



**PCPLD Network**

Palliative Care for People with Learning Disabilities

## **CHAIR ANNUAL REPORT 2014**

*Irene Tuffrey-Wijne*

### **Introduction**

This is my last Annual Report. After six years as chair of the PCPLD Network (the maximum allowed mandate), it is time for me to step down.



It has been a real privilege to serve as chair of such a wonderful organisation. Wonderful, not only because of its important aims and objectives and its inspirational work, but also because of the passion and commitment of its members. This is perhaps most evident during our annual conferences, which always feel like a meeting of old and new friends. Supporting people with learning disabilities at the end of life can sometimes feel like a lonely endeavour. The Network reminds us that we are not alone. I always come away from our local meetings or national conferences feeling inspired and uplifted.

Looking back over the last six years, a lot has changed...

- Our membership has grown from under 100 to over 600.
- Back in 2008, we had no website (this seems almost impossible to imagine now!), so networking happened mostly through local meetings.
- The Linda McEnhill was introduced in 2008 and has gone from strength to strength, providing an excellent benchmark for good care. Many of the winners have inspired others to achieve similar outstanding care.
- Perhaps most significantly, the issue of palliative care for people with learning disabilities has become much more “mainstream”, no longer just the concern of dedicated individual practitioners, but picked up by national organisations. I believe that the PCPLD Network has played a significant part in this.

During the past eight months, I have not been able to attend to my duties as chair in the way I would have liked, because of on-going treatment for breast cancer (with a good outlook, so no need to worry), as well as a family bereavement. This has had some unexpected and positive effects. It has made me experience both cancer and end-of-life care from the inside, which brings an entirely new perspective. I am now filled with even more admiration for people with learning disabilities who cope with serious illness, gruelling treatments and physical decline. But it has also highlighted the care, support and recognition we need to give to families and carers. No two patients (or carers) are the same. We need to find what their stories are, their strengths, and their vulnerabilities.

This year has made me realise yet again how many fantastic members our PCPLD Network has. The Steering Group members have kept things going in my absence. This is my chance to say THANK YOU to them.

## Peggy Fray

This year saw the sad loss of Margaret (Peggy) Fray, who died in April 2014 at the age of 90. Peggy was a long-standing supporter of the PCPLD Network. She was the carer representative on our Steering Group for many years.

Peggy cared for her sister Kathleen, who had Down's Syndrome, until Kathleen's death in 1997. She used that experience to advocate for the needs of people with learning disabilities (and especially those with Down's Syndrome and dementia).

Peggy was highly committed to our work, making a huge effort to travel to meetings and conferences, even when she was increasingly frail. She would turn up good humoured and looking stylish. Her final contribution to the PCPLD Network was the judging of the Linda McEnhill Award 2013. We will miss her friendship and wisdom.



Peggy Fray (centre) presenting the Linda McEnhill Award in 2012

## Membership, website and social media

Membership of PCPLD Network is free of charge. A simple email membership list is kept, and members are kept informed of events and items of interest through occasional emails. Membership has increased from 442 members in Oct 2013) to 606 members in Nov 2014).

### ***Karen Watchman, our website and social media coordinator, reports the following:***

We have 502 followers on Twitter and this has been our most successful means of engagement through social media. We have 91 members in our LinkedIn group and our Facebook page has 78 'likes'. We share our PowerPoint presentations on a new slideshare page following the conference last year, with the different presentations viewed between 300 and 900 times each. The forum added to our website was short lived as unfortunately we were vulnerable to spammers and received tens of thousands of spam emails, most of a dubious nature, so this was a very short lived venture.

The rise in awareness created through social media has been echoed in the website views with 3,415 unique views over the past twelve months, and 11,227 page views in total. 70.8% were new to the site and 29.2% were return views. 76.20% were from the UK, 6.18% from Ireland, 3.84 from the USA, 2.77% Brazil and the remaining visits from Australia, Canada, Germany, Netherlands, France and India.

A new research page has been added to the website although we do rely on members to keep us informed of local and national updates.

## 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).

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. Several groups have changed the way they operate, investing more in fewer meetings, almost turning them into mini-conferences with networking opportunities. Some groups keep active email lists.

**We have the following area groups:** Dorset, Hertfordshire, Kent, London, Northern Ireland, North West, Oxfordshire, Republic of Ireland, Scotland, South West, Yorkshire.

**The following groups are no longer active:** Continental Europe, Wiltshire/Banes/Bristol.

There has been interest and inquiries from several other areas within the UK about starting a new group.

## 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.

### *Steering group membership*

This year, the following members left the Steering Group. We thank them for all their work.

- **Amelia (Milly) Oughtibridge** (PCPLD Network Vice Chair 2008-2013)
- **Maggie Coombes** (Oxford Area Coordinator; Palliative Care Nurse, Douglas House Hospice, Oxford)
- **Pat Charlesworth** (Representative with Learning Disabilities) (London). *Pat continues to attend Steering Group meetings in a new role as 'buddy' and supporter for the new Learning Disability Representative*
- We also lost **Peggy Fray**, carer representative.

Current Steering Group Members are:

1. **Irene Tuffrey-Wijne** (Chair) (Associate Professor in Nursing; Palliative Care/Learning Disability Nurse, London)
2. **Peter Allum** (NEWLY APPOINTED Learning Disability Representative, London)
3. **Jason Davidson** (London Area Coordinator; Patient and Family Support Team Manager, Marie Curie, London)
4. **Beverley Dawkins OBE** (CEO of Generate, London)
5. **Louise Jenkins** (Hertfordshire Area Coordinator; Health Liaison Team Lead Nurse, Learning Disabilities, Hertfordshire)
6. **Dorry McLaughlin** (N.Ireland Area Coordinator; Lecturer in Palliative Care and Chronic Illness, Belfast)
7. **Allison O'Donnell** (Scotland Area Coordinator; Practice Development Coordinator, Palliative Care, Glasgow)
8. **Annie Stewart** (Associate Specialist in Palliative Medicine, Plymouth)
9. **Karen Watchman** (PCPLD Network Website Coordinator; Alzheimer Scotland Lecturer in Dementia, Hamilton, Scotland)
10. **Jean Willson OBE** (NEWLY APPOINTED Carer Representative, London)

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, giving consideration to the balance of available skills and expertise.

The following Steering Group members are standing for re-selection this autumn: Jason, Louise, Dorry, Irene. We have received a further four nominations. As there are a maximum of 12 places on the Steering Group, there are a total of six vacancies. The steering group will (re-)select the members at its meeting on 25<sup>th</sup> November, and will present their selection to the AGM for ratification (26<sup>th</sup> November 2014).

### *New Chair*

The position of Chair is open to election by the full membership (if there is more than one nomination). All members were notified of this year's vacancy. Only one nomination was received: **Jason Davidson**, current Steering Group Member and London Area Coordinator. Following our constitutional rules, an election is therefore not necessary. Jason will (hopefully!) be proposed and seconded as new chair during the forthcoming AGM on 26<sup>th</sup> November, and his new position will take effect at the end of that meeting.

### *Steering Group meetings*

Because of its geographic diversity, with Steering Group members in Cornwall, Northern Ireland and Scotland, it has become too onerous to hold our biannual meeting in person, both in terms of financial and time commitments. We have therefore held two telephone conference meetings, with a physical meeting planned to coincide with our autumn conference. There has also been much email contact about progress and decisions. We will review these virtual meetings, paying particular attention to the challenges for our Steering Group members with learning disabilities.

Minutes of the Steering Group Meetings are available on request.

## **Membership survey**

In September 2014 we conducted a membership survey using survey monkey; this was completed by 67 members. Primarily we wanted to find out about website use and relevance of our correspondence. 66 of the 67 respondents had accessed the website with the majority doing so every three to six months; information, events and links to similar organisations were the most commonly visited web pages.

The majority of respondents had not visited our social media pages with little difference in preference among those who had. The majority had attended a PCPLD network conference previously, with time and money being the primary reason for not attending, although one respondent did say 'because I live in Australia!'.

32 respondents had not attended a local event, with the reason for not attending usually being that there was not a group in their local area.

Email communication was positively received as very helpful (72%) or slightly helpful (28%).

40% of respondents would pay between £5-£10 for membership fees although it was noted that most would need to pay this themselves as it would not be supported by employers, we also received a request to clarify how the fee would be spent.

The majority of respondents were learning disability professionals (55%), palliative care professionals (18%) and academic staff (11%). The remainder were social care staff, family carers, volunteers, students and a chaplain.

## Conferences

In November 2013, we held a wonderful conference in Birmingham, with a focus on “Loss, bereavement and end-of-life care for people with learning disabilities”. It was extremely well evaluated.

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.

During the 2013 AGM, members said that they appreciated the excellent, professional venue (a good hotel near the railway station), but wanted to keep the delegate cost at £100 maximum. With this in mind, we have used a similar venue for the 2014 conference in Glasgow, with delegate cost set at £100 (projected to break even if there are around 80 paying delegates). 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 after the 2014 conference whether this is sustainable.

## 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.

Congratulations to the winners of the 2013 Award:

**Liz Smith and Allison O'Donnell**, Project Leads, The Prince & Princess of Wales Hospice (PPWH), Glasgow. *Category: “Practice and service development”*

**Staff team of KEY Community Supports**, Glasgow. *Category: “Outstanding end of life care of an individual”*

Both sets of winners will present at our conference in Nov 2014. The winners of the 2014 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 fortunate to have found **Steve Mitchell**, a volunteer with considerable skills in auditing charity accounts. Steve has scrutinised our accounts for 2013. See attached financial balance sheet and breakdown. Further details and breakdown of finances are available on request.

One of Steve's recommendations is that all financial transactions, however small, require two people to authorise them. (At present, only I can authorise payments.) This will protect

both the PCPLD Network and the individual. We are currently in the process of setting this up.

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.

We will need to reassess the sustainability of our expenses, as we do not currently have any income except through conferences. This is, as stated above, highly unreliable. Our financial resources have reduced in recent years as conferences have more or less broken even, rather than yielded a profit.

## **Charitable status**

Currently, the PCPLD Network has no formal status as a company, charity, social enterprise, community interest company or otherwise. This is unsustainable, not least because over the past five years, we have had an annual income of between £5,000 and £15,000 (through donations and conference fees). Therefore, we need to think about income tax, accountability and liability.

In addition, the PCPLD Network has grown in size and status. It is seen by other organisations and individuals as a worthwhile organisation which deserves support. The Steering Group believes that gaining a formal, recognisable status is an important step forward.

Over the past year, the Steering Group has researched a range of options, including becoming a charity, a social enterprise, or a community interest company. We have sought independent professional advice on these options, and has debated them extensively. In October 2013, the Steering Group recommend to the membership that the PCPLD Network should register as a Charity, and has asked members to express any questions or concerns. A decision on the way forward will be taken at our next meeting on 25<sup>th</sup> November.

If we decide to gain charitable status, we will need to amend our constitution, which will require a membership vote. Watch this space.

## **Finally**

I would like to thank all of you who have supported the Network over the past six years. This feels like the end of an era, but also the beginning of one. I am looking forward to seeing where the Network will go in the years ahead, and I will offer my continuing support.



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

*12<sup>th</sup> November 2014*

# Financial Balance Sheet 2013

Balance Sheet

**PCPLD Network**  
Cranmer Terrace, London SW17 0RE

**Balance Sheet**

	2013 £	2012 £
<b>Fixed Assets</b>	<u>0.00</u>	<u>0.00</u>
<b>Current Assets</b>		
Cash at Bank	8,027.40	15,726.44
Debtors	<b>1</b> <u>1,680.00</u>	<u>15,726.44</u>
	<u>9,707.40</u>	<u>15,726.44</u>
	<b><u>9,707.40</u></b>	<b><u>15,726.44</u></b>
 <b>Represented By</b>		
Unrestricted	<u>9,707.40</u>	<u>15,726.44</u>
	<b><u>9,707.40</u></b>	<b><u>15,726.44</u></b>

**Note 1**

The 2013 conference attracted 111 paying delegates but as at the 31st December 2013, income had been received for 90 delegates. An assumption has been made that the remaining 21 delegates will pay the discounted rate of £80.

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

Independent Examiner,

I have examined the books and accounting records presented to me and found them to be a true and fair representation of the activities of the PCPLD Network

Signed Steve Mitchell Dated 25/3/2014  
Steve Mitchell

## Breakdown of income and expenditure 2013

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### PCPLD Network Cranmer Terrace, London Sw17 0RE

	2013 £	2012 £
Income		
Conference Income	10,645	8,293
Other Income	0	5,000
	<u>10645</u>	<u>13293</u>
 Expenditure		
Conference Fees	10,873	5,331
Website	3,777	222
Linda McEnhill Award	884	845
Steering Group	836	375
Area Groups	295	
Other Expenses	0	341
	<u>16,664</u>	<u>7,114</u>
 Surplus/(Deficit)	-6019	6179
 B/fwd	15726	9547
	<u>£9,707</u>	<u>£15,726</u>

## **Area Coordinator Reports 2014** *(NB Not all area coordinators have sent a report)*

### **Dorset** *(Report by area coordinators Val Cope and Jill Mildon)*

The Dorset group has had a change of Co-ordinators this year as Jo Findlay and Cheryl Egan stepped down and two new Co-ordinators were elected. Jo and Cheryl were founder members of the group and it is thanks to their hard work that we have made some really good progress in Dorset. During their time as Co-ordinators the group was founded and the membership was grown to its present level of 51 members. The End of Life Care Resource Pack was put together and made available to all those caring for people with a learning disability on the Dorset County Council website. This can be viewed by anyone who wishes to at: <https://www.dorsetforyou.com/end-of-life-care> in the Resources section.

This year the new Co-ordinators, Val Cope and Jill Mildon, have built on this work and the Resource Pack has been updated in light of some of the changes that have taken place with regard to the Liverpool Care Pathway in particular. A new document has been added to the pack which helps care home staff to identify how to support people to remain in their own homes, rather than be taken to hospital, when it would be more appropriate for them to stay in familiar surroundings with people who know them well. We are currently asking residential homes to pilot this tool and to feedback to us early next year. Two of our pilot sites are homes that are also currently undertaking the Gold Standard Framework accreditation for End of Life Care.

We also have a local conference/workshop planned for April 2016, which will focus on planning care for those who would prefer to be cared for in their own homes and how this can be achieved. It promises to be an inspiring day and we have some excellent speakers lined up.

In Dorset we have found that, as is probably the case in most other areas, it is difficult for all members to be able to meet up regularly. We have a core group that we now refer to as a 'steering group' that meets to plan the work and all other members receive regular email updates to keep them informed of latest developments. This seems to be working so far!

We are really looking forward to next year's event and hope that this will inspire all those who attend to keep up the good work.

Lastly, we would like to say a big thank you to Jo and Cheryl for all their hard work over the last three years. We hope to continue where you have left off and to make sure that excellent end of life care is available to all people with a learning disability in Dorset.

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

The London area group has continued to attract new members over the last 12 months. We held two successful learning events, one in April and the other in October. We are extremely fortunate as St Joseph's Hospice in Hackney continue to offer us the use of their brilliant education facilities to hold our events, thank you St Joseph's! These learning events were well attended although there were fewer people at the October event but this could have been due to the school half term. The events run for 3 hours, always on a Tuesday afternoon and they are a mixture of bite size presentations and networking opportunities where members get to share good practice and have tea and biscuits! We always welcome new faces at each event which is brilliant. In April we had approximately 40 attendees and at least 8 of these were new members.

I would like to take this opportunity to thank all of the London wide membership for their continued support and dedication to the network. The learning events are only a success because of your commitment. You have shared some incredible work over the last 12 months and I know this is just a tiny fraction of the care, support, innovation and development that goes on every day in your day to day jobs. We have heard about the use of art therapy for those who are bereaved, the design and implementation of local palliative care pathways, the delivery of training and education to both learning disability staff and palliative care staff. We have heard case studies of incredible person centred care given by individuals and teams working together with joint approaches. However, we also continue to hear stories where it doesn't work, stories that shock us and remind us that we still have a lot to do. It is those stories that remind us of the importance talking and sharing and networking. I look forward to the next 12 months.

**N. Ireland** (*Report by area coordinator Dorry McLaughlin*)

Northern Ireland and the Republic of Ireland are planning a joint Master Class on Palliative Care for People with Learning Disability next year under the auspice of the PCPLD Network. This was originally planned for 2014, but due to other circumstances was postponed until 2015. In addition Master Classes in this area of practice are being hosted by Health and Social Care Trusts. Dorry McLaughlin (QUB/ Area Rep), Owen Barr (Ulster University) and Vivienne Williamson (Lead Speech and Language Therapist) facilitated a Master Class in Southern Health and Social Care Trust attended by 80 people in September 2014. The PCPLD Network and website was promoted at this event. Other Health and Social Care Trusts in Northern Ireland are expressing interest in replicating this event. Teaching in undergraduate learning disability and adult nursing programmes has palliative care for people with learning disability input and promotion of the PCPLD Network and website to students.

**North West** (*Report by area coordinator Carol Beaumont*)

I have just re-launched the North West group at a fantastic launch event on 17<sup>th</sup> October, shared with the Yorkshire group (see Amanda McKie's report below). Lots of interesting speakers and over 70 attendees. I have set two dates for 2015 meeting to be held here in the North West and so I am hoping to have a look what's out there and what needs to be out there in terms of end of life care - treatments and support for patients and their cares and families. Plans in place, so next year will be a better year for us here in the North West.

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

In Oxford we have continued to meet every 3months at Douglas House Hospice and have had various numbers at the meetings from 3 to 6 members we have had various discussions around learning disabilities and palliative care. On November 18th we are holding a study morning and have got a group of learning disability actors who are going to do a session on DNR, we are hoping from this that we will have more interest in the meetings and are open to suggestions on how to move forward.

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

Membership of the network in the Republic of Ireland has continued to grow in 2014. This year there was an increase in requests from members requesting examples of policies guidelines or protocols relating to both palliative care and end of life care for people with an Intellectual Disability. Another welcome development has been the recognition by national groups and organisations that the PCPLD Network is an important platform for them to share their latest publications or updates. The joint face-to-face All Ireland Event for members that was due to take place in 2014 is now planned for 2015 by both myself and Dr. Dorry McLaughlin. Contact between members of the PCPLD Network has been electronic with no face to face meetings since the PCPLD Network conference last year. Other activities that I as Area Representative have been involved in include working with the Irish Hospice Foundation "Changing Minds Programme". Indeed we have a joint poster that will be displayed at this year's annual PCPLD conference in Glasgow entitled "The Palliative Care Needs of People with an Intellectual Disability & Dementia: A Literature review".

**South West** (*Report by Annie Stewart*) (*GROUP NOT YET STARTED*)

I had intended to set up an email group, and following last year's conference, contacted all South West attendees. A few people responded with contact details but I have not taken anything further. I will re-look at establishing this group in the coming year with the minimum aims of sharing local best practice & encouraging local cooperation.

**Yorkshire** (*Report by area coordinator Amanda McKie*)

The group met twice this year, the first time in January with the lead for end of life care from NHS England who was reviewing the end of life strategy and requested the views of professionals to see if the national strategy met the local needs of people with learning disabilities. He listened to patient stories and professionals in both their concerns and achievements. The group felt valued and that their professional voices had been heard about what made good end of life care for people with learning disabilities.

The second meeting was a network event to try and widen the membership of the group. We held a full day of presentations from speakers from both the Yorkshire and North West groups, showcasing the good practice in end of life care. From training packages in end of life care in care homes, to decision making about DNACPR training DVD, to dementia pathways. Over 60 people attended and it received positive feedback. We now have over 80 members on the email circulation list in the Yorkshire region and continue to have great support for the PCPLD network and continue to promote good practice and network to support professionals locally.

The group will continue to meet twice yearly at Kirkwood Hospice in Huddersfield and have a virtual network using emails as needed.