



In this section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

## Palliative Care for People with Learning Disabilities Network

Founded in 1998, the Palliative Care for People with Learning Disabilities (PCPLD) Network fosters exchange, collaboration and the dissemination of best practice in order to provide the best possible support for this patient group at the end of life.



**Irene Tuffrey-Wijne**, Chair, PCPLD Network

Around 2.5% of the population have intellectual disabilities (in the UK also known as 'learning disabilities').<sup>1</sup> They are among the most vulnerable and marginalised people in society. Historically, people with intellectual disabilities were often hidden or sent to live in long-stay institutions, away from the world. Thankfully, things have changed in recent decades. Many people with intellectual disabilities now live in the community, either with their families, alone with support, or in small-scale residential settings, depending on mainstream healthcare services. People with intellectual disabilities are living longer, with many more now dying from age-related conditions, including cancer.<sup>2,3</sup> This means that an aging and vulnerable population now relies on mainstream health services, including palliative care services, to meet their needs when they become terminally ill.

### We need to supplement our own expertise with that of others

### Who are people with intellectual disabilities?

People with intellectual disabilities have:

- Impaired intelligence (intelligent quotient [IQ] below 70)

- Reduced ability to cope independently
- Disabilities that started in childhood, with a lasting effect on development.

### Why a network?

For many professionals, supporting someone with intellectual disabilities at the end of life is a step into the unknown, which can provoke anxiety and fear. They worry. Common thoughts might include: 'I don't know anything about dying!' or: 'I don't know anything about people with intellectual disabilities! What if I can't understand them, or communicate with them, or assess their symptoms and problems?'

We may well wish to leave such care to people who know how to support this group properly. We may well wish for an expert. It was, however, the realisation that nobody is an expert and that we need to supplement our own expertise with that of others, which led to the founding, in the UK in 1998, of a new network. A small group of intellectual disability and palliative care professionals came together, concerned by their experience that people with intellectual disabilities who were facing a life-limiting illness did not seem

to access the same services or receive the same quality of service as the rest of the population. These professionals established the National Network for Palliative Care of People with Learning Disabilities (NNPCPLD), which later changed its name to the Palliative Care for People with Learning Disabilities (PCPLD) Network.

## Aims of the network

The aims have not changed much since the early days of the PCPLD Network. The network brings together service providers and carers working for the benefit of people with intellectual disabilities who have palliative care needs, in order to provide the best possible support for this group. It is based on the belief that people with intellectual disabilities should receive all the co-ordinated help they need in living their lives to the full until the end of their lives. The PCPLD Network is part of the network of professional associations supported by Help the Hospices. I have been its chair since 2008,

## We now have growing numbers of palliative care professionals joining

when I took over from Linda McEnhill who had founded the network.

## Our members

We are a membership organisation with over 300 members. Membership is free and members are kept up to date with developments and events. Our membership shows that the issue of palliative care for people with intellectual disabilities has now entered the mainstream. Whereas, in the past, the vast majority of our members were staff working in intellectual disability services, we now have growing numbers of palliative care professionals joining us. Palliative care services may previously have had little experience of, and exposure to, people with intellectual disabilities, but this is clearly changing. Most of our members live and work in the UK, but we also have growing numbers of people joining us from continental Europe and beyond. We have a steering committee made up of professionals from across services, a family carer and a member with intellectual disabilities.

### Box 1. Examples of excellence: the winners of the Linda McEnhill Award 2012

■ **Dr Ruth Brown**, who works at the Isbister Centre, a palliative care centre in Hertfordshire, won the Linda McEnhill Award 2012 in the category 'New development/overall excellence in end-of-life care provision'.

Dr Brown has helped the specialist intellectual disability nurses in Hertfordshire to support people with an intellectual disability in the last year of their lives. She has also been instrumental in a county-wide multidisciplinary referrals group. Every month, nurses and social workers from community intellectual disability teams meet with palliative care specialists to discuss service users who are at the end of life or expected to die within a year. The group follows nationally established frameworks and pathways and has developed these to suit the needs of people with intellectual disabilities.

In Hertfordshire, each person with intellectual disabilities is now offered the opportunity to be involved in end-of-life planning, with a clearly recognisable folder for their health action planning and communication tool. Dr Brown developed a local resource pack, making use of national best practice documents.

She also organises training for community intellectual disability nurses.

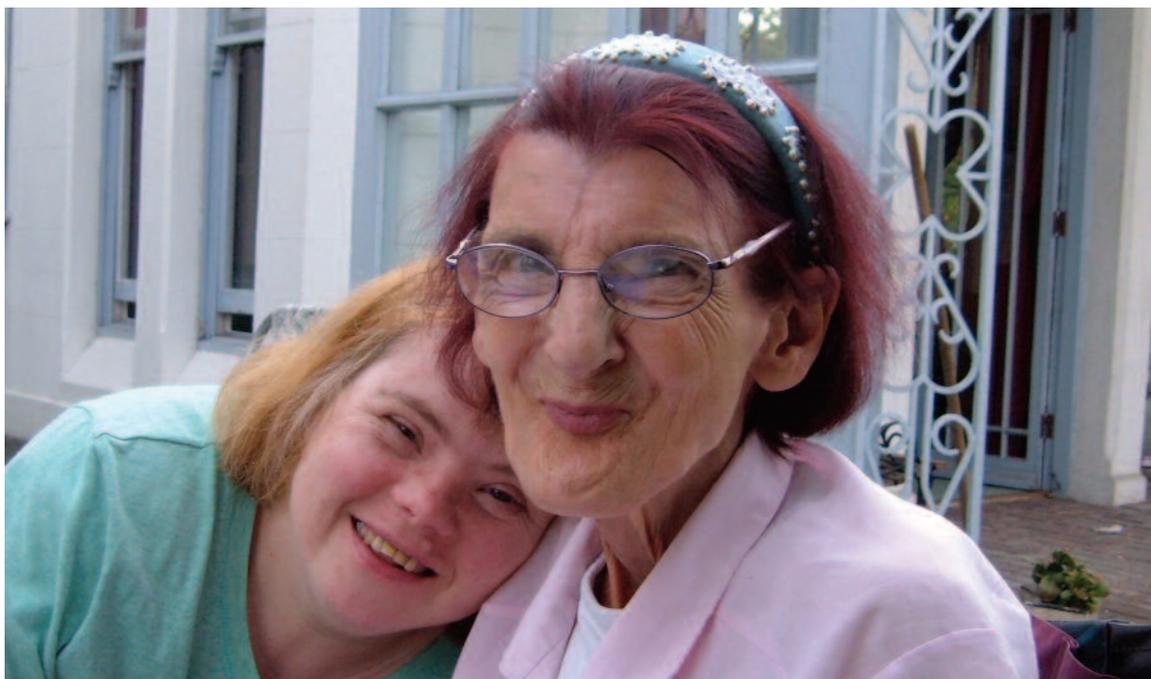
■ **Janice Byford**, family carer, and **Wendy Broom**, Clinical Nurse Specialist (CNS) for Older Persons with Intellectual Disability in Cornwall, won in the category 'Outstanding end-of-life support of an individual with intellectual disabilities'.

Ms Byford is the mother of Elaine, who had Down syndrome and lived at home all her life. During her last years of life, Elaine developed Alzheimer's disease. She was referred to the memory service where Ms Broom is the CNS. Ms Byford not only helped Elaine to remain at home in a remarkable way, but she also provided the professionals with insights on how it felt to be the mother of a daughter who was losing all her skills. While it may have seemed obvious to them that Elaine needed their professional services, Ms Byford helped them to see how difficult and distressing this could be for families. Ms Byford did not find it easy to accept the suggestions of the memory service. This prompted the professionals to reflect on what they offered families. As Elaine's health deteriorated, Ms Byford found ways to

support her daughter while keeping her at the centre of family life. For the last 18 months of her life, Elaine was cared for in bed, downstairs in the conservatory, where she was surrounded by brightly coloured cushions and parasols. Carers came three times a day to carry out personal care and Ms Byford supplemented this by meticulous attention to detailed care and wholesome cooking in a way only she could do. The district nurse who had predicted that Elaine's pressure sore was the beginning of the end had to review her expectations when it eventually healed after ten months of diligent care and attention. Ms Broom provided invaluable support to Ms Byford, understanding her needs as a family carer. She helped to get all the right services in place at the family's home when Elaine deteriorated during a weekend. Elaine died at home with her family around her.

This story demonstrates how families and professionals can work together, each bringing skills that do not replace but complement each other. In order for this to happen, it needs not only a very special family carer, but also a professional who is willing to be challenged ■

■ The PCPLD Network is based on the belief that people with intellectual disabilities should receive all the co-ordinated help they need in living their lives to the full until the end of their lives



PCPLD NETWORK

## What does the network do?

### Networking

We offer opportunities for networking, collaboration, exchange of ideas and development of 'best practice'. In some areas in the UK, there are local groups that hold regular meetings. Our website<sup>4</sup> is an important place for sharing best practice; it contains a growing pool of materials, including easy-read and pictorial information for people with intellectual disabilities. We are looking to develop it further in the year ahead – with a view to include a discussion forum for members.

### Training

We host a major conference at least once a year and support local training opportunities. The conferences are hugely inspiring events. It is so important to meet new people and old colleagues, and realise that we do not have to work in isolation.

### Promoting best practice

The PCPLD Network recognises and shares best practice through the annual Linda McEnhill Award, given to individuals or teams who have made an outstanding contribution to end-of-life care of people with intellectual disabilities. Box 1 outlines the contributions of the 2012 winners. It is striking that best practice almost always implies collaboration between all the services involved, an emphasis on inclusion, careful listening to the patient's needs, concerns and wishes, and the provision of support for the family. The network also contributes to the development of national and international best practice guidelines.<sup>5,6</sup>

## Conclusion

The way palliative care services are integrated within intellectual disability services, and the readiness of palliative services to provide good care for patients who have intellectual disabilities, will be different in every country. How people with intellectual disabilities are supported at the end of life is dependent on the place people with intellectual disabilities have in society and their level of integration; on the training and attitudes of those who provide care for people with intellectual disabilities; and on the availability of palliative care services for the general population

In the UK, there is a strong emphasis on involving people with intellectual disabilities in all aspects of their lives, and that includes end-of-life care. The PCPLD Network has undoubtedly played a part in bringing professionals from diverse backgrounds together, and in helping those working with people with intellectual disabilities at the end of life to feel less isolated ■

### Declaration of interest

The author declares that there is no conflict of interest.

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