



The Palliative Care for People with Learning Disabilities Network (previously the NNCPLD) was established in 1998. It brings together service providers and carers working for the benefit of people with learning disabilities who have palliative care needs. It is based on the belief that people with learning disabilities should receive all the co-ordinated help they need in living their lives to the full until the end of their lives.

Contact details
Email: info@pcpld.org

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Editorial

In May, we gathered for our Spring Conference in Devon (see page 4). The theme was “Excellence in end of life care for people with learning disabilities”. A hall full of people listened to a line-up of wonderful speakers who shared their examples of good practice. Many of us came away with a feeling of hope and inspiration. We can’t deny that for most of us (and that must include people with learning disabilities), dying can’t ever be something to look forward to. But here, at least—and at last—was a day where we could really begin to believe that it was possible for things to be better.

Then, in June, Mencap published its latest survey of healthcare services for people with learning disabilities. They found that 45% of doctors and a third of nurses had witnessed learning disabled people receiving poor care. It is clear that we cannot be complacent. People with learning disabilities are still

getting a rough deal when healthcare is concerned—and that includes healthcare at the end of life. Yes, things have improved in the last decade, but there is still a long way to go. We need our champions (that’s you!), and we need to continue to share our positive experiences and our learning.

New groups are popping up to help with this: there’s now a group in Devon, and a rejuvenated group in Wiltshire, BANES and Bristol (see p. 5). We are also contemplating setting up a continental European branch...

I am delighted that we have now launched our new website (www.pcpld.org). Do have a browse, and let us know what you think!

Dr Irene Tuffrey-Wijne
(Chair)



Latest News

Macmillan Nurse for People with Learning Disability wins "Palliative Care Nurse of the Year" Award



Dorothy Matthews, who is a Macmillan nurse for people with learning disabilities at Northumberland Tyne and Wear NHS Trust (Northumberland) and St. Oswald's Hospice (Newcastle-upon-Tyne), has won the prestigious "International Journal of Palliative Nursing" Palliative Nurse of the Year 2010 Award.

Dorothy is a founder member of the PCPLD Network, and she is always eager to share her experiences and knowledge and likewise learn from the experiences of oth-

ers. This award recognises not only her inspirational contribution, but also the importance of providing excellent end of life care to people with learning disabilities.

During many years working with people with learning disability Dorothy's interest in palliative care evolved from caring for those with life limiting and life threatening conditions. She was involved in developing a palliative care unit for people with learning disabilities at Northgate Hospital in 1999. She was also part of the development of a clinical tool to identify and document distress in people with alternative communication, the Disability Distress Assessment Tool (DisDAT) (www.disdat.co.uk) a much-needed tool enabling identification of distress in people with severe communication problems. Dorothy was appointed to her current role in 2004. The role has three

main elements: clinical, developmental and training. These include health facilitation, research, advocacy, coordinator and a support network for others, hence developing a seamless service for people with learning disabilities who have developed life threatening and life limiting illnesses, such as cancers and dementias. She has worked to develop partnerships with others across the health and social care community in order that the palliative care needs of people with learning disabilities can be met.

Dorothy works with professionals in palliative care services to ensure that, wherever the patient is living, whether in their own home, in a small group home, in residential or nursing home they access appropriate interventions, working collaboratively in this way ensures that clients their families and carers have access to services which are tailored to meet their individual needs. She has also contributed to the writing of papers and book chapters.

Many congratulations to Dorothy on her fantastic achievement!

Nominations now open for the Linda McEnhill Award 2010

Do you know someone whose work to improve end of life care for people with learning disabilities should be recognised? Why not nominate them for this year's award? You can also nominate yourself, or your team or group.

Closing date: 31st August 2010

For a nomination form, contact award@pcpld.org
Once our website has gone live, you will be able to apply online: www.pcpld.org

New website launched!



PCPLD Network
Palliative Care for People with Learning Disabilities



Photo: Mencap 2010

Promoting excellence and networking in end of life care for people with learning disabilities

www.pcpld.org



PCPLD Network
Palliative Care for People with Learning Disabilities



For anyone who is interested in promoting excellent palliative and end of life care for people with learning disabilities.

Our members are mostly professionals, but also include some (family) carers, and some people with learning disabilities.

For further information:
info@pcpld.org

www.pcpld.org

The PCPLD Network is a professional association of help the Hospices.

Supported by Mencap



The voice of learning disability

Conference Report

Excellence in end of life care for people with learning disabilities

Buckfast Abbey, Devon

10th May 2010

Michelle Brooks reports on an inspirational conference

The conference took place in the beautiful surroundings of Buckfast Abbey on a glorious sunny day. It amplified the uplifting and restorative qualities the day imparted to myself and I think to most of those attending. Qualities so important for those involved in end of life care. All the presentations and workshops contained insight, passion and the application of much rich experience into developments that exemplified outstanding examples of best practice.

The day was very full with four presentations and a choice of workshop before lunch, and a further four presentations after a most delicious lunch.

We began with a clear and extensive overview of PC for people with learning disabilities by **Linda McEnhill** illustrating what had been

achieved and how far there is yet to go. In looking at the WHO 2004 definition of palliative care she stressed three key words — physical, psychosocial and spiritual — and reminded us that we have made strides in addressing the first, inroads into the second but perhaps we are overlooking the special importance of the latter. I will remember in particular the notion of “total pain” that relates to an individual’s narrative biography, and what can help us to think holistically about each person’s individual needs at end of life. She ended with outlining the steps to excellence and what we need for the journey: *Curiosity; Listening and learning; Travelling light* – leave aside pre conceptions and remember the resilience of people with learning disabilities! This is something that I will hold onto as important in all aspects of working with people with learning disabilities at whatever stage they are in their life.

We looked at the End of Life Care Checklist with **Lorraine Youdle** from

her Learning Disability Team in Devon, who were Highly Commended at the 2009 Linda McEnhill Award. What is memorable here was the passion and commitment that stems from the overlay between professional and personal towards extending the best possible care at end of life, using the three elements embedded in the checklist: *Emotional/Physical/Practical*. They are eager to promote dissemination of this work so download their presentation and help them get it out there!

Dr Corinna Midgley was an inspiration. Her presentation “Collaborative Working: Palliative Care and Learning disabilities” came from **St Francis Hospice**, winner of the Linda McEnhill Award 2009. They set about learning from practice where things were not working, looking to learn from the learning disability community about what was needed. This brought together specialists in palliative care with frontline learning disability staff. It was a journey begun in 2007 at a Help the Hospice conference workshop, and culminated through partnership working in a revised hospice referral form which now picks up vulnerable adults and their support network. The hospice has created a fast track pathway engaging the circles of support; provided and created teaching, resources and tools for all staff to promote confidence and competence; and conducted a rigorous monitoring and audit. They are well on their way in the planning to take the work forward, to support the momentum and spread of the



good working practice.

We heard a joint presentation on "Reflections on supporting someone with complex needs to die at home, Sharing the lessons" a joint piece of work between **Dorothy House Hospice** and **Wiltshire Learning Disability Service** and the staff of one residential service. Their open honest shared experience around one man's journey and the multi professional partnerships of those supporting each other and his journey really brought home the beauty and rewards of our work.



Three workshops followed each providing insights and opportunities to think and talk about important issues around 3 distinct areas:

- Young people transition and end of life care with **Maggie Coombes** from Douglas House Hospice
 - Dementia and LD: keeping relationships alive with **Michelle Brooks**, RESPOND
- "Death by Indifference" – Love, loss and dependence with **Beverly Dawkins**, MENCAP and **Noelle Blackman**, RESPOND.

After a gorgeous lunch we looked at

our new all dancing all singing and accessible website, down to the hard work, skills and dedication of **Irene Tuffrey-Wijne**, the Chair of PCPLD Network. Irene spoke later of her moving research undertaken with people with learning disabilities and written up in her book "Living with Learning Disability, Dying with Cancer".

We had a networking workshop where delegates had a chance to meet with others from the same region. We came together finally to sum up the day and say goodbye to a day to be long remembered where I

am sure each person left with more than they came with and re armed with renewed energy ideas and inspiration to last at least till the next conference.

Thanks to ALL involved in organising this wonderful conference, for being such an active presence as a participant and for those who couldn't make it for your absent support.

Michelle Brooks
RESPOND, London

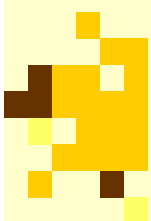
New and Rejuvenated Area Groups

Dorset

A new group met for the first time on 15th June 2010 in Wareham. Jo Findlay, a primary care facilitator for people with learning disabilities, took the lead. She attended the conference in Devon and felt inspired to get things going in Dorset. There was good attendance and great enthusiasm. A date has been set for the next meeting (14th September, 10.30-12.30), where the group will look into pathways for people with learning disabilities at the end of life. For further information and details, contact Jo: tel **01305 368010**, email dorset@pcpld.org

Wiltshire, BANES and Bristol

This used to be the Wiltshire group, but has now rejuvenated itself, following an inspired networking session at the conference in Devon. The group will meet on 8th September. For further details, contact Amelia Jones, email wiltshire@pcpld.org





How to join

Members of the PCPLD Network can attend meetings of regional groups. They receive a regular newsletter and reduced fees to UK study days, and they have voting rights within the NNPCPLD.

Annual membership costs:

£25 (individuals)

£65 (group of 3 members at the same address)

Free for anyone unable to pay

For a membership form: contact info@pcpld.org
Tel. 07977 260967

Area groups meetings

These meetings are open to anyone who is interested in meeting others in their local area to discuss issues around palliative care for people with learning disabilities. For further details, contact the area representative.

Wiltshire. BANES and Bristol

When: 8th Sept 2010

Where: Venue to be confirmed

Contact: This is a newly rejuvenated group. For further info, contact Amelia Jones, wiltshire@pcpld.org

London & Home Counties

When: 8th Sept 2010, 2-4pm

Where: Respond Office (near Euston Underground Station in London)

Contact: Noëlle Blackman, london@pcpld.org

Yorkshire

When: 6th Oct 2010, 10am-12.30pm

Where: Kirkwood Hospice, Huddersfield

Contact: Amanda McKie, yorkshire@pcpld.org

Forthcoming Conference

PCPLD Network

19th November 2010

**Springhill Hospice
Rochdale (nr Manchester)**

People with learning disabilities, dementia and end of life

**Details to be confirmed
Bookings from September 2010
Keep an eye on our website!**

East Midlands (incorporates Stoke/ Derby/Nottinghamshire)

When: 18th October 2010

Where: Derby (venue to be arranged)

Contact: Deb Cooper, midlands@pcpld.org

Dorset

When: 14th Sept 2010, 10.30am-12.30pm

Where: Purbeck Day Centre, Wareham

Contact: Jo Findlay
dorset@pcpld.org

Journal Watch: newly published papers

Whittington, J. (2010) **A fast track path improves access to palliative care for people with learning disabilities.** *Nursing Times* 106 (19), 13-14.

This paper describes the work at St Francis Hospice, which won the Linda McEnhill Award.

Tuffrey-Wijne, I. (2010) **Exploring the lived experiences of people with learning disabilities who are dying of cancer.** *Nursing Times* 106 (19), 15-18.

Tuffrey-Wijne, I., Bernal, J., and Hollins, S. (2010). **Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: findings from an ethnographic study.** *European Journal of Cancer Nursing* 14(3):224-230.

Wagemans, A., van Schroyen Lantman-de Valk, H., Tuffrey-Wijne, I., Widdershoven, G., and Curfs, L. (2010). **End of life decisions: an important theme in the care for people with intellectual disabilities.** *Journal of Intellectual Disability Research* 54(6):516-524.