care planning, where appropriate and desired. This includes discussions and recording of choices regarding preferences for end of life care, funeral wishes and wills.**



- 10b** Such discussions could take place as early as is appropriate. They could take place before the need for palliative care arises.
- 10c** Once the need for palliative care has been identified, carers and professionals should put into place a care plan, anticipating future holistic needs for treatment and care. The wishes of the person with intellectual disabilities should be incorporated in this plan.
- 10d** Where families are not routinely responsible for funeral arrangements, professionals and care services should recognise the role of the family in organising the funeral, and provide the family with the necessary support to do so.

## Resources

### Easy-read advance care planning documents

There are a number of easy-read documents (or examples of documents) available on-line that can be used with people with intellectual disabilities to record their wishes and choices related to the end of life. They are especially helpful for people with mild intellectual disabilities. For example:

“Preferred Priorities for Care” document (English)

[http://www.changepeople.org/wp-content/uploads/2013/01/PreferredPrioritiesforCareEasyRead\\_V41.pdf](http://www.changepeople.org/wp-content/uploads/2013/01/PreferredPrioritiesforCareEasyRead_V41.pdf)

“When I die” (English) is an example of what to discuss and record, and how

[http://www.pcpld.org/beta/wp-content/uploads/when\\_i\\_die\\_2\\_0.pdf](http://www.pcpld.org/beta/wp-content/uploads/when_i_die_2_0.pdf)

“Wat wil ik? Als ik niet meer beter word” (Dutch)

<http://www.nivel.nl/sites/default/files/bestanden/Rapport-wat-als-ik-niet-meer-beter-word.pdf>

### Film for people with intellectual disabilities

“*We’re living well but dying matters*” is a film in which people with intellectual disabilities tell their stories and share their wishes to support other people with learning disabilities to become more comfortable talking about dying, death and bereavement.

<http://dyingmatters.org/page/were-living-well-dying-matters>

# 11. BEREAVEMENT SUPPORT

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Bereavement care is an important part of the support needs of family members or those who matter to the person. There is guidance available to assess the bereavement needs in the general population.<sup>106</sup>

Until the late 20<sup>th</sup> century, it was assumed that people with intellectual disabilities did not experience grief. Oswin (1991)<sup>107</sup> was the first researcher to discredit this view by demonstrating that people with intellectual disabilities can, and do, experience profound loss. However, the theory of ‘disenfranchised grief’, where the person’s loss is not recognised or validated,<sup>101</sup> is particularly relevant in relation to people with intellectual disabilities. They are often not given the opportunity to talk about what has happened.<sup>69</sup> The grief responses of people with intellectual disabilities are sometimes delayed or expressed in unconventional ways, so that they may not be recognised as a grief reaction (but could, for example, be described as ‘challenging behaviour’). The pain of grief can be hidden. Sinason<sup>108</sup> coined the term “the handicapped smile” to describe the way in which many people with intellectual disabilities have learned to hide their true feelings in order to meet people’s expectations of them.

There is now considerable evidence to suggest not only that people with intellectual disabilities experience the full range of grief reactions, but that they are at increased risk of experiencing complicated grief.<sup>109–114</sup> Risk factors that they are more vulnerable to than the general population include:

- Social isolation
- High dependency on a small group (or even a single) significant other(s), with limited opportunities for developing new roles and relationships
- Exclusion from death rituals (such as attending funerals or visiting the grave)
- Difficulties with attachment in early life
- Low self-esteem
- Limited power or control over one’s situation
- Associated, often hidden and multiple losses that accompany the death of a parent or close relative (eg loss of home)

Blackman<sup>114</sup> has developed a bereavement risk assessment tool for use with people with intellectual disabilities. This tool focuses on three main areas of support (p.165):

- Practical issues: has the person's ability to communicate with others been affected by this loss?
- Social issues: what impact has the death had on the person's familial network?
- Emotional issues: does the person recognise their emotions and can they express them?

People with intellectual disabilities who have been bereaved should have a continuum of support, involving strategies at different levels such as: *facilitation* of the person's grief, *participation* in death rituals following a death and planned *education* around loss prior to personal experience of death.<sup>115,116</sup> The following are important when someone with an intellectual disability has been bereaved:<sup>117</sup>

- Ensure the active involvement (as they wish) of the person with an intellectual disability in the funeral and/or other death rituals. (This is also important in residential care settings to ensure residents are supported following the death of a peer).
- Maintain consistency in being open and honest with the person with an intellectual disability.
- Provide information about bereavement in a format that the person can understand. This may need to be repeated often.
- Memory books and life story books in an accessible format may be helpful in helping the person to remember and have a link with the person who has died
- Bereavement counsellors may also need to use a variety of approaches to help someone with an intellectual disability experiencing grief, such as art work, creating family trees, use of pictures, photographs, videos, poetry and reminiscence work.

How people with intellectual disabilities respond to loss and can be best supported in their grief depends, in part, on their understanding of mortality, which is affected by their intellectual capacity.<sup>11</sup> Supporting people with profound intellectual disabilities in grief can be particularly complex. They will need to be provided with supportive relationships and sensory experiences in order to increase their sense of safety, enhance a sense of security and facilitate expression of their grief.<sup>103</sup>

## Norm 11: Bereavement support

- 11a** People with intellectual disabilities experience loss and grief, just like the rest of the population (although they may express it differently).
- 11b** People with intellectual disabilities are at a higher risk of complicated grief than the rest of the population. Those who support and care for them should be alert to the possibility of complicated grief reactions.
- 11c** Those who support and care for people with intellectual disabilities should also be aware of any available mainstream and specialist bereavement support services to refer people with intellectual disabilities to if necessary.
- 11d** People with intellectual disabilities should be offered the opportunity and necessary support to attend funerals.

### Example

#### Helping fellow residents to say goodbye (Belgium)

A large residential facility for people with intellectual disabilities in Belgium has developed clear policy guidelines for supporting residents through bereavement in ways that suit their intellectual and social-emotional abilities. This includes guidance and examples of how to make the loss concrete by offering physical and visual experiences, to help people visualise, ritualise and symbolise the loss. This could be: active support in going to see the body; using photographs and candles; involvement in wakes, funerals and memorial services; involving residents in helping to clear the person's room, putting up a photograph of the person, or inviting the family round after the person's death.

*Information provided by care organisation 'DVC 't Zwart Goor',  
<http://www.zwartgoor.be>*

## Resources

### Book

A book with contributions from international experts exploring contemporary theory and practice surrounding loss and bereavement for people with intellectual disabilities:

Read, S. (ed) (2014). *Supporting people with intellectual disabilities experiencing loss and bereavement: Theory and compassionate practice*. London: Jessica Kingsley Publishers.

### Supporting bereaved people with profound intellectual disabilities

An award winning learning resource pack, including a DVD and a unit about supporting bereaved people with profound intellectual disabilities:

**Young H, Garrad B, Lambe L. (2014) *Bereavement and loss: supporting bereaved people with profound and multiple learning disabilities and their parents***. Dundee: PAMIS

Available through the PAMIS website: <http://www.pamis.org.uk/>

### picTTalk app

A downloadable communication tool for use on tablet computers, to help people with intellectual disabilities communicate about loss and bereavement.

*Freely downloadable from iTunes and Google Play*

### Books Beyond Words

A series of picture books to help people with intellectual disabilities communicate about sensitive issues, including bereavement. Relevant titles are:

***When Dad died***

***When Mum died***

***When somebody dies***

See: <http://www.booksbeyondwords.co.uk/>

## 12. EDUCATION AND TRAINING

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Education and training will not, in itself, guarantee high standards of palliative care provision for people with intellectual disabilities, but they provide important building blocks and support for achieving excellence. Services should aim for cross-fertilisation of knowledge and skills between palliative care staff and intellectual disability staff, and wherever possible include carers and people with intellectual disabilities themselves. This could be through formal training sessions and through informal exchange of expertise around a particular individual with intellectual disabilities.

People with intellectual disabilities themselves often lack essential and basic knowledge around illness, death and dying, and will benefit from education in this area.

Workforce development has been highlighted as pivotal to the mission of providing high quality care to all at the end of life.<sup>62</sup> A number of studies across different settings have highlighted that there are unmet educational and training needs of professionals in the provision of palliative and end of life care to people with intellectual disabilities.<sup>53,55,94,97,118–123</sup> Staff have consistently reported that they lack confidence in caring for people with intellectual disabilities at end of life. Staff training can increase such confidence.<sup>124–126</sup>

For those working in palliative care services, a lack of confidence may be due to the fact that there are a limited number of people with intellectual disabilities referred to their services and thus knowledge and skills are not being developed. They find assessment and communication issues particularly difficult.<sup>53,97,122</sup>

Staff working in intellectual disability services may not have any experience of death and dying, and may be frightened by it.<sup>16,121,127</sup> In addition, they may experience anticipatory grief reactions themselves (*see Norm 9: Support for families and carers*). The EAPC has recognised the importance of meeting educational needs around self-care and self-awareness in working with people who are dying.<sup>128,129</sup> This, and addressing death anxiety,<sup>130</sup> can be particularly important for staff working in intellectual disability services.

## 12. Education and training

- 12a *Staff training:*** Carers and professionals involved in supporting people with intellectual disabilities at the end of life should be trained in order to deal with their specific needs. This includes training on death, dying and palliative care for staff working in intellectual disabilities services, and training on intellectual disabilities for staff working in palliative care services.
- 12b *Death education for people with intellectual disabilities:*** Throughout their lives, people with intellectual disabilities should not be protected from information and discussions about illness, death and dying. This could, for example, include sessions at Day Centres or special education facilities, as well as discussions at home. Families and carers should be given help and support in encouraging such discussions.

### Example

#### Learning from a bad experience (Switzerland)

The development of structures and support to improve end-of-life support for people with intellectual disabilities and their families often arises out of bad experiences. A difficult situation arose around woman with Down Syndrome and dementia, who lived in an institution. She was frightened and cried a lot. She needed an increased level of care, but there was not enough staff, and some staff members did not want to care for a dying person. There was no pain assessment and no knowledge of any suitable assessment tools. The woman's husband (who lived in the same institution) was not supported. The family was contacted only by telephone, and was not involved in the woman's care or in any decision making.

Following this poor experience, the institution set up training for staff, as well as collaborative links with the palliative care team.

## 13. DEVELOPING AND MANAGING SERVICES

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The World Health Organisation has pointed out that without policies that support the provision of palliative care, it is quite difficult for any palliative care to develop.<sup>131</sup> Ensuring that people with intellectual disabilities have equitable access to palliative care services is likely to require extra resources. They may need extra staff time, additional resources to help them communicate and additional time to manage their often complex needs. There may be a wide range of carers and professionals involved.

Palliative care services will need to consider whether they are sufficiently prepared to have patients with intellectual disabilities on their caseload.

Many people with intellectual disabilities may wish to choose to remain in their existing home environment. If this is a residential care setting, provision will have to be made to make that possible. This is likely to need advance planning, as it will require adequate resources in terms of staff and physical environment.

Data and information about the care journey of people with intellectual disabilities experience at the end of life is rarely documented. The presence of intellectual disability is not usually documented on death registers, so there are only very limited statistics to show the numbers of people with intellectual disabilities who are dying, or where or how they die.<sup>35,132</sup> It is therefore difficult to know how service improvement and development can best be addressed across Europe. More adequate data sets need to be developed in each European country to capture information around death and dying in relation to people with intellectual disabilities.

Recommendations on the development of palliative care services across Europe have been provided through published EAPC Standards and Norms<sup>133</sup> It is recommended that palliative care should be delivered on three levels:

- 1) Palliative care approach where professionals use palliative care principles in their practice;
- 2) Generalist palliative care provided by primary care and hospital based teams and teams working in nursing homes who have good basic palliative care skills and knowledge;
- 3) Specialist palliative care provided by a specialist multi-disciplinary team whose main activity is palliative care provision for people with more complex needs.



Key goals associated with these European norms for palliative care which resonate with quality care for people with intellectual disabilities at end of life are to:

- Develop and encourage continuity of care across settings;
- Ensure that good basic palliative care skills and knowledge are held within staff teams working in intellectual disability services;
- Facilitate collaborative partnerships among palliative care programmes, community hospices and a wide range of other healthcare delivery settings.

## Norm 13: Developing and managing services

**13a Policy makers should prioritise equitable palliative care for people with intellectual disabilities.**

**13b Policy makers should commit adequate resources to the provision of palliative care for people with intellectual disabilities.**

**13c Organisations providing care services for people with intellectual disabilities should plan for the provision of palliative care for them.**

**13d Organisations providing palliative care services should plan for the inclusion of people with intellectual disabilities among their case load. This includes planning for adequate space, equipment, staffing and the provision of expertise.**

### Example

#### Providing palliative care support and expertise within a residential care service (The Netherlands)

A residential care service supports over 2,000 adults with intellectual disabilities who live in small home settings throughout one county.

Following pressure from its own staff, the Executive Board agreed to

## Example

fund two of their nurses to become palliative care specialists. They have set up a team that includes a physician, psychologist, behavioural therapist and a spiritual leader. They visit people with intellectual disabilities who have palliative care needs throughout the organisation, and support their staff teams. This includes emotional as well as practical support and advice. There are strong links with the mainstream specialist palliative care services who provide additional advice and support, including specialist symptom control. Twice a year, there is a meeting with nurses fulfilling similar roles across the Netherlands, to exchange information (including the latest published research findings) and best practice.

### **A range of initiatives (Switzerland)**

Through a collaboration of local public health services and social services, and funded by local government, a number of initiatives have been set up:

- An interdisciplinary four-day training course in palliative care for staff in all residential homes, which is obligatory for at least 20% of staff.
- Obligatory 16 days' training of two link workers in a palliative care setting (one nurse and one social worker).
- Collaboration between palliative care teams and residential homes.
- A support team for people with intellectual disabilities to talk about dying and bereavement.
- A pictorial book helping people with intellectual disabilities to prepare for the death of a loved one.
- A common assessment tool, describing the behaviour of a person with intellectual disabilities.

# CONCLUSIONS

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## An invisible population

One of the most striking findings of the Taskforce has been the difficulty in establishing what happens to people with intellectual disabilities when they reach the end of life, where they live and are cared for, and where they die. To a large extent, this is due to the lack of population data on people with intellectual disabilities in almost all European countries. This problem was not unexpected, and was the main reason for the Taskforce's decision to describe *aspirational norms*: without sufficient knowledge about actual palliative care provision (or lack thereof) for people with intellectual disabilities, it was simply not possible to produce more concrete guidance or direction.

The failure to identify people with intellectual disabilities within official systems and services, including palliative care services, has serious implications. It renders this population invisible, with hidden needs. There is a risk that these needs are not seen as a priority, or even as a problem. This makes it much more difficult to engender system changes that would ensure all people with intellectual disabilities have access to palliative care support and services that meet their specific needs.

It is perhaps not surprising, therefore, that much of the good practice identified by the Taskforce depended on the dedication of individual practitioners. One of the challenges for the future is to find ways to 'scale up' good practice and ensure that they are embedded within services and systems.

## What is different about providing palliative care for people with intellectual disabilities?

One important question the Taskforce member considered was: *Why do we need specific norms for people with intellectual disabilities?*

On the face of it, the norms described in this White Paper represent best practice that would benefit all people, not just those with intellectual disabilities. There are many overlaps with the ten core interdisciplinary competencies in palliative care, as described in an earlier EAPC White Paper (see Box 7).

### Box 7

#### Core competencies in palliative care<sup>128</sup>

1. Apply the core constituents of palliative care in settings where patients and families are based
2. Enhance physical comfort
3. Meet patients' psychological needs
4. Meet patients' social needs
5. Meet patients' spiritual needs
6. Respond to the needs of family carers
7. Respond to the challenges of clinical and ethical decision-making
8. Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
9. Develop interpersonal and communication skills appropriate to palliative care
10. Practise self-awareness and undergo continuing professional development

However, it is clear from the discussions within the Taskforce, as well as the feedback and examples received from the European experts, that people with intellectual disabilities face specific barriers in accessing palliative care. All the core competencies in Box 7 are indeed applicable to people with intellectual disabilities. In practice, however, people with intellectual disabilities need extra attention and knowledge to ensure that the general standards for good palliative care are met.

It is often not so much a question of *what* needs to be done, but *how*. For this reason, the norms in this White Paper are specific in their descriptions of how each norm can be achieved, with the wider text providing further background and guidance.

### The relevance of this White Paper for the general population

'Getting it right' for people with intellectual disabilities has huge advantages for palliative care services (or any other mainstream services). Those who are able to provide good care for patients with this level of complexity and challenges, are likely to be able to provide good care for *all* their patients – including those presenting with other challenges, such as patients with dementia or mental health problems. The skills needed to meet the norms in this White Paper are transferable. The way in which palliative care is provided for people with intellectual disabilities could thus be a benchmark for palliative care services everywhere.

Palliative care services could start by acknowledging that some of the problems faced by people with intellectual disabilities are unique to this population only by degree. Preparing to meet those needs as a matter of course would benefit a much wider group of patients. For example, making palliative care services routinely hospitable in terms of health literacy would benefit not only people with mild and moderate intellectual disabilities, but also the much broader group of patients with low literacy skills or foreign language barriers.

## Cross-fertilisation of expertise

The importance of collaboration (see Norm 8) is not limited to local collaboration between disciplines. The establishment of the EAPC Taskforce on Intellectual Disabilities has highlighted the benefits of learning from each other, both within and across national boundaries.

The *Palliative Care for People with Learning Disabilities Network* (<http://www.pcpld.org>), which has a strong UK focus, has spearheaded such cross-fertilisation of expertise in a variety of ways, including online signposting of resources and the establishment of an annual award for best practice in the provision of palliative care for people with intellectual disabilities. However, as different European countries will face different challenges, there will be enormous benefit in ‘comparing notes’ with practitioners in other countries, sharing both difficulties and best practice in a range of settings, on an on-going basis. This could be done by virtual means (such as an online depository for resources and best practice examples) as well as physical means (such as establishing regular European forums or meetings, organising exchange visits or expert lecturing and teaching across national boundaries).

Currently, many of the helpful literature and resources are in the English language, as is evident from the examples in this White Paper. This may simply be because the English-language resources were more easily accessible to the authors, or it may be a genuine lack of other-language resources. If the latter is true, this is an area for further development.

# RECOMMENDATIONS

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In order to improve palliative care provision for people with intellectual disabilities across Europe, it is essential to acknowledge that this is indeed a problem that must be addressed. The Taskforce believes that this EAPC White Paper is an important first step.

The following would make a significant contribution to ensuring that people with intellectual disabilities across Europe have their palliative care needs met. It is worth noting that the Taskforce has produced this White Paper without funding, but to take the work forward and achieve some of these recommendations, funding will be essential.

- **Palliative care services actively reaching out** to *find* the population of people with intellectual disabilities within their catchment areas.
- **On-going exchange** of experiences, expertise and best practice on a range of 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
  - Internationally within Europe
- **International exchange of expertise** could be achieved through:
  - An on-going, regularly updated online multi-language resource, signposting relevant literature, resources, contacts etc.
  - A dedicated person or team who can act as a “point of contact” for palliative care provision to people with intellectual disabilities in Europe. Their role could include: collating relevant information and resources (see above online resource); facilitating contact between different services in different countries; organising exchange visits; signposting training opportunities.
- **Further research** (see below).

## Further research

The research evidence in this field is limited. Further research is essential in order to understand and address the challenges involved in meeting the needs of people with intellectual disabilities at the end of life. There are many research questions to be answered.

A group of 17 researchers in the field of palliative care and intellectual disabilities, representing six European countries, met for two days in February 2015 (Zürich, Switzerland) to discuss the current state of empirical knowledge as well as this White Paper. They identified the following main research priorities:

### 1. What are the issues around end of life decision making for people with intellectual disabilities across Europe?

There are international concerns around the following issues, which may have a profound effect on the palliative care for people with intellectual disabilities and need further investigation:

- the profile of end of life decisions (including the decision to start a palliative care pathway; withholding or withdrawing life prolonging treatment);
- the methods and processes of decision making (including issues around communication and patient participation);
- the factors influencing end of life decision making;
- the possibilities of developing a decision making framework.

### 2. “Mapping”: What is the current state of affairs around palliative care provision for people with intellectual disabilities in Europe?

In order to address inequalities, it is important to gain insight into the scale of the problem. Studies are needed to investigate the following, and contrast it with data for the general population:

- where people with intellectual disabilities die and who supports them at the end of life;
- to what extent they access mainstream services, including palliative care services;
- current relevant national and international laws and policies, and their effect on palliative care provision for people with intellectual disabilities;
- the influence of societal attitudes towards dying and towards people with intellectual disabilities.

### 3. What are the challenges in providing high quality palliative care for people with intellectual disabilities across Europe?

In order to address such challenges, the following research questions needs to be addressed:

- What are the challenges in achieving the consensus norms set out in this White Paper, in a sample of European countries?
- What are the perspectives and experiences of people with intellectual disabilities, families, carers and professionals with regards to palliative care for people with intellectual disabilities?

### 4. Developing outcome measures for palliative care of people with intellectual disabilities

In order to be able to compare and contrast palliative care for people with intellectual disabilities, (a) between settings/regions/countries and (b) in comparison with palliative care for the general population, a common European instrument is needed for measuring the quality of palliative care provision. This could be an adaptation of measures that currently exist for the general population, and/or development of new measures.

### And finally...

We hope that this White Paper has highlighted the importance of having a specific focus on the palliative care needs of people with intellectual disabilities. We have been encouraged by the enthusiasm and commitment of Taskforce members and experts across Europe.

In the light of this White Paper, we would like to encourage National Associations, key stakeholders, palliative care services, intellectual disability services and all individual practitioners to examine their own practice and policies, and make the changes required in their own countries in order to meet the Norms set out here.



# ACKNOWLEDGEMENTS

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The Taskforce would like to thank:

- **All members of the ‘group of experts’** (see Appendix), who sent out the online survey across their own networks and collected best practice examples, and **all other respondents** of the online survey.
- **The EAPC Board of Directors** for their encouragement and support.
- **Prof Sheila Payne and Prof Chris Hatton**, for their constructive feedback on an early draft of the White Paper.
- **Faculty of Health, Social Care and Education at Kingston University & St George’s University of London** for providing practical support, including the administration of the online survey, support for the analysis and support for the writing of the White Paper.

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## APPENDIX: MEMBERS OF THE GROUP OF EXPERTS

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AUSTRIA	Sonja Thalinger
BELGIUM (Flamish)	Bea Maes
BELGIUM (Flamish)	Guy Hannes
BELGIUM (Wallonian)	Ingrid Foucart
BELGIUM (Wallonian)	Anne Bindels
BOSNIA HERZEGOVINA	Melita Murko
CZECH REPUBLIC	Marie Macková
CROATIA	Ljiljana Igrić
CROATIA	Vesna Vučevac
DENMARK	Per Holm
DENMARK	Tove Svendsen
FRANCE	Michelle Rustichelli
GERMANY	Rahmona Bruhn
GERMANY	Hubert Jocham
ICELAND	Tora Torarinsdottir
ICELAND	Hanne Sigurjónsóttir
ITALY	Fabrizio Fea
ITALY	Raffaella Dobrina
ITALY	Raffaella Antonione
NETHERLANDS	Annemieke Wagemans
NORWAY	Lisa Ingebretsen
REP IRELAND	Mary McCarron
POLAND	Jacques Scheres
POLAND	Piotr Krakowiak
SPAIN	Teresa Garcia Baquero
SPAIN	Miguel Fombuena
SPAIN	Benito Enric
SWEDEN	Eva Flygare Wallén
SWITZERLAND	Laetitia Probst
SWITZERLAND	Doris Moser
SWITZERLAND	Monika Wicki
UK	Pauline Heslop
UK	Amanda McKie
UK	Iain Lawrie