PCPLD Network
Palliative Care for People with Learning Disabilities

Network News

Network News Volume 3, Issue 2 Atumn/Winter 2011

Editorial

If you are one of the many new members of the PCPLD Network: welcome! Since we have waived our membership fees at the start of this year, membership has more than doubled. There is a clear need for networking and sharing best practice. There are so many aspects to supporting people with learning disabilities (and their families) at the end of life, that none of us can do it on our own. It is good to be able to share with others, who may have a very different area of expertise from ourselves. I am delighted that so many of you are signing up, meeting and emailing, and linking into the support we can give each other.

We start this issue with the winners of this year's Linda McEnhill Award. For me, this is one of the highlights of what we do. It is simply inspirational to hear about the wonderful things that are happening in the field, and an honour to sit on the judging panel.
You can read about the care given to Tim at the end of his life—the team supporting him was one of the winners of the award.

For the Annual Report, both from myself and from some of our Area Representatives, see page 8.

Our conference in London in October was, as always, successful and inspiring. The Annual General Meeting was held at this conference, and we discussed the new proposed constitution. For a full report of both the conference and the AGM, see page 8.

Dr Irene Tuffrey-Wijne *(Chair)*

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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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The Linda McEnhill Award 2011

The PCPLD Network awards the annual **Linda McEnhill Award** to a team or individual who has made a positive difference to the end of life care of people with learning disabilities. The 2011 Awards were announced at our national conference in October.

Left to right: **Irene Tuffrey-Wijne** (chair), **Carolyn Manktelow** (receiving the award on behalf of Hft Fallstaff House), **Linda McEnhill** (who presented the award); **Amelia Oughtibridge** (vice chair)

The judging team consisted of five people, including leading professionals in the field of learning disabilities and palliative care; a family carer; and a person with learning disabilities.

The nominations for the award were of a very high standard. It was, as always, very difficult to compare nominations describing the end-of-life care given to an individual (usually by a care home for people with learning disabilities) with some of the nominations describing new service or practice developments. The judges therefore decided to have two categories, each with a winner.

Category: OUTSTANDING CARE OF AN INDIVDUAL

The winner

The nominations describing the end of life care of an individual are usually a delight to read, despite the obvious sadness involved in someone's dying. This year, **Hft Falstaff House** in Bidford on Avon, Warwickshire, stood out for the care they gave to Tim, one of their residents who developed dementia. Tim's story is told on page 6. The judges were impressed by the way the team did their utmost to keep Tim's best interest (rather than their own) at the heart of everything they did. This was not always easy. It involved engagement with a staggering number of outside agencies and professionals (including the funding authority) and with Tim's family. The manager and the support team were staunch advocates for Tim, and this meant that he was able to be in the place where he felt most comfortable. They showed flexibility, creativity and a 'can-do' attitude. One of the judges commented: 'If I was looking for a case study to use when teaching professionals what is involved in supporting someone really well, this would be it.' Hft Falstaff House is a worthy winner, indeed.

Category: SERVICE AND PRACTICE DEVELOPMENT

The winner

Sharon Hicks is a staff nurse at Severn Hospice Shropshire and Telford & Wrekin. She worked on a project called "Widening Access to Severn Hospice for people with a Learning Disability", which involved a partnership between the hospice , service users, carers, the Primary Care Trust and Independent Sector Services. Sharon worked to create organisational change, mostly through the delivery of training the multi-disciplinary team within the hospice, and through ensuring collaborative working with outside agencies. To ensure that the project could achieve its objective, Sharon shadowed members of the learning disability teams and networked with local authority services. She embarked on a level 4 qualification (diploma in caring for people with learning disabilities). She also worked with people with learning disabilities, involving them in the training sessions at the hospice. In collaboration with the service users, she developed an easy read hospice leaflet.

Sharon's work is on-going. A hospital policy and care pathway are underway. She also has plans to look at support after bereavement with the hospice social work team.

Sharon Hicks and **Linda McEnhill**

The judges thought that Sharon's work shows how much one dedicated and determined individual staff member can achieve. There was clear support from the hospice and other agencies, but the enthusiasm and commitment of one member of staff really can make a difference. Sharon was nominated by Karen Breese, team leader of the local Community Learning Disability Team, who wrote: 'Sharon's enthusiasm and passion is infectious. She strives to ensure an equitable service while delivering person centred care. Although she has had some protected time to complete this work, she has always worked long and hard in her own time. Sharon is highly regarded among her peers for having taken this work on with the support of managers… she is supported and encouraged by people with a learning disability.'

Real life story

Supporting Tim

This is the story of how a dedicated team of staff at **Hft Falstaff House** in Warwickshire supported a service user with dignity, respect towards his rights of choice during a time of ill health and final stages of his life. The story, told by **Jeannette Rix** (Area Manager, Hft Arden Vale) won his care home the 2011 Linda McEnhill Award.

Tim lived at the home for thirteen years together with seven other people, enjoying life to the full with his friends. In the summer of 2005 the staff team observed changes in Tim's general health and well being. The manager liaised closely with Tim's GP and the community learning disability team. A full health screening and dementia assessment resulted in a diagnosis of Alzheimer's.

Tim's parents had passed away. His remaining relative was his brother, who lived in Devon. As soon as the Alzheimer's diagnosis was made, the home manager engaged with Tim's brother, the community health team and funding authority, to start planning how Tim could be supported both at that point and through the potential unpredictable time ahead. The dedicated staff team were all committed to helping Tim live the last part of his life as he wished. Training, awareness and preparation was sought for them.

In August 2009 Tim entered a later stage of dementia. He could no longer manage stairs. No downstairs bedroom was available. Through the creative thinking of the team, the office on the ground floor was converted into a bedroom. It was achieved in one day and Tim was able to keep some level of independence and mobility for a while.

Physiotherapy input was very important. It helped the staff to learn new skills around how to support Tim. It also helped to identify equipment that would be of assistance. The home had developed an excellent relationship with the local GP practice over the years, which meant that when Tim's health changed, access to community nurses and other professions were deployed with minimal delay.

Regular care planning and review meetings were very important, engaging the support of key professionals. At one review Tim's changing support needs were discussed and it was clear that further funding was required if his higher level of personal support needs were to be met. The funding authority wanted to make enquiries about mainstream provision for dementia care in elderly care services in the area local to Falstaff House. At this stage Tim was still quite able to state that his choice was to remain at Falstaff house. The team advocated determinedly for Tim, so that he could achieve this goal. They used the Mental Capacity Act to demonstrate that Tim had the ability to make choices. The team talked with Tim's brother who was happy that Tim should try and stay in Falstaff house, as it was his home. The home manager continued to liaise with Tim's funding authority about the funding of equipment and additional hours of staff support including some waking night hours. The care home organisation, Hft, had funded extra hours to make sure Tim was safe and well—but this was not something that they could sustain so they had to negotiate hard on this. Eventually, after long and difficult negotiations, agreement was reached to pay for the additional support hours, which enabled the home to continue with the support that Tim needed.

In February 2010 Tim became immobile and needed to be hoisted in and out of bed and into his wheelchair. Tim was assessed for a new wheelchair and for a specialist bed and air mattress . Advice and further training was taken from the community and incontinence nurses about skin care and the use of equipment, as bathing was now not possible.

Tim's care and support was now well managed and although the Alzheimer's disease did mean that he had some days when he was less well, and he had a lack of mobility, he was able to be with his friends. The staff support team felt Tim should be able to get out and about and visit the day centre he had been attending regularly before his health deteriorated. The home's minibus was not suitable for Tim, so the team looked at the option of an adapted vehicle being acquired for Tim. In August 2010 he had a demonstration of an adapted vehicle. Tim was delighted, showing smiles, pointing and saying he was happy to have one. Tim received delivery of his vehicle in January 2011.

In late January 2011 Tim became acutely unwell and was admitted to hospital following a period of unconsciousness from which staff were unable to rouse him. During the following months, Tim was in hospital several times, sometimes for a number of weeks when he was too ill to remain at home. He had suffered a cerebral bleed. It was becoming apparent that Tim was coming towards the end of his life. His last admission to hospital was necessary as he experienced further periods of unconsciousness and a prolonged seizure. Hospital liaison commenced for Tim to be discharged home as no further medical procedures were needed, but just prior to discharge it was discovered that he had tested positive for M.R.S.A. The manager and support team felt that Tim and he could best be supported back in his own home, with his friends and familiar surroundings. They wondered how they should support him at home, bearing in mind that there are other vulnerable people sharing the house with Tim. The local GP practice was contacted who reassured the team that there was no threat to others and that given normal good hygiene practice, there should be no problem.

Tim came back to Falstaff house in May. He was pleased to be home and as always the perfect gentleman. He thanked everyone for their help and support. Tim seemed to be stable but tired. He snuggled into his own bed that night, surrounded by things he loved and photos of his family. The next morning Tim was pleased to be supported by people he knew. His friends popped in and out throughout the day . Later Tim indicated his wish to go to sleep, so his pillow was plumped up and his duvet tucked in. A short while later a member of staff popped their head around the door. Tim had passed away peacefully in his sleep.

Although everyone was very sad that Tim had passed away they felt that the right things had been done to make sure that Tim spent the last two years of his life among the people who knew him, and that this had clearly been his wish. To achieve this for Tim the team had needed to mobilise all of the support that was available. They had to review constantly their own processes in terms of how they worked with and supported Tim. Most importantly, they needed to be completely honest about whether what they were doing in terms of helping Tim stay where he wished was in his best interest and could they continue to provide the support and care that he needed. This was a team effort in every sense of the word.

Tim's family have agreed to the use of his name

"He snuggled into his own bed that night, surrounded by the things he loved and photos of his family."

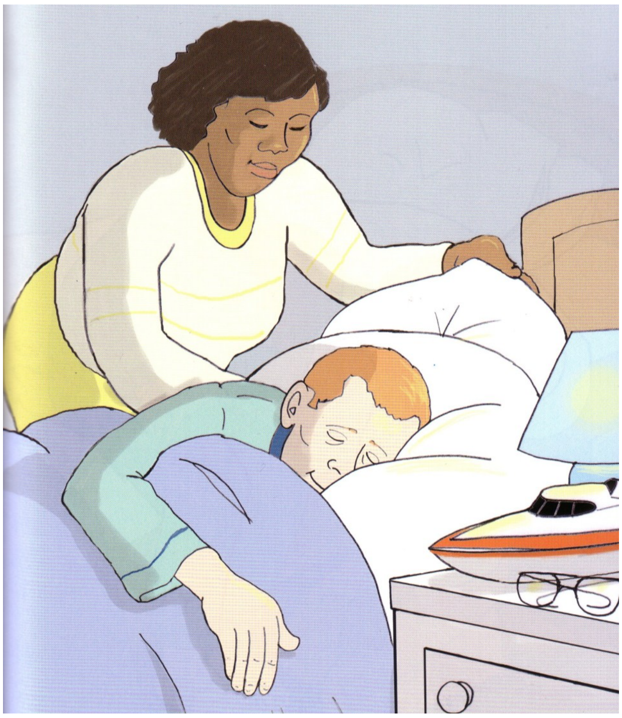


Image taken from ***Am I going to die?*** *by Hollins & Tuffrey-Wijne (www.booksbeyondwords.co.uk)*

Chair Annual Report 2011

by Irene Tuffrey-Wijne

Introduction

There was no annual report last year, as I was unable to contribute much of my time and energy due to family illness. This is therefore a report of the past two years!

The Network is now 13 years old, and I have been its chair for three years. I continue to be impressed by the passion, commitment and creativity of our members. The palliative care needs of people with learning disabilities have received a raised profile over the past decade, and in particularly in recent years. This is reflected in a growing number of resources, reports and initiatives. Palliative care organisations have really taken on board the fact that they need to go an extra mile to ensure that people with learning disabilities can access good end of life support. There are also many more practitioners now, across disciplines, who are looking for information and support. This makes the role of our Network all the more important. Our aims are to enhance collaboration between all service providers and carers, and to share and promote best practice. With so much excellent work going on everywhere, these aims are more important than ever.

The 2009 Annual General Meeting voted for a change of name, from the National Network for Palliative care of People with Learning Disabilities (NNPCPLD) to the Palliative Care for People with Learning Disabilities (PCPLD) Network. This reflects the fact that our networking is not limited to the UK.

Membership

We are a membership organisation. Previous membership fees of £25 per year were waved in 2011. Since then, our membership has more than doubled, from around 100 at the end of December 2010 to exactly 200 at the start of October 2011. Most members are practitioners in either learning disability services or palliative care services, with some other areas represented too, including academia. There are a couple of family carers and people with learning disabilities.

Geographically, these members are not spread equally, although exact details are not known, as we currently keep email contact details only (not postal addresses). It seems, though, that there continue to be relatively more members in London & Home Counties, and in Yorkshire and the North West. Eleven of our members are non-UK: in the Netherlands (4), Norway, Germany, Ireland, Switzerland, Australia, the USA and South Africa. Most of these non-UK members (and, indeed, many of our UK members) have found their way to the Network through our website.

Area groups

The area groups have always been a fundamental part of the PCPLD Network. They provide regional opportunities for networking, collaboration, and development of local "best practice". Each group is coordinated by an area representative (some areas have two representatives who share the role). Some groups have around three meetings a year; some have not been active during recent years; and some are only just beginning, and have not yet held any meetings.

The following area representatives have stood down since 2009, and we thank them warmly for their contributions:

Josephine McCulloch (Scotland)
Rachel Lucas (Northumberland)
Mary Bogue (Northern Ireland)
Noëlle Blackman (London & Home Counties)
Stuart Todd (Wales)

The following groups are active (area representatives in brackets):

Continental Europe (Catherine Hoenger) *New group and representative*
Derbyshire (Debra Cooper)
Dorset (Cheryl Egan and Hilary Lawson) *New group and representatives*
Hertfordshire (Louise Jenkins)
London & Home Counties (Jason Davidson) *New representative*
Northern Ireland (Dorry McLaughlin)
North West (Carol Beaumont and Sharon Dewhurst)
Oxfordshire (Maggie Coombes)
Wiltshire (Amelia Jones)
Yorkshire (Amanda McKie)

Steering Group

The Steering Group has been responsible for overseeing the general direction of the Network, ensuring it meets its aims, taking decisions about the use of resources (in particular, its finances), and any other decisions necessary, including those around conferences and the Linda McEnhill Award. An important role of Steering Group meetings has also been to provide each other with support and inspiration for our Network activities.

The Steering Group currently includes all the area representatives, plus:
Irene Tuffrey-Wijne (Chair and Treasurer)
Amelia Jones (Vice Chair)
Pat Charlesworth (Steering Group member with learning disabilities)
Beverley Dawkins (Mencap)
Peggy Fray (family carer)
Dorothy Matthews (Macmillan Nurse, learning disabilities)

David Oliver has stood down from the Steering Group. Stuart Todd has stood down as Treasurer. We thank them for their contributions.

The Steering Group met twice in 2011. It is often difficult to arrange meetings and get everyone together, as we are all geographically diverse. Some of the work of the steering group (for example, planning changes about the Constitution) was conducted between members via email and over the phone.

There are plans to change the structure and membership of the Steering Group, to make it more effective and manageable (see New Constitution). Currently, the automatic Steering Group membership of all area representatives makes it rather large and unwieldy, and therefore slow to respond to events and changes.

Newsletter

The newsletter was re-launched in February 2009. The aim is to produce three issues a year, but in 2010 and 2011, we will have managed only two issues. This is because newsletter is edited by myself. I also write most of the features, although there have been some contributions from other members. Producing the newsletter regularly has been difficult due to work and family pressures.

However, the newsletter has proved to be an effective and popular means of communication with members, and we will endeavour to continue producing them. Any feedback, contributions or ideas for future issues will be most welcome!

Website

Our website (www.pcpld.org) was launched at the start of 2010. We received a grant of £5,000 from Mencap to set up and maintain the website, and we are very grateful to them.

The website has been very successful in sharing information, resources and news. The Resources page is particularly popular. The site is currently fairly simple, with static pages and no interactive or members-only areas. There is great scope for development, but we would need to have someone among our members willing to take this on. If anyone feels they might be able to help, do get in touch with me!

Conferences

We have held two very successful conferences last year, accommodating around 90 delegates each:

- **Devon (May 2010):** "Excellence in end of life care for people with learning disabilities"
- **Rochdale, Yorkshire (November 2010):** "People with learning disabilities: dementia and end of life care".

Feedback from both conferences was overwhelmingly positive. This is always a fantastic opportunities to meet members and other colleagues across disciplines, and to share ideas and information. There is a tremendous buzz at our conferences, leaving people feeling positive about their work and opportunities.

Our next conference will be in London, 20th October 2011: "Best practice in end of life care planning for people with learning disabilities".

Next year's conference is planned to take place in Dublin, Northern Ireland on 20th June 2012. There may be a second conference in the late autumn.

Linda McEnhill Award

We launched the Linda McEnhill Award in November 2008. This award aims to recognise an individual or group who has made a positive difference to the end of life care for people with learning disabilities. There are five judges on the panel: three senior practitioners in the fields of learning disabilities and palliative care; one person with learning disabilities; and one family carer.

The 2008 Award was presented to Linda McEnhill herself. The 2009 Award went to St Francis Hospice. Runner-up was Lorraine Youdle, learning disability nurse in Devon, for her drive, passion and practice developments. Both Lorraine and St Francis Hospice's palliative care consultant, Dr Corinna Midgley, made inspiring presentations at our Spring 2010 conference.

The Award for 2010 went to Heatherstones Nursing Home in Halifax, for its outstanding end of life care to a woman with Down syndrome and dementia, and the way this home made use of the Gold Standard Framework. Runners-up were Jason Davidson, social worker at St Joseph's Hospice in London, for his inspirational networking, teaching and collaborative efforts; and Denise Heals, education facilitator at Dorothy House Hospice, Wiltshire, for the wonderful educational and practice developments.

It has been particularly good to see how the winners have been able to share their best practice, partly through the benefits of winning the award. Heatherstones Nursing Home, for example, has seen its best practice example featured in a couple of national publications.

The winners of the 2011 Award will be announced at our Autumn Conference in London.

Proposed new constitution

The need to change our existing constitution has been clear for several years, but it has taken a long time to organise a new proposal. The main problems include:

- The old constitution no longer fits our current way of networking, which included virtual networking. It is rather prescriptive about the way we work, in particular the way Area Groups work. As you will see from the local Area Reports, it can be a huge challenge for the regional groups to keep going and to meet in person. This is increasingly the case in the current economic climate. Some areas are geographically large, and it can be difficult for people to free time from their work and travel long distances to a meeting. There is also inequity for members who do not have a local area group, and currently have much less opportunity to network.
- Membership of the Steering Group is also rather prescriptive and does not reflect what actually happens in practiceOur relationship with Help the Hospices is more complicated in the old constitution than it needs to be. This includes the way we manage our finances.

We have had wonderful support from an expert at Help the Hospices, who has drawn up a new draft constitution following the directions and wishes from the Steering Group. In this draft proposal, the aims of the PCPLD

Network remain the same, but we will have much more freedom to work in ways that suit our times and resources. We will ask members to vote on this during our AGM on 20th October 2011.

Help the Hospices

We are part of the Network of Professional Association (NPA) at Help the Hospices. The NPA include a wide range of organisations, ranging from social workers to nurse managers and from fundraisers to complementary therapists. Being part of the NPA brings much support from Help the Hospices, and we are particularly grateful to Anne Garley who runs the NPA and who has much knowledge, insight and advice about how organisations like ours could work. Help the Hospices has supported us, not only in drafting a new constitution, but also in doing all the administration of our conferences. That's a huge job, and without this support we would not have managed to run our conferences so successfully.

Financial report

I currently have the task of administering the organisation's finances, dealing with in- and outgoings, and keeping accounts. I am looking for a Treasurer (someone who is willing to manage the accounts). Anyone who feels they might have the skills and enthusiasm to be part of our Network in this way: please get in touch!

Our financial situation is very healthy at present. This is due mostly to very prudent housekeeping (for example, we try to keep Steering Group costs to a minimum), a donation of £5,000 from Mencap for the website (ring-fenced), and profit on recent conferences, that have attracted healthy numbers of delegates). This has enabled us to waive membership fees in 2011, so that as many people as possible can benefit from our activities.

Closing balance Dec 2009: **£2,625.23**
Closing balance Dec 2010: **£8,751.63**
Closing balance Sept 2011: **£10,314.01**

Please note that the Sep 2011 balance shows some of the income from our latest conference, but as yet none of the outgoings.

A more detailed breakdown of the finances is available on request.

The future

We have achieved quite a lot in the past two years, despite the limitations of our time. The website has been particularly important.

We are now in a great position to build on the future. I very much hope that the new constitution will receive a YES vote. If it does, we can start planning ahead, and putting in place people and structures to support future developments. We have the following hopes and ideas for the future:

- Develop the website further. Include possibilities for members to networking on-line.
- Encourage email contact between members, possibly through an on-line forum.
- Develop certain areas of practice, for example, by finding "experts" among our members who are willing to take a lead on this. Such areas could include, for example: bereavement; transition; dementia; research.

We will also think carefully how to be prudent with our finances. We do have a healthy bank balance, but we want to spend it wisely. This may include paying for secretarial support, so that we can provide members with a better service.

The PCPLD Network is first and foremost a *NETWORK*. Its members, and their willingness to share ideas, are fundamental. I am always inspired by the fantastic work many of our members do, and I really hope that you are too!

I. Tuffrey-Wijne

Irene Tuffrey-Wijne
Chair,PCPLD Network
15th October 2011

Local Area Reports

written by the Area Representatives

Please note: not all active areas have sent in a report

DORSET

Cheryl Egan, *Assistant Team Manager, Adult Learning Disability Team, Ferndown Local Office*

On behalf of the Dorset Group, here is a summary of our activities this year. We are continuing to meet as a group twice a year. I have taken on the area representative role. We have approx 25-30 people who are on our email list and approx 10 people who regularly attend our meetings. Any information on EOL resources, training events, conferences etc is emailed to everybody on the list who then disseminate it to their respective teams and colleagues. We are focussing on trying to publicise the "Dorset" End of Life Care documents and other accessible information and raising awareness among professionals and other interested parties.

We are putting together an EOL and LD "pack" to give out to professionals, consisting of Dorset EOL checklist, Dorset EOL pathway, "My end of Life" Plan, DISDAT, Routes to success, accessible resource list and contact details of the Community LD Team. This should be completed by Dec 2011. The documents have been publicised to the Generalist Palliative Care Teams in the Local Hospitals. There are plans to deliver training around the specific needs of people with learning disabilities to these teams. The training is likely to take place early 2012.

We have had representation at Care Home Forums to share the EOL documents. We have also had stands at a local EOL conference and a bereavement stakeholder event which generated a lot of interest.

In relation to strengths I think we have a diverse mix of professionals from specialist nursing backgrounds, general hospitals, Community Learning Disability Teams, advocacy etc, so we are able to share the different knowledge and skills that we have. I think we have built up a network of people we can contact and discuss issues with to improve the experiences of people with LD at the end of their life and to improve access to appropriate support and services (though of course we still have a long way to go). It's a positive group with lots of ideas generated and everybody is really committed and wanting to learn from each other and share best practice.

HERTFORDSHIRE

Louise Jenkins, *Health Liaison Team Lead Nurse, Hertfordshire*

This is a rejuvenated group. The local membership email list has about 90 members and average of 25 attend meetings. We are just about to have our fourth meeting since I took over last year. The three meetings so far have been a variety of speakers from Palliative care/ LD specialism/ Loss and Bereavement counselling service and also showed a Dying Matters DVD at the last meeting. I network regularly with the members updating them on new articles/guidance/ interesting reading that I am aware of. Strengths of the group is the sharing of knowledge that is happening through the meetings, also increased referrals to Palliative care for people with a LD, increased awareness of professional roles of others. Challenges of the group ares the large geographical area that Hertfordshire covers and the variety of service provision across the county.

LONDON & HOME COUNTIES

Jason Davidson, *Senior Social Worker, St Joseph's Hospice, London*

Our area contact list now has 53 names on it. We continue to meet every 3 months at Respond offices in Euston and we usually have a core group of between 8 and 10 attendees. So far we haven't had any study days but I have a few ideas regarding this that I would like to bring to the group for next year. We haven't been emailing locally but this is something I think we should also consider. The group meetings last for 2 hours. We usually have an update from each person for the first hour and then spend the following hour with a presentation/guest speaker. I think people's commitment to attending and taking it in turns to present has been a real strength. This is a well established group and has been running for many years long before my time. I think for next year we need to have a think about how we get representation from other parts of London and how we can support one of our regular, committed attendees to set up a group in Kent - which may mean we lose the Home Counties but widen out across London.

NORTHERN IRELAND

Dorry McLaughlin, *R&D Fellow/ PhD Student, School of Nursing, University of Ulster*

I am currently the sole area representative for N.Ireland, but I am trying to get a joint representative from learning disability services. I have a local email list for emailing people who are interested in the area, but trying to develop this further. These are key contact people who then forward the circulated information within their own networks. The number of key people are around 60.We have had just a few meetings in the past with small numbers and have mainly taken the decision to go with an electronic format for the network. The limited face to face contact may be a limitation, but it seems that this is simply due to the current economic climate. There are also some people interested in the South- it seems that there will need to be one or two area representatives in the Republic of Ireland.
Strengths of our network is that it is a mix of practitioners/ researchers/ educationalists and people from policy/ service improvement. A regional study has been on-going which has kept some focus alive in N. Ireland on this area.
The N.Ireland group will be hosting the PCPLD Network Conference in June 2012.

OXFORD

Maggie Coombes, *Helen & Douglas House Hospice, Oxford*

We are a fairly new group and have altered our meeting time from the afternoon to lunch time to enable people who work in the community to come in between visits. I have about 15 to 20 people on my email list but the meetings vary between 4 to 8. Often it is different people each time. We meet every 3 months. We have looked at resources and the Route to success pathway and are holding a mini conference in November about the Route to success for a selected group of people including GPs consultants and End of life team. The strengths of the group is that it is diverse as it has a number of different professions who come along and we always have some sort of discussion.

YORKSHIRE

Amanda McKie*, Matron Complex Needs Care Coordinator, Calderdale and Huddersfield NHS Foundation Trust*

Our group has 34 members on the email circulation list. We meet twice a year 10-12.30 at Kirkwood Hospice in Huddersfield; around 9-16 members attend each meeting. Members are in full support of meeting in person. They feel supported by the group. We continue to have an educational element as well as a round robin/ information sharing. We support each other via email throughout the year, sending out requests for support and conferences/resources etc.
The future concern is whether we will be able to continue to use the meeting room free of charge. Members state their employers are at present continuing to support them to attend. Whether in the future climate this continues and we become a virtual group is unknown. We have considered whether we break the Yorkshire region down into areas and are at present consulting with members. The feel is that because the group remains strong and continues to meet, that we continue.

Many thanks to all these area representatives for their wonderful work in keeping local networking going!

Conference Report

Best practice in end of life care planning for people with learning disabilities

London, 20th October 2011

'Brilliant', was a repeated comment on the feedback forms for the conference.
One delegate wrote: 'I have been to three conferences now and always take something away that I immediately implement into my practice.'

The conference took place at St George's University in South London. Over 80 people attended the day, some having travelled a long way, including from overseas!

The day chaired by **Amelia Oughtibridge** who is vice-chair of the PCPLD Network and a Lead Nurse in Wilthsire Learning Disability Services. Unfortunately, our first speaker, Rosaleen Bawn, was unable to make it at the last minute. This meant missing out on her presentation of the Gold Standard Framework.

The team for **Heatherstones Nursing Home**, who won last year's Linda McEnhill Award for their care of a resident with learning disabilities and dementia, therefore had to fill in a few gaps. **Gerard Wainwright,** supported by his team members **Sara Lockwood** and **Josephine Crossley,** explained how they had used the Gold Standards Framework to make sure the support they gave to Patsy was outstanding. The Gold Standard Framework is a national programme that helps care homes to recognise and the various stages of end of life care and ensures that everything necessary is thought of. Signing up to this programme and obtaining accreditation was a huge commitment, and is on-going for all their residents—the home is re-assessed every three years and has to demonstrate that they have plans in place for all their residents. One delegate commented: '*Such an inspiring, wonderful story!*'

Denise Heals is Education Facilitator at Dorothy House Hospice Care. She was a runner-up of the 2010 Linda McEnhill Award. She told the conference how she used a wide-ranging set of educational measures and tailor-made meetings with learning disability care staff teams, to help them support people with learning disabilities at the end of life. Her talk was inspirational, with one delegate commenting: '*I wish Denise worked in my area!*', and another: '*I felt very inspired after this talk in having a go at developing services in my area.*'

The other runner-up was **Jason Davidson** (pictured), Senior Social Worker at St Joseph's Hospice in London. He outlined how he reached out and networked with a range of agencies and professionals, both within the hospice and in his local catchment area. Jason works in some of the most deprived areas of the UK, and he had many poignant examples that showed how much work there is to be done… including that of a son and daughter with learning disabilities he found hidden away in the home of a family he had known for months—he only came across these siblings when he asked to use the toilet! Many delegates found his talk inspirational. '*I could have listened all day,*' said one delegate.

Linda McEnhill, founder of the PCPLD Network and Palliative Care Social Worker in Scotland, wrote the important new guide from the National End of Life Care Programme, **The route to success in end of life care: achieving quality for people with learning disabilities**. Many people within the PCPLD Network contributed to this work, including a range of examples. All the previous speakers are in this publication somewhere! Linda outlined how and why the publication was developed. Delegated appreciated her presentation very much, and in the ensuing discussion several people said that the Route To Success had become their bible. It sets out very clearly what an optimal pathway for end of life care should look like. Delegates were also very pleased to find a copy of the publication in their packs.

Irene Tuffrey-Wijne, chair of the PCPLD Network and Senior Research Fellow at St George's University of London, presented her most recent research on breaking bad news to people with learning disabilities. This has resulted in a new model for breaking bad news. She explained how and why this new model was needed. For example, breaking bad news may be affected by the recipient's concept of time and future. Lots of delegates were nodding as Irene asserted that breaking bad news was a process, not a one-off event.

The last speakers of the day were **Paul Adderley** (pictured) and **Daniel Gower** from CHANGE. Paul told the conference that he has autistic spectrum disorder, and went on to explain how he worked at CHANGE to help make information accessible. He was involved in the making of the DVD **'We are living well, but dying matters'**, in which people with learning disabilities discuss what they want to happen when they die, and how they would like to be remembered (see back of this newsletters for details of where to access this). His talk was most highly rated of all, with one delegate giving it a mark of 11 out of 10!

The day also included a networking session, where delegates could share their experiences and ideas. Although some did not find this necessary, most appreciated the opportunity to meet people from different backgrounds and said it was very useful.

People came away from the conference inspired: *'It was well worth the trip from the North of England'.* Final comments included:

'I work in palliative care (community) so I have taken up some valuable pointers, eg breaking bad news, the importance of links and partnership working and most especially raising the profile of people with learning disabilities.'

'We are currently working on setting up end of life plans for all our residents and this day has been extremely helpful in giving ideas on how to approach the subject.'

'Lovely to hear how some people have developed their practice and that it is possible to get others involved with a little persuasion and a lot of hard work!'

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

Conference delegates share their experiences and ideas

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.

Annual General Meeting

The AGM was held during the conference on 20th October 2011. The chair, Irene Tuffrey-Wijne, presented the Annual Report (see page 6). She then outlined the content of the new proposed Constitution, which had been sent to all members beforehand, and explained why the changes had been proposed. This was followed by a short debate.

One amendment to the proposal was put forward: that the Steering Group includes a person with learning disabilities and a family carer. This amendment was voted on, and accepted (36 in favour, 15 against, 17 abstentions).

The proposed constitution was then voted on, and accepted (72 in favour, 0 against, 4 abstentions).

The new constitution will now be finalised and sent to all members in due course. It will also be available on our website.

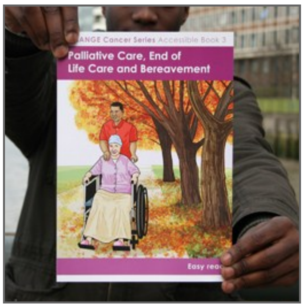
New accessible resources for people with learning disabilities

Some excellent new resources produced by CHANGE:

'We are living well but dying matters': A DVD to encourage people with learning disabilities to express their thoughts and questions about death, dying and planning for the end of life. You can order a copy, or download from the CHANGE website: **www.changepeople.co.uk**

Six easy-read accessible books about cancer

These illustrated books are for people with learning disabilities and their carers. Macmillan Cancer Support has bought thousands of copies to distribute free of charge, but they are not unlimited, so don't miss out: go to **http://be.macmillan.org.uk/be/s-428-accessible-information.aspx**



A new, improved website for Books Beyond Words:

Books Beyond Words tell stories in pictures to help people with learning and communication difficulties explore and understand their own experiences. Titles include "Am I going to die?" (see picture on page 5), "When Dad died", "When Mum died" and "When somebody dies". There is now a new website full of information about the books and how to use them, including on-line video tutorials. Go to **www.booksbeyondwords.co.uk**