PCPLD Network
Palliative Care for People with Learning Disabilities

Network News

Network News Volume 3, Issue 1 **Winter/Spring 2011**

The Palliative Care for People with Learning Disabilities Network 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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Inside this issue

Editorial

It has been a while since the last newsletter was published. Family illness took me out of action for a number of months. It brought home to me how busy most of our lives are, and how amazing it is that so many of you manage to fit in all the extra stuff you do—whether it's organising a meeting or conference, or simply going the extra mile to ensure that we provide the best possible support for people with learning disabilities at the end of life.

This issue is full of news, reports and events that have taken place in the past 6 months. The winners and runners-up of the Linda McEnhill Award were announced in November. You can read about their inspiring work on page 2.

Heatherstones Nursing Home won for their outstanding support to one of their residents and her family. We often hear examples of poor practice (and the feeling that things "could be better" is what motivates many of us to be part of this network). But we can learn as much from situations were things went well, and the care given to Patsy is a great example. Read more about this on page 4.

On page 6, we interview Noëlle Blackman about her work in bereavement services and her pivotal involvement with the PCPLD Network. Noëlle has really driven things forward in the area of bereavement support for people with learning disabilities, and it is people like her who keep us motivated!

Finally, Amanda McKie reports on a wonderful conference in November (page 8).

The world is changing, and the needs of the people within the PCPLD Network are not the same as they were a decade ago. We have currently waived membership fees and are keeping in contact with you all via a mailing list. If you don't receive updates by email but would like to, just send us your details. You can also find much relevant information on our website.

We will share our thoughts about further changes in our structures and activities in due course! If you have any ideas, let us know (see back page).

Dr Irene Tuffrey-Wijne *(Chair)*

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The Linda McEnhill Award 2010

The PCPLD Network awards the **Linda McEnhill Award** every year to a team or individual who has made a positive difference to the end of life care of people with learning disabilities. The 2010 Awards were announced at our national conference in November.

Left to right: **Linda McEnhill** (who presented the award)**; Gerard Wainwright, Sara Lockwood** and **Josephine Crossley** from Heatherstone Nursing Home; **Amelia Jones** (vice chair)

The winner

The Linda McEnhill Award 2010 was won by **Heatherstones Nursing Home** in Halifax, Yorkshire. Heatherstones is a nursing home for eight adults with learning disabilities. When one of their residents, Patsy (a woman with Down Syndrome who had lived there for eight years), developed dementia and end of life care needs, Patsy's sister brought the Gold Standards Framework to the attention of the staff team. The Gold Standards Framework (**http://www.goldstandardsframework.nhs.uk/**) is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It runs a national training and quality assurance programme for care homes, aimed at building confidence and experience, and based on up-to-date evidence of best practice.

The team, led by manager Gerard Wainwright, completed the comprehensive training programme and have maintained GSF accreditation through annual re-assessments. This enabled them to support Patsy with confidence and skill.

- They brought in the relevant outside professionals when needed.
- They where able to anticipate problems and be pro-active, including problems with symptom management.
- They supported Patsy to live fully until the end of her life, and to be able to remain at Heatherstones where she felt safe.
- They supported her family to be fully part of Patsy's life.

The judges were impressed with the way the team at Heatherstones combined their dedication and obvious commitment to Patsy and her family with skilled professionalism that is sustainable and replicable. Their outstanding care and support for Patsy did not depend solely on the goodwill of the staff: it was sustained by rigorous training and commitment of resources. We are delighted to hold up this home as a beacon of excellence.

You can read the full story of Patsy, her family and Heatherstones Nursing Home on page 4.

Highly Commended

Jason Davidson, social worker at St Joseph's Hospice, London

Jason Davidson , social worker at St Joseph's Hospice in London, was Highly Commended for the Linda McEnhill Award.

Jason has worked at St Joseph's Hospice for two years. He has past experience of working with people with learning disabilities. He first started to talk about the opportunities available to the hospice to address the end of life care needs of people with learning disabilities at his job interview!

Jason had a major role in establishing a strong and increasing commitment on the part of the hospice to improving the experience of people with learning disabilities who approach the end of life, their families and carers. Within a short space of time, he has established important links between the hospice and learning disability services in the area; ran training for hospice staff; and made a significant contribution to high quality care provision of patient with learning disabilities referred to the hospice. He has attracted funding for the hospice to support a project concerned specifically with improving the experience of people with learning disabilities at the end of life.

Highly Commended

Denise Heals, Educations Facilitator at Dorothy House Hospice, Wiltshire

Also Highly Commended was Denise Heals, Education Facilitator at Dorothy House Hospice Care in Wiltshire. She has been innovative in shaping her new role as a Practice Development Nurse, Learning Disability/ Palliative Care covering a wide geographical area.

The role started in 2009. It includes running a two day training programme for direct care staff in learning disabilities, supporting practitioners within their own working environment, and helping teams and managers in learning disability services to identify training needs and practice development initiatives.

One of her roles is to work with a core group of learning disability staff (could be managers, whole care team or interested care workers) over a set period of time (6-9 months) to help them in their identified area of need around end of life care provision. Additional meetings are scheduled at which progress is reviewed against the plan, issues discussed and explored. There is clear evidence of the positive impact Denise's work has had on the provision of end of life care by learning disability teams in her area.

Nominations for the Linda McEnhill Award 2011

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.

Nominations for the Linda McEnhill Award 2011 are now open.

Closing date::
31st August 2011

For a nomination form, go to
www.pcpld.org
or contact
award@pcpld.org

Real life story

Caring for Patsy

Patsy lived in a nursing home for people with learning disabilities. When she developed dementia, the staff at her home signed up to a national training programme in end of life support. Here, home manager GERARD WAINWRIGHT tells the story that won his team the Linda McEnhill Award.

Patsy's life

Patricia Healy (known as Patsy) lived at Heatherstones Nursing Home for about eight years. On admission she was an outgoing lady, who was full of life and still retained some of the independence that had helped her lead a full and active life. She had previously lived with her family in Ireland. One of her achievements had been to take part in the disabled Olympics.

Dementia

Following a diagnosis of dementia, Patsy gradually lost many of the skills she'd previously possessed and became more dependent on the staff to meet her needs. She lost the ability to mobilise and feed herself. Her sister Margaret took a keen interest in ensuring Patsy received the best possible care at Heatherstones. Indeed, it was Margaret who first brought the Gold Standards Framework (GSF) to the attention of the team, as she believed that it would be of benefit to her sister, and ultimately to all the clients at Heatherstones.

The Gold Standard Framework

The Gold Standard Framework (GSF) is a systematic evidence based approach to optimising the care for patients nearing the end of life. It runs a national training and quality assurance programme for care homes, aimed at building confidence and experience, and based on up-to-date evidence of best practice. See www.goldstandardsframework.nhs.uk

In order to meet the GSF, our team had to complete a comprehensive training programme. To achieve and maintain GSF accreditation we had to provide evidence of best practice:

- an assessment of the home
- the submission of a portfolio of evidence
- annual re-appraisal by self assessment and a full re-accreditation every three years.

The GSF helped us to identify Patsy's palliative care requirements, assess her needs, symptoms and preferences and plan her care accordingly. The "prognostic indicator guide" and "coding register" enabled us to plan her care in the final years, months, weeks and days of life - this helped us identify the support she required at different stages.

Expect the worst but hope for the best

Patsy showed a quite gradual deterioration in her health. Typically a period of ill-health such as a chest infection would be followed by a reasonable period of stability. Gradually she spent more time being cared for on her bed with shorter periods spent mixing with her fellow clients in the lounge area. In line with the GSF, a multi-disciplinary meeting was held with Patsy's GP, her sister, her Named Nurse and the Home Manager. We put in place an Advance Care plan

Patsy Healy surrounded by members of her family detailing Patsy's and her family and carers' wishes for her end of life care. Everyone strongly agreed that it was in Patsy's best interests to be cared for in the familiar surroundings of Heatherstones, surrounded by her family, carers and loved ones. Anticipatory medication was also put in place to meet her possible future needs for pain and symptom control. Our practice was guided by a maxim used frequently in GSF: to expect the worst but hope for the best.

Outside support

When Patsy's care needs increased, the GP and District Nursing team provided much support. The Community Macmillan Nurse (who had helped us to achieve GSF accreditation) was also able to provide invaluable help and advice.

Strong personality

Throughout this time Patsy retained a great deal of personality, charm and strength of character and this spark remained an essential part of her. People often said what a big impact she had on those she knew and what a strong presence she retained at the home.

Supporting the family

For me, one of the most rewarding aspects of supporting Patsy was being able to provide an environment where her relatives felt comfortable to spend time with her. Her sister was with Patsy for much of the time during the last week of her life, sometimes spending the night in her room in an easy chair. We gave her the opportunity to help with Patsy's personal care, so she felt she could provide practical as well as emotional support. Patsy's elderly father was able to visit and spend time with her, as well as her brothers, nieces and their young families. The local Priest was a regular visitor – Patsy was raised with a strong Catholic background, and her religion, although no longer so significant to her family, was acknowledged to be a source of comfort to her.

Last weeks

Far from being a sombre time, Patsy's last week was full of happy memories. In line with her Advance Care plan she had her favourite Irish music and Daniel O'Donnell CD's playing. Her family put on a number of videos of her at dances, weddings and other happy family occasions. There was lots of laughter during this time, as well as tears and reminiscences about her life. We took photographs to provide a lasting visual record of what was a very precious time for her and her family – this was later presented to them as a gesture of thanks and appreciation from everyone at Heatherstones.

Death

Patsy's sister Margaret often commented that in her final week, she looked more relaxed and peaceful – serene as she described it – than she had seen her for a long time. During her final days there were a number of occasions when it seemed that her time had come. At such times Margaret always wished to be alerted so she could be with her when she died. In the end Patsy died shortly after her sister had gone home for the evening. Her family's wish was that she should remain at Heatherstones overnight, so she would not be alone. Patsy's funeral was a fitting tribute to a full and happy life which reached a dignified and peaceful conclusion.

Final thoughts

Following the introduction of the GSF at Heatherstones, end of life care has undoubtedly been given greater thought, including the discussion of people's preferences, effective symptom management, dignity, respect and humanity, bereavement support and co-ordination of care. In the case of Patsy it had a profound impact on the quality of end of life care she received, and provided a framework upon which to plan her care, as well as providing clear guidance of best practice for those of us supporting her. Having GSF accreditation not only gave the staff team the skills to optimise Patsy's quality of life; it also enabled us to provide support for her relatives and each other. Patsy died free from pain and distress, surrounded by those closest to her in a peaceful, positive and dignified environment.

> "Far from being a sombre time, Patsy's last week was full of happy memories. There was lots of laughter as well as tears and reminiscences about her life."

Patsy's family have agreed to the use of her name and photograph

Do you have a story to share? Email Irene on info@pcpld.org

In the spotlight

In each newsletter, we put one of our members in the spotlight. Here, Noëlle Blackman talks to Irene Tuffrey-Wijne about what has inspired her over the years to dedicate herself to improving end of life and bereavement care for people with learning disabilities.

Noëlle Blackman (52) is Deputy Chief Executive of RESPOND (an organisation working with people with learning disabilities who have experienced abuse or trauma). She has a background in Drama Therapy and is a leading expert in bereavement support for people with learning disabilities.

Back in 1998, Noëlle co-founded the National Network for Palliative Care of People with Learning Disabilities (NNPCPLD, now the PCPLD Network) together with Linda McEnhill. She was its vice chair until 2009, and also ran the London & Home Counties regional group for over a decade. She has recently handed over the role of regional representative.

Noëlle has been instrumental in nurturing the growth of the PCPLD Network. Now that she has taken a step back from the responsibilities of her roles, we wanted to find out what started it all.

Nobody explained

"Looking back, I think it really started very early on, when I was a girl of eight or nine," she reflects. "I had a friend who had a brain tumour. She was getting more and more ill, but nobody explained this to me, and I couldn't understand why she couldn't always play with me. When she died two years later, it was like a sudden death. I was utterly shocked. Not understanding what was happening was awful." She likens this to the experience of people with learning disabilities, who are often similarly kept in the dark about illness, death and loss.

Long-stay hospital

In the 1990s Noëlle was based in a long-stay hospital for people with learning disabilities. Her job was writing and delivering training courses to learning disability staff. Shortly after starting the job she wrote a Loss and Bereavement Course, this was well received. However, delegates to the course would often say at the end of the course, 'we can't find bereavement counsellors for people when they need more support than we can give .' Noëlle remembers: "I thought, well, if there was no bereavement service for people with learning disabilities, I'll set one up. A year later, Linda [McEnhill] was brought in as the second bereavement counsellor."

It was a pivotal moment, because just at that time, the hospital's sick ward closed. "People were being resettled into the community, but when they were ill, they used to come back into the hospital", Noëlle explains. "Including those that were terminally ill. But when the sick ward closed, we were really worried that people didn't get good care in the community."

A Network is born

Linda and Noëlle started talking to professionals in other parts of the country who were also working in the area of loss, terminal illness and learning disability. They went to see John Murdy at Northgate & Prudhoe Trust, where they met several people who are still actively

Noëlle Blackman: "I thought: if there's no bereavement service for people with learning disabilities, I'll set one up."

involved in this area now, such as Dorothy Matthews. "We were hoping to learn something from them, but when we got there, they'd got a room full of people together, all looking at us expectantly!" Noëlle laughs. "There was just nothing happening really, and nobody knew anything. That's where the first seeds of the Network were sown." The NNPCPLD was launched soon afterwards, and the rest is history. Several regional groups started to meet, and the Network slowly evolved over the next decade.

Twelve years later

What is it like not to be at the helm anymore? "I think it's very exciting now to see what's happening in the Network. Having stepped aside, I can see that better. The Network is fully embedded in practice, and it doesn't depend on just a few people to keep it going. It has a full and breathing life of its own."

Bereavement support

Noëlle is currently writing up her PhD about bereavement and people with learning disabilities. She is clearly passionate about bereavement support for this group and has already written a book on the topic (2003).

"The one thing I do feel sad about is that the bereavement aspect has got lost within the Network," she says. "We rarely talk about it or give it a platform. Palliative care for people with learning disabilities, including the medical aspects of it, has developed its own momentum, keeping up with developments in mainstream palliative care services. We haven't developed that same clarity around bereavement support for people with learning disabilities. We haven't kept up with the generic world of bereavement support. My hope is that once I've completed my doctoral thesis, I'll be able to bring that aspect back to the Network."

Noëlle is in no doubt about the benefits that being part of the PCPLD Network have brought her personally. She particularly appreciates the encouragement and peer support. "I feel that it has given me an enormous amount in terms of speaking out about what matters to people with learning disabilities. I could never have envisaged myself standing up to give a talk, or writing a paper for publication!"

We certainly hope that we haven't seen the last of Noëlle. The PCPLD Network has benefited greatly from her dedication and expertise, and we look forward to her continued contributions in the years to come, whatever form that may take. Thank you Noëlle!

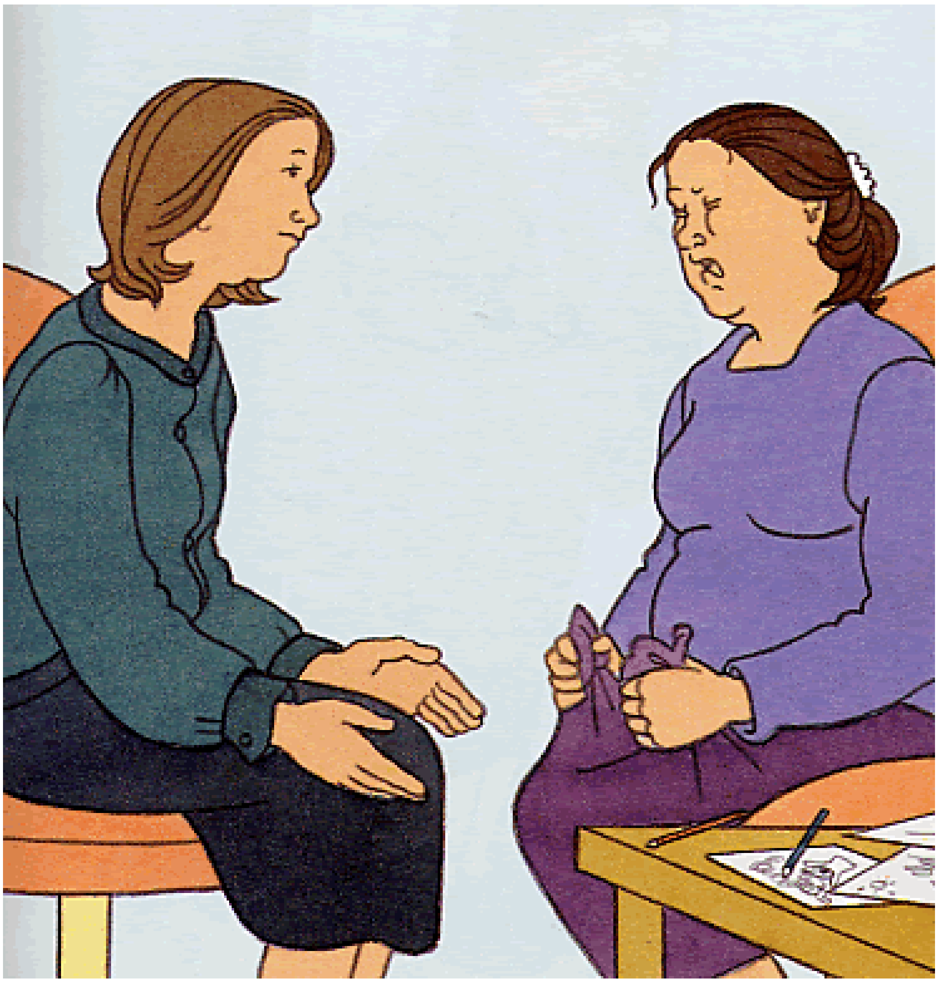

Image taken from "When Somebody Dies" by Sheila Hollins, Sandra Dowling & Noëlle Blackman www.rcpsych.ac.uk/publications/booksbeyondwords.aspx

Conference Report

People with learning disabilities: Dementia and end of life care

Rochdale, 19th November 2010

Image and copyright: GOLD Group, RESPOND

Our annual conference focused on end of life care for people with learning disabilities and dementia. **Amanda McKie** reports.

The conference took place on a very grey and cold November day in our local hospice in Rochdale, in the North West region of England. Over 80 people attended the day and we turned away many more interested people.

The day chaired by **Kim Wrigley** who is End of life care lead for Greater Manchester and Cheshire Cancer Network. She had us laughing from the start by telling us about Rochdale, the famous people who were born there. Lisa Stansfield the singer, Ken Dodd the comedian and many more.

Dr Diana Kerr gave the keynote lecture "Getting it Right for people with a learning disability and dementia at end of life". She talked about dementia as a terminal condition. She explored the concept of diaries for each month and decade being stored on shelves in our memories. How dementia affects them, losing pages and then entire books until decades are gone leaving the person with only early childhood memories. She talked about the communication difficulties associated with dementia, pain being a big issue if you can't find or remember the words to use. She then discussed the implications for staff and service providers, telling us about the models ageing in place, in place progression, and referral out. This started a debate in the audience especially with the one and only commissioner in the audience. She told us about her findings from "Home for good" in relation to end of life care. People being moved in crisis, inadequate use of palliative and district nursing services, and how often moving into a nursing home for older people led to a poor experience that shortened life. She told us what was needed and how we should look at in place progression as a good model and that we must use palliative care services. The session evaluated really well and the audience told us that they could have listened to Diana all day!

Kim Wrigley presented her session on 'High quality end of life care… the story so far'. She started the presentation by telling us what end of life care is. She gave us the background to end of life care and dementia care, she put it all in context for us. She told us about the key areas to be addressed by the end of life care strategy. She ended with a quote from Dame Cecily Saunders that was the theme for the event:

"You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but to live until you die."

Sue Smith, Health Assessment Lead for the North West Joint Improvement Partnership, told us about the regional self assessment framework for people with a learning disability, and what she had found in the North West so far.

Elaine Horgan, the End of Life Home Coordinator, informed us of the NHS End of Life Care programme. She told us about Gold Standard Framework, Liverpool Care Pathway and Preferred Place of Care. She talked about the government's initiative for people to die in their preferred place. She explained that the research evidence was that people with dementia receive poorer end of life care. She told us about the training and education she had provided to homes throughout the north west and this had increased the number of patients that died in their preferred place of death.

We then needed a coffee break the morning session had people thinking and wanting more. The only slight hiccup was that we forgot to order biscuits. It was a good job the shop had chocolate to keep people going!

After break we divided up into three regional group and shared our ideas and experiences. We explored the regional groups, how often should we meet, what might attract people to attend, how we could involve people with a learning disability to be more involved in the network. ***On the back of this newsletter, you can read what the delegates said.***

We then a fantastic lunch provided by the hospice and people had a chance to network.

After lunch **Amelia Jones**, Vice Chair for the network, announced the winners of the **Linda McEnhill Award**. Linda herself was there to give out the well deserved awards!

We then had a very emotional presentation from **Lesley Taylor**, Lead Nurse from Bradford District Care Trust and **Margaret Cooney**, shared lives carer. They talked about Elizabeth and her story through diagnosis of dementia to her very last days of life. The photos of her life raised some giggles and some tears. It left people with lots of questions especially about the insertion of PEGS in dementia care. Margaret was very brave and answered questions from the audience about the very emotional experience she had been through.

Our last session was presented by **Pat Charlesworth**, Self Advocate and GOLD group member and **Michelle Brooks**, Therapist/Trainer from Respond. They presented the DVD "Dementia and people with learning disabilities": Recognising the importance of friendships (the photograph on the previous page is taken from this). After a minor technical problem "no sound" we managed to get the DVD to play and be heard. This session was the finale of the day.

People went home happy, having enjoyed a very successful thought provoking day. Some went away with new information and many with questions, but all with enthusiasm and determination. The day was extremely well evaluated!

Some of the conference presentations will be available on our website shortly (go to www.pcpld.org/conferences)

Conference delegates discuss what they would like from the PCPLD Network

Join our mailing list

Membership fees are currently waived. If you would like to keep in touch with the work of the PCPLD Network, email us:

info@pcpld.org

We will add you to our mailing list. You will receive early notification of conferences and newsletters, as well as any other carefully selected information that may be of relevance to you.

How would you like the PCPLD Network to work for you?

Times are changing. The climate in which we work is changing.
We asked delegates at the conference how the PCPLD Network could work best for them.
Delegates (some of whom were PCPLD Network members) agreed that the PCPLD Network was important, but they made some poignant comments:

Difficulty of getting to regional meetings
The local meetings (set up to provide people working in the same region with mutual support, and run by a Regional Representative) are great, but they can be difficult to get to:

- The regions are large, so people may have to travel quite far to get to the meeting, taking a large part out of their working day
- Employers don't always support their staff attending meetings

Membership fees
Not all employers support payment of membership fees. Some people found it difficult to pay the fee.

Do people know about the Network?
Over half the delegates had never heard of the PCPLD Network before. We should promote it!

In response to these comments, and feedback from regional groups, we have waived membership fees for 2011.
We are currently reviewing the role of regional groups, meetings and conferences, and our website.
If you have any thoughts on how you would like to see the Network develop, please let us know! Email Irene on ***info@pcpld.org***

The route to success in end of life care - achieving quality for people with learning disabilities

This publication aims to provide a practical guide which supports anyone caring for people with learning disabilities to ensure that those who may be in the last months of their life receive high quality end of life care.

It may also be useful to health or social care professionals who come into contact with people with learning disabilities in clarifying what measures need to be taken to ensure that they can access appropriate care.

Download the publication from **http://www.endoflifecareforadults.nhs.uk/publications/route-to-success-people-with-learning-disabilities**