PCPLD Network
Palliative Care for People with Learning Disabilities

CHAIR ANNUAL REPORT 2011

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)

Some current area representatives have written a report about their group's membership, activities, strengths and challenges (attached).

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 practice
- Our 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 large donation 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.

Here is a breakdown of our finances since 2009. PLEASE NOTE that in the 2011 column, significant income from the October 2011 conference has been processed, but no invoices have yet been paid – expected to total around £3,000.

	2009	**2010**	**Jan-Sep 2011**
Opening balance	1,115.32	2,625.23	8,751.63
Closing balance	2,625.23	8,751.63	10,314.01
INCOME			
Membership	1,915.00	1,215.00	25.00
Conferences	3,500.00	9,505.00	2,423.00
Other	270.00	5,265.00*	0.00
TOTAL	**5,685.00**	**15,985.00**	**2,448.00**
EXPENDITURE			
Conferences	2,613.56	5,946.06	363.08
Steering group	1,107.85	700.95	200.00
Website	0.00	2,749.57	208.94
Other	453.68	462.02	113.60
TOTAL	**4,175.09**	**9,858.60**	**885.62**

Includes £5,000 ring-fenced donation from Mencap for Website

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

Area Representative:
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

Area Representative:
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

Area Representative:
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

Area Representative:
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

Area Representative:
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

Area Representative:
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.