



Network News

Network News Volume 2, Issue 1

February 2010

The Palliative Care for People with Learning Disabilities Network (previously the NNCPD) 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.

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Editorial

Welcome to our first newsletter of this decade. The first thing you will notice is that our name has changed from NNCPD to the PCPLD Network. It has been evident for several years that we needed to drop "National" from our name, as our work is not limited to the UK. We have had good links with people in Ireland, for example. Members voted for the PCPLD Network as their preferred new name. Hence the new logo!

This issue is packed with good news. I am delighted to introduce the winners and runners-up of the Linda McEnhill Award 2009. It was clear from all the nominations that there is a lot of excellent work going on across the UK, with staff from all fields working hard to improve end of life care for people with learning disabilities.

The award was won by St Francis Hospice in Romford. Lorraine Youdle, learning disability in Devon, received a special commendation. On the next pages you can read about their work, and that of the runners-up.

If you want to hear more about such excellent new initiatives in palliative care for people with learning disabilities, why

not join us at our forthcoming conference in Devon on 10th May, where "Excellence" will be our theme? Details on the back of this newsletter.

There is an inspiring "Real Life Story" on page 4, describing how one team managed to give support to Frank who died at home. On page 6, you can read how the Northern Ireland group got off to a flying start.

Finally, I am delighted to welcome our new vice-chair, Amelia Jones (known as Milly). Milly has been running the Wiltshire Area Group for a number of years.

I would also like to say a huge thank you to the outgoing vice-chair, Noëlle Blackman, who has held the post for over 10 years. Noëlle has been a tremendous support and inspiration for the Network, and continues to contribute as a member of the steering group and as co-ordinator of the London & Home Counties Area Group.



Dr Irene Tuffrey-Wijne (*Chair*)

Our new email address: **info@pcpld.org**

Our email system has been troublesome for a while, so if you've not managed to get through, do try contacting us again at our new address.

...and watch this space for the launch of our new website:
www.pcpld.org

The Linda McEnhill Award 2009



The winner

The Linda McEnhill Award 2009 was won by **Saint Francis Hospice** in Romford, Essex. Saint Francis Hospice had initiated a project to improve care for people with learning disabilities who have advanced life-limiting illness. The judges were impressed with the hospice's sustained commitment to meeting the needs of people with learning disabilities, leading to changes in practice and excellent collaboration with local learning disability services. New initiatives included:

- Changes in the hospice referral form
- Fast-tracking patients with learning disabilities
- Making resource packs and communication tools available to staff
- Staff training
- Identifying among hospice staff 'champions' for adults with learning disabilities
- On-going regular collaborative meetings

These changes have led to tangible improvements in the support of people with learning disabilities at the end of life. The judges felt that Saint Francis

Hospice has set a bench-mark for palliative care services everywhere.

In her acceptance speech, palliative care nurse specialist Janet Kirby explained how the hospice had worked towards this:

"In November 2006, Jane Sutherland (Director of Patient Services) and Corinna Midgley (Medical Director) attended a conference at Help the Hospices on widening access for marginalised groups to palliative care. On return from the conference, they recognised their shortfalls in knowledge and confidence but had a passion to bring best care to those who need it. They invited local experts working within learning disabilities services in the community and colleagues within the Hospice to join a process mapping exercise at the Hospice, using the Help the Hospice Widening Access model.

The process mapping exercise identified a huge gap in understanding of support services and supportive material for people with learning disability and a huge gap in understanding of specialist palliative care services available for support through difficult times. Several key action points emerged from the mapping, along with a real commitment to work together – a working group was formed. The commitment by everyone in the group to work together on this project was exciting and inspiring – it has resulted in some excellent developments.

- A change to the hospice referral form to ensure that people with vulnerabilities such as learning disability are highlighted.
- A greater knowledge and understanding by learning disability staff of hospice services, and better knowledge of when a referral would be appropriate.
- A greater understanding of the challenges people with learning disability have, and how to best support them.
- The creation of resource packs to support the hospice team, of common conditions

and communication tools.

- The development and implementation of a Fast Track Pathway towards early face to face contact with the client and their key worker.

To mark this joint working initiative and to publicise our work together, the hospice held an excellent one day Conference – 'Learning Disability; Ensuring Excellence and Empowerment in End of Life Care'.

The initial enthusiasm has not diminished... We presented posters at the European Association of Palliative Care Congress in Vienna (May 2009) and at the Help the Hospice Conference in Harrogate (November 2009). An audit of 8 patients referred to St Francis Hospice with learning disability in the last 16 months has just been completed. This reveals real benefit from the changes made, with recognition that there are areas for improvement and future development.

We would particularly like to acknowledge the work and support that Jane Whittington (Community Learning Disability Nurse) and Peng Ma (Learning Disability Health Care Co-ordinator) have given to the project and thank them for nominating St Francis Hospice for this Linda McEnhill Award."



Janet Kirby receives the Linda McEnhill Award on behalf of St Francis hospice

Highly commended

Lorraine Youdle showed how one person's drive, commitment and determination can inspire everyone to provide better care. She received a special commendation.

Lorraine is a learning disability nurse in Devon with a special interest in end of life care. She has become well known in her local area for her knowledge and expertise.

When Lorraine moved into a community based service, her team encountered a high number of people with learning disabilities who had life limiting conditions, dementia, and palliative care needs. In addition, they found that carers and families were struggling with relatively new issues of an ageing population.

The community team began meeting regularly to address someone's changing care needs, involving a range of people involved in that particular person's care. As their understanding grew, Lorraine led a special interested group which developed an End of Life Checklist Tool, to try and ensure a high quality care for people with learning disabilities. This is now being used and piloted by learning disability nurses throughout Devon.

Many congratulations to Lorraine for her fantastic achievements. More about Lorraine's work will follow in a later newsletter.



Irene Tuffrey-Wijne, Lorraine Youdle, Janet Kirby and Noëlle Blackman

Runner-up

Close runner-up was the **Advance Decision Making Tool Party** in Kent, a collaboration between EllenorLions Hospice Team, Oxleas NHS Trust CLDT and Mcch Society Ltd. This joint piece of work was to address the need for considering end of life care issues for adults with learning disabilities who lacked capacity. The group devised a Forward Planning Tool for health care decisions. It incorporates relevant aspects of the Mental Capacity Act 2005, and evidence of best interest consideration.

The tool has already had a positive impact on the care of several people with learning disabilities who were dying. The judges were impressed with this work, and felt that it could benefit people not only in Kent, but had relevance for people with learning disabilities across the UK.

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



Lorraine Youdle (left) receives a Highly Commended certificate

Keeping Frank at home

Real life story

When Frank was diagnosed with lung cancer, Macmillan Nurse Christine Reddall was called to his care home to offer support. She was impressed by how home manager Lisa Quinlan and her team managed to care for him. Here, she tells Frank's story: an example of outstanding care.

I recently worked with a small team of untrained nurses who found themselves in a very unusual situation for their service. Used normally to promoting, as far as possible, 'normal living' for their clients, they suddenly found themselves caring for someone who was going to die from a cancer diagnosis.

Frank

Frank (not his real name) was a 42 year old man with severe learning difficulties. He lived in a care home with six other people with similar disabilities, supported by carers 24 hours round the clock. Frank had been in institutional living most of his life and he was settled, comfortable and much loved by all the carers and the other clients.

Cancer diagnosis

Leading up to Frank's diagnosis, his carers noted that he seemed unwell. He was losing weight, seemed breathless at times and had a cough that was not responding to antibiotics and cough medicine. Not content with how Frank was, they badgered his GP with their concerns. Eventually, following tests Frank was found to have lung cancer. A decision was taken between the medical professionals, his next of kin and his carers that it would not be in Frank's best interests to do further investigations or to give active treatment such as radiotherapy or chemotherapy, as he became very distressed with anything or anyone medical.

Frank's carers very quickly decided that they were going to do everything possible to enable Frank to remain in his home, in the surroundings he knew with the people who he looked upon as 'his family'.

Coping with pain

They decided that as well as keeping his routine as normal as possible, they needed to be observant to any changes that may indicate he was uncomfortable or in distress. Frank did not often complain of pain, and when asked about his health he would often become quite defensive, saying 'I'm alright—there's nothing wrong with me.' They were concerned that he would be in pain and they would not know, so together, they discussed the use of a pain/distress tool, and had a look at some of the well known charts. However, they felt that such a chart might be difficult for the carers to interpret, so they decided to talk together and come up with something that would work for all of them.

Frank's Book

After discussion, they came up with a 'Frank's Book' and each of them wrote in

it as and when they wanted if they had any concerns, or if they felt something was not quite right. Because the carers knew Frank so well, they were by far the best people to detect any changes in him. Frank trusted them, whereas he had a real fear of anybody medical. Together, led by Lisa, the carers developed a 'palliative care resource file' that included details such as contact numbers, his end of life wishes, and information on symptoms. I got very used to one of them phoning me just to check something out, and often an answer over the phone was all that was



Frank's carers provided exemplary care for Frank, his family and each other

needed. I was amazed at how quickly this team of carers adapted to the situation in front of them, whilst still allowing time to care for their other 'healthy clients'.

Becoming more ill

Over the 18 months Frank lived following his diagnosis, his needs gradually became more complex. He developed haemoptysis (*vomiting blood*) and was at risk of a large bleed; his pain and breathlessness escalated requiring bigger doses of morphine; he lost a large amount of weight and subsequently developed pressure sores despite the very best efforts of all concerned. Towards the end of his life, Frank had a syringe driver set up (*continuous infusion of drugs through a needle under the skin*). Though the care of the syringe driver was managed by district nurses, Frank's carers were indispensable—being with Frank whenever it was changed to ensure that his needle phobia was not an issue for him or the nurses. They developed brilliant strategies!

Supporting Frank's friends

Frank defied all predictions as to when he was likely to die, and though incredibly frail and ill, he continued to surprise us all with his strength of mind. As well as caring for Frank, the carers had the added burden of helping to support one of their other clients who was very close to Frank. Doreen and Frank had known one another for years and she would mother him, and spend a lot of time sitting with him.

Coping with an uncertain future

From Frank's diagnosis through to his death, and beyond, Frank's carers, led by their manager Lisa, provided exemplary care for Frank, his family and each other. They attended group sessions to listen and learn about what was happening to, and what was likely to happen to Frank. Though scared, they prepared themselves for

the event of a major bleed and wrote out an end of life plan based on Frank's best interests, knowing that he would not want to be moved away from his home.

Dying

On the night of Frank's death, all his main carers were with him. Again, I was amazed (and I think they were to) at how well they coped. They decided to me afterwards how it seemed so natural and right for them all to be there and how they were able to make sure he was clean and 'comfortable' before the funeral directors came. They woke Doreen and supported her as she said goodbye.

Sharing experiences

Since Frank's death, Lisa has helped me in my role as by accompanying me to other homes who find themselves in a similar situation—caring for one of their clients with a life limiting disease. She also provides support and advice over the phone, and shares her paperwork with others. As a Macmillan Nurse with many years' experience in palliative care and none in learning disability, I believe that Lisa and her team have demonstrated an excellent level of care for Frank. The impact of their caring is already beginning to impact on others who are caring for

"I got very used to one of them phoning me just to check something out, and often an answer over the phone was all that was needed."

Macmillan Nurse
Christine Reddall

people in similar circumstances to Frank.

Do you have a story or experience to share? Contact Irene on ituffrey@pcpld.org

Picture taken from 'Am I going to die?' www.rcpsych.ac.uk/publications/booksbeyondwords.aspx



Some of Frank's carers

Northern Ireland Group

Dorry McLaughlin and Mary Bogue, our Area Representatives for Northern Ireland, report on their first meeting.

The first meeting of the Northern Ireland Palliative Care for People with Learning Disabilities (PCPLD) Network Regional Group took place on Wednesday 10th February at Muckamore Abbey Hospital in Northern Ireland. Thirty professionals representative of learning disability and palliative care, across a number of service settings and sectors, attended the meeting.

Following an overview of the aims, history and background to the PCPLD Network by Dorry McLaughlin, a short presentation was given by Lorna Nevin the Regional Supportive and Palliative Care Co-ordinator, which focused on the direction of the palliative and end-of-life care strategy in Northern Ireland, including the regional service model and palliative care pathway, and highlighted the relevance of the PCPLD Network for practice today.

Dr. John Kyle, MacMillan GP Facilitator, Belfast Health and Social Care Trust, talked about the Gold Standards Framework for End-of-Life Care and what this meant for people with learning disabilities. A case study was used to illustrate the benefits of this end-of-life care tool in the provision of palliative and end-of-life care to someone with learning disabilities.

Partnership in Action was the title of the session taken by Mary Bogue (Ward Manager) and Marie Nugent (Palliative Care Nurse Specialist) which showed the outcomes

obtained through collaborative working between specialist palliative care and learning disability services, in Muckamore Abbey Hospital, Belfast Health and Social Care Trust. This partnership involved learning from each other and showing mutual respect and trust which lead to outcomes of professional empowerment and increased confidence, the person with learning disabilities being able to stay in their preferred place of care and family satisfaction with the end-of-life care that they received. A similar partnership and outcomes were reflected in the collaborative working relationship between Stephanie Reid (MacMillan Nurse) and Majella McGeeney (Staff Nurse), in Longstone Hospital, Southern Health and Social Care Trust, who highlighted that what makes a partnership joined up thinking/ joined up care is being willing to learn from each other and having an awareness of professional knowledge deficits. The meeting closed with Arlene Workman, a Community Nurse Learning Disability, talking through her role as a Palliative Care Link Nurse within Northern Health and Social Care Trust and the



Speakers: Lorna Nevin, Stephanie Reid, Majella McGeeney, Arlene Workman, Dr. John Kyle, Dorry McLaughlin, Marie Nugent and Mary Bogue

potential benefits of this role to both palliative care and learning disability services.

Other work on going in Northern Ireland includes developing a web page for the Regional Supportive and Palliative Care website-palcareni which will signpost people to a variety of resources relevant to palliative and end-of-life care for people with learning disabilities, provide a link to the new PCPLD website when available and highlight details of the location of learning disability and palliative care services in Northern Ireland. In addition a regional mixed methods research study, funded by HSC Research and Development Office, is developing an educational resource for professionals working in both learning disability and palliative care services, which aims to promote collaborative working and make recommendations to inform policy and practice in palliative and end-of-life care for people with learning disabilities.

Conference Report

Quality transitions in end of life care for people with learning disabilities

Glasgow, 10th November 2009



Over 125 delegates gathered in Glasgow on 10th November 2009 for our annual conference. It marked the rejuvenation of the Scotland area group, co-ordinated by Josephine McCullogh.

Maria McGill, chairman of the Scottish Partnership for Palliative Care, led everyone through the day. She recognised that palliative care professionals often do not have much expertise around supporting people with learning disabilities, and highlighted the need for this to change. It was important to have professionals from both palliative care and learning disability settings in the audience, encouraging an exchange of experience.

The morning started with four concurrent workshops. Several delegates complained that these were so good, it was a shame they couldn't attend all of them!

- **Prof Claud Regnard** and **Dorothy Matthews** led one of their ever-popular workshops on symptom assessment and the use of DisDAT (Disability Distress Assessment Tool).
- **Maggie Coombes** led a much appreciated workshop on palliative care issues for young people with learning disabilities.
- **Noëlle Blackman** led a workshop on end of life dementia care for people with learning disabilities.
- **Irene Tuffrey-Wijne** ran a practical workshop on using the Nominal Group Technique to find

out what people with learning disabilities think is important in end of life care.

The popularity and clear relevance of these workshops means that we are likely to repeat at least some of them at future conferences!

What followed was a powerful and moving personal account of xxx, who spoke of her experiences of the death of her husband, and of supporting her son (who has learning disabilities and autism spectrum disorder) in his bereavement. She and her son were supported in this by the **Josephine McCullogh**, as well as by **Susan Cotterill** and **Mary Lynas**, who explained how they set up a bereavement support group for people with learning disabilities.

Claire Salt, social worker, told delegates about her research findings regarding the social workers' role in situations where there is loss and grief.

George Beuken, chaplain at St Andrews Hospice in Airdrie, gave an interesting overview of the use of personality typing (including Myer Briggs), and explained how this can help us not only to understand ourselves, but to understand the responses of bereaved patients.

Katherine Spencer, senior nurse at Marie Curie Hospice in Edinburgh, looked at the benefits of working across boundaries of palliative care and learning disabilities, using two case studies as an example..

Carol Turnbull ended the day by briefly explaining the development of easy-to-understand pictorial leaflets for people with learning disabilities about cancer and palliative care.

A highlight of the day was the presentation of the **Linda McEnhill Award**, of which more elsewhere in this newsletter!

Many thanks to Linda McEnhill and Josephine McCullogh for organising this excellent conference.

Our next conference will be held on 10th May 2010 in Devon. See back of this newsletter for details.



Maria McGill chaired the conference



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 group 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.

London & Home Counties

When: 10th March 2010, 2-4pm

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

Contact: Noëlle Blackman, london@pcpld.org

Yorkshire

When: 2nd June 2010, 10am-12.30pm

Where: Kirkwood Hospice, Huddersfield

Contact: Amanda McKie, yorkshire@pcpld.org

Forthcoming Conference

10th May 2010, 9.30-3.30
Buckfast Abbey, Devon

Excellence in end-of-life care for people with learning disabilities

This conference will celebrate good practice in the end-of-life care for people who have learning disabilities, including presentations from the winners of the Linda McEnhill Award 2009.

There will be a structured opportunity to network with other professionals.

The conference is suitable for professionals from primary and secondary health care settings, learning disability services, carers and families.

Topics will include:

- Collaboration between learning disability and palliative care services
- End-of-life care checklist for people with learning disabilities
- Enabling people with complex needs to die at home
- Supporting people with learning disabilities who have cancer

Cost:

£65 (incl. lunch and refreshments)

£50 PCPLD Network members

Information and registration:

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