



**PCPLD Network**

Palliative Care for People with Learning Disabilities

## **CHAIR ANNUAL REPORT 2013**

*Irene Tuffrey-Wijne*

### **Introduction**

The National Network of Palliative care for People with Learning Disabilities was founded in 1998. At that time, very little was known about the palliative care needs for people with learning disabilities. People working in palliative care services thought there might be a learning disability expert out there somewhere who would know everything. People working in learning disability services thought that somewhere, someone would know everything about supporting their clients at the end of life. The Network started as small numbers of practitioners realising that no-one had all the answers, and that the only way forward was by sharing their experiences together.

Fast forward fifteen years, and we are in a very different place. We have a number of thriving local networks where dozens of committed professionals from both palliative care and learning disability services collaborate to offer outstanding end of life support to people with learning disabilities. We have local and national training events. There are useful publications, including good practice guidelines from Help the Hospices and the National End of Life Care Programme. There is an international team working to produce European norms for palliative care and intellectual disabilities. There is a growing body of relevant research. And with the explosion of the internet, all of this is available to people not only in the UK but around the world. People are meeting and tweeting.

Yet our original aims have not changed. We have dropped the “National” in recognition of the fact that we have gone well beyond our UK borders; we are networking in new ways; but our aims remain: to raise awareness; to share and promote best practice; and to enhance collaboration.

### **Membership**

We are a membership organisation. Previous membership fees of £25 per year were waived in 2011, which has widened our membership considerably. The Steering Group has reviewed this decision every year, and has agreed that free membership is affordable (as we have other income to sustain us) and desirable (as it enables true networking for all who need and want it).

Dec 2010	90 members
June 2011	163 members
Jan 2012	254 members
Oct 2012	315 members
Oct 2013	442 members

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.

Membership details are kept on a simple email list, without systematic postal details or details about members' backgrounds. Such information would be very useful, but it has simply been too time consuming to maintain more detailed lists. Currently, the list is used and kept updated by Karen Watchman, our new website coordinator.

## 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 coordinator (some areas have two representatives who share the role). We thank them all for their hard work in fulfilling this crucial role: without the coordinators, the groups would not be possible. Some of the area coordinators have written a report (see end of this chair report).

*We have the following area groups (area coordinators in brackets):*

**Continental Europe** (Catherine Hoenger)  
**Dorset** (Cheryl Egan and Hilary Lawson)  
**Hertfordshire** (Louise Jenkins)  
**Kent** (Helen Filmer and Sue Marsden)  
**London** (Jason Davidson)  
**Northern Ireland** (Dorry McLaughlin)  
**North West** (Carol Beaumont and Sharon Dewhurst)  
**Oxfordshire** (Maggie Coombes)  
**Republic of Ireland** Lasarina Maguire  
**Scotland** (Allison O'Donnell)  
**Wiltshire, Banes and Bristol** (Amelia Oughtibridge)  
**Yorkshire** (Amanda McKie)

*The following group is hoping to start this year:*

**Devon** (Annie Stewart)  
**North Somerset** (Amelia)

## How do the area groups work?

Each area group has a different way of working, depending on its members' needs. Some areas are geographically large, and therefore holding regular meetings may be more challenging. For the past few years, area group coordinators have reported that it is becoming more difficult for local members to negotiate time away from their usual work duties in order to attend meetings. In the current economic climate, it is also getting more difficult for some groups to negotiate free meeting space or refreshments. Several groups are considering a change in the way they operate, but investing more in fewer meetings, possibly turning them into mini-conferences with networking opportunities. Some groups keep active email lists.

Reflecting the above trends, each active area group can apply for up to £200 of PCPLD Network funding per year to support their group, for example, to organise meetings or mini-conferences. Funding will be provided at the discretion of the chair and vice-chair.

## 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.

The Steering Group has met twice this year (in June and November 2013). Minutes are available on request.

Each year, one third of the Steering Group membership stands down and nominations are invited for new Steering Group members (this could be from the person standing down; they can serve a maximum of two 3-year terms). New members are selected by the Steering Group. This month, the following members stood down:

**Pat Charlesworth** (representative with learning disabilities)

**Peggy Fray** (carer representative)

This means that those two specific positions are vacant. There is also an on-going vacancy for any member to join the steering group. These vacancies were announced to our membership. Peggy Fray has indicated that she is willing to stand again; no other carers have come forward for this position. Pat indicated that she does not wish to be the only person with learning disabilities standing for this position; she has introduced Peter Allum to the steering group, who is interested in joining and observed the June 2013 meeting. The steering group will select the new (or re-selected) members at its meeting on 5<sup>th</sup> November, and will present their selection to the AGM for ratification (6<sup>th</sup> November 2013).

In addition, **Karen Watchman** (our new website coordinator) has joined the steering group as an ex officio member.

Current Steering Group Members are:

1. **Irene Tuffrey-Wijne** (CHAIR) (Senior Research Fellow, London; Palliative care/LD nurse)
2. **Amelia (Milly) Oughtibridge** (VICE CHAIR) (Area manager North Somerset CTPLD))
3. **Pat Charlesworth** (REPRESENTATIVE WITH LEARNING DISABILITIES) (London)
4. **Margaret (Peggy) Fray** (CARER REPRESENTATIVE) (Lancashire)
5. **Maggie Coombes** (Oxford Area Coordinator; Palliative Care Nurse, Douglas House Hospice, Oxford)
6. **Jason Davidson** (London Area Coordinator; Palliative Care Social Worker, St Joseph's Hospice, London)
7. **Beverley Dawkins** (Mencap, London)
8. **Louise Jenkins** (Hertfordshire Area Coordinator; Team leader,
9. **Dorry McLaughlin** (N.Ireland Area Coordinator;
10. **Annie Stewart** (Associate Specialist in Palliative Medicine, St Luke's Hospice, Plymouth)
11. **Karen Watchman** (website coordinator)
12. **Vacant**

In the autumn of 2014, the positions of chair and vice-chair will become vacant. The chair is the only position that is selected through a majority vote from the full membership of the PCPLD Network; details will be sent in due course. Following this election, the position of vice-chair will be selected by the steering group.

## Newsletter

With the website and e-networking being taken to a new level, our traditional newsletter has been discontinued. Old issues are available through the website.

## Website

Our website ([www.pcpld.org](http://www.pcpld.org)), launched in 2010, continues to be very successful in sharing information, resources and news. Our main development this year is the appointment of a new website coordinator, whose task it is to manage the PCPLD Network emails, send out information to members, keep the website updated, and develop new e-networking opportunities (including social networking). There were three candidates for this position. The steering group selected Karen Watchman, by virtue of her involvement in the PCPLD Network, understanding of the issues involved, and expertise in developing websites and social networking. (Her own area of expertise is learning disability and dementia, and she has developed her own website). Because of the significant time commitment needed, the PCPLD Network pays her £200 per month.

Karen has done a fantastic job in managing our e-activities. The following have been achieved in the past year:

- The website is now updated more regularly
- Karen answers emails and processes membership requests
- The website was developed before browsing by mobile phone became popular. The website has now been re-programmed and a new mobile version has been added.
- Twitter and Facebook pages have been launched. The Twitter group is particularly active. There was a successful Twitter chat in October, hosted by LDnursechat.
- We have worked on adding a forum to the website, which is almost ready to go live. Anyone will be able to read posts to the forum, but you will need to log in to reply to a post or to start a new topic.

Over 5,600 people have visited our website in the past year (not counting repeat visits: these are all different people). Breakdown per country (top 25) is as follows:

UK	4,789	Germany	24	Greece	8	Isle of Man	5
Ireland	290	New Zealand	23	Switzerland	7	Austria	4
USA	154	Philippines	17	Norway	7	South Africa	4
Australia	80	India	15	Singapore	7	Brazil	3
Canada	31	Sweden	11	Ukraine	7		
Netherlands	28	France	9	Italy	6		
(not set)	26	Spain	8	Belgium	5		

## Conferences

In November 2012, we held a wonderful conference in Hertfordshire, with a focus on “Transition in palliative care for people with learning disabilities”. It was not as well attended as we had hoped, but it was extremely well evaluated. The day ended with a stunning performance by the Purple All Stars Drama Group of people with learning disabilities.

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.

## **Future conferences**

Organising a national conference is quite a lot of work. Last year, the steering group decided to focus our efforts on one, not two, major conferences each year, to be held in the autumn. The theme for this year's conference is *Loss and bereavement*, with Dr Noelle Blackman (a co-founder of the Network and international expert in the area of loss and learning disability) as keynote speaker.

We have received invaluable support from Help the Hospices in organising our recent conferences. Unfortunately, they are no longer in a position to provide such support. Anne Garley, who used to work at Help the Hospices, has agreed to help us organise our conference this year at a very reasonable price. However, it is not yet clear how we will manage to organisation next year.

We decided to move this year's conference to a central venue in Birmingham. (The feeling was that last year's less-than-expected attendance may be been due in part to its location.) This means that for the first time, our conference venue is not linked to a PCPLD Network member and their organisation. We have had to increase the cost of the conference to reflect this – although still very competitive at £100.

The conferences are our only source of income, yielding unpredictable and variable income (between £200 and £2,000 so far). We will have to assess next year whether this is sustainable, particularly in view of the likelihood that without Help the Hospices' support, it will cost us more to organise them.

## **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. This year the award was again judged by seven panel members: five senior practitioners in the fields of learning disabilities and palliative care; one person with learning disabilities; and one family carer. We have said before that the benchmark seems to be set higher every year, and this has continued. It is wonderful to see how previous winners are helping to set this benchmark.

Congratulations to the winners of the 2012 Award:

**Dr Ruth Brown**, Associate Specialist, Hertfordshire Community NHS Trust, Department of Palliative Care. *Category: "Practice and service development"*

Janice Byford, Family Carer and Wendy Broom Clinical Nurse Specialist for Older Persons, Neuro-Psychiatry Epilepsy and Memory Service, Truro. *Category: "Outstanding end of life care of an individual"*

Both will present at our conference in Nov 2013.

The winners of the 2013 Award will be announced at this conference.

## Financial report

I currently have the task of administering the organisation's finances, dealing with in- and outgoings, and keeping accounts. We are still 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 healthy at present. We try to keep Network running costs to a minimum; all of us give our time freely, although we pay expenses for steering group and other meetings, and we decided to pay for a website coordinator in recognition of the workload involved. Last year, the Steering Group decided that most of our current financial assets should be used for developing the website and supporting area groups.

### Finances Jan-Sep 2012

Opening balance      **15,726.44**  
Closing balance      **16,441.10**

*(please note that there has been conference income, but as conference expenditure for Nov 2013 has not yet shown in the accounts – this is likely to be over £10,000)*

#### INCOME

Conferences            6,203.00  
TOTAL                    **5,380.00**

#### EXPENDITURE

Conferences            1,564.16  
Steering group        586.80  
Website                2,112.78  
LMcAward              107.00  
Area groups            294.60  
TOTAL                    **4,665.34**

## Finally

I am honoured to have been chair of the PCPLD Network for the past five years. As six years is the maximum length of service, this will be my final year in this role. I will be looking to hand on the baton soon. There are several ways in which you can become more involved in this wonderful, friendly and supportive organisation: becoming more active in your local network (or even setting one up, if you don't have a group in your area); joining in with the electronic networking and sharing of resources; or perhaps finding out more about serving on the steering group. I am certainly looking forward to the year ahead!



**Irene Tuffrey-Wijne**  
*Chair, PCPLD Network*



7<sup>th</sup> November 2012

## **Area Coordinator Reports – October 2013**

### **London** (*Report by area coordinator Jason Davidson*)

2013 has been a time of great change for the London group. For well over ten years there has been a strong cohort of approximately eight to ten dedicated individuals who met up four times a year at the Respond offices in Euston. In 2012 we used some of those meetings to think about the future of the London wide group and explored ways we could widen the network especially as we had identified several gaps in areas of London where we had not had any representation. We agreed to change the format of the meetings and instead hold just two meetings a year but make them larger events, almost like mini conferences. We called them learning events.

So, in April of this year after a lot of marketing and advertising and the generosity of others we held our first event at St Joseph's Hospice in East London. We had two fantastic guest speakers (Irene Tuffrey-Wijne and Linda McEnhill) who kindly offered their time, expertise and wisdom to launch these events. We had an overwhelming response and over 60 people registered their interest with well over forty turning up on the actual day. The feedback was really positive. I used this event to ask members of the audience to volunteer to present at our next event which we have just held.

Five people volunteered to present from both palliative care and learning disabilities services across London, sharing their experiences and good practice. Again we had over forty people in attendance and the feedback was really positive. And again we have a list of volunteers preparing presentations for our next event in April 2014.

In addition to this our email contact list has grown this year from approx 35 names to 86!

### **Northern Ireland** (*Report by area coordinator Dorry McLaughlin*)

Contact between members of the PCPLD network, and other interested people, has been electronic with no face to face meetings since the PCPLD Network conference last year. This is mainly due to the current economic climate. However, discussions are on-going between Dorry McLaughlin and Lasarina Maguire, the area coordinator in the Republic of Ireland, with a view to the planning of a joint face-to-face All Ireland Event for members in 2014. In addition an article highlighting the work of the PCPLD Network, contact details and role of the two area coordinators in Ireland, has been published in the bulletin of the Irish Association of Palliative Care.

Partnership between learning disability and palliative care services continues in Northern Ireland although patchy. There is now input of palliative care for people with learning disabilities in the pre-registration nursing, undergraduate learning disability and adult branches. This is also taught in some of the post-registration nurse training. Funding applications are planned for further research studies on palliative care for people with learning disabilities and family carers and for knowledge transfer from research that has been completed.

**Oxford** *(Report by area coordinator Maggie Coombes)*

The Oxford branch meets 4 times a year at Douglas House in Oxford . We meet over lunch time 12.30 to 14.00. Numbers vary from 3 to 10. Usually we have a discussion about an issue which is topical for those present and twice a year we invite a speaker along.

**Republic of Ireland** *(Report by area coordinator Lasarina Maguire)*

I have been in regular email contact with the member passing on all updates from the Network and updates of local interest . I have been trying to encourage active networking with somewhat limited success. I have made two presentations to groups about the network and one of which is on the NNIDI webpage @ [www.nnidi.com](http://www.nnidi.com).

**Scotland** *(Report by area coordinator Allison O'Donnell)*

We are holding an afternoon event following the Conference covering the same issues- around Bereavement loss and Grief on the 26<sup>th</sup> November 2013. We aim to use this opportunity to Network and discuss how we best meet the needs of such a large geographical group. It is hoped that we can hold similar events at least on an annual basis. We will be making an approach to the Network for £200 to help us facilitate this and we plan to discuss on the day how we finance similar opportunities, again given the logistics of such a large geographical area.

**Devon** *(Report by Annie Stewart) (GROUP NOT YET STARTED)*

I am based at St Lukes Hospice in Plymouth , Devon and have been involved in teaching on our Six steps EOL programme for learning disability which has been produced and managed by Mrs Paula Hine ( Education coordinator for St Lukes Services)

This teaching programme has brought together many different learning disability health care professionals, and it has been my intention to establish a group here in Devon. At the very least, this will be an email group with the aim of arranging a local annual meeting.

We would aim to involve anyone involved in the LD sector who lives or works in Devon and Cornwall. If anyone wishes to join our intended group please contact me, Dr Annie Stewart on [annie.stewart@stlukes-hospice.org.uk](mailto:annie.stewart@stlukes-hospice.org.uk)

**Wiltshire** *(Report by area coordinator Amelia Oughtibridge)*

The Wiltshire group has not been active this year. Amelia and some of the other key people in Wiltshire who kept the group active have left or gone on maternity leave!

However others are still very active-Denise Heals of Dorothy House Hospice continues in her role working with providers and carers to support the palliative care needs locally. The



hospice held a conference on the 10<sup>th</sup> October 2013 during which Denise asked delegates to show their interest in a local group. The results of which are still to be established. .

The conference show cased some innovate and interesting work that the Hospice is doing, involving people with learning disabilities in developing accessible information about the hospice services and its related work.

**North Somerset** (*Amelia Oughtibridge*)

Amelia is now working in North Somerset and is very active in the partnership board and its health groups. There is a lot of proactive work going on in North Somerset which Amelia would like to connect to the PCPLD network. Work towards formalising this will happen in the New Year.