



PCPLD Network

Palliative Care for People with Learning Disabilities

CHAIR ANNUAL REPORT 2012

Irene Tuffrey-Wijne

Introduction

Fourteen years after the founding of the Network, the issue of palliative care of people with learning disabilities has now entered the mainstream. Whereas in the past the vast majority of our members were staff working in learning disability services, we now have growing numbers of palliative care professionals joining us. Palliative care services may previously have had little experience of and exposure to people with learning disabilities, but this is clearly changing.

I have been chair for four years, and every year the work of our members seems to go from strength to strength. This is particularly evident when it comes to judging nominations for the Linda McEnhill Award. There are so many excellent developments and initiatives, from partnership working to developing tools and guidelines, that I could not possibly list them all! The PCPLD Network has undoubtedly played a part in this by bringing professionals from diverse backgrounds together, and by helping those working with people with learning disabilities at the end of life feel less isolated.

We are also gaining an international profile, with people and services from other countries across the world looking to us as experts. I notice this when I attend international conferences. I also get occasional emails and new members from countries as far away as Canada and New Zealand. Our members are getting involved in international initiatives (for example, a new Taskforce for the European Association of Palliative Care, which I chair. This aims to set European standards for palliative care of people with learning disabilities, and would not have happened without our Network's members, networking, expertise and activities). The primary aim of the PCPLD Network is networking, not developing guidelines and standards – but it is clear that such networking can lead to the development of good practice, whether on a local level or on an international level!

Membership

We are a membership organisation. Previous membership fees of £25 per year were waved 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

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.

We have 18 non-UK members: in Australia, Canada, Germany, Rep Ireland, Netherlands, New Zealand, Norway, South Africa, Switzerland and the USA.

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 myself.

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.

The following area coordinators have stood down since 2011, and we thank her warmly for all her years of work:

Derbyshire (Debra Cooper).

There is no new coordinator, so this group has disbanded.

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

Continental Europe (Catherine Hoenger)

Dorset (Cheryl Egan and Hilary Lawson)

Hertfordshire (Louise Jenkins)

London (Jason Davidson) *This was previously "London and Home Counties", but we now have groups in Kent and Hertfordshire, so this group is now focused on London)*

Northern Ireland (Dorry McLaughlin)

North West (Carol Beaumont and Sharon Dewhurst)

Oxfordshire (Maggie Coombes)

Wiltshire, Banets and Bristol (Amelia Oughtibridge)

Yorkshire (Amanda McKie)

Two new groups have started this year:

Kent (Claire Hall and Helen Filmer)

Scotland (Allison O'Donnell)

There are seeds for a new group in Rep Ireland.

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.

Support for area groups

Reflecting the above trends, the steering group has decided that 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. This decision will be reviewed next year.

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 January and November). 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:

Deb Cooper
Beverley Dawkins
Amanda McKie

Of these three, **Beverley Dawkins** stood again and was re-selected. Also nominated and selected as **Annie Stewart** (Associate Specialist in Palliative Medicine, St Luke's Hospice, Plymouth). Both are presented to the AGM for ratification.

Current Steering Group Members are:

1. **Irene Tuffrey-Wijne** (CHAIR) (Senior Research Fellow, London; Palliative care/LD nurse)
2. **Amelia (Milly) Oughtibridge** (VICE CHAIR) (Specialist Health Team Co-ordinator and Lead Nurse, Wiltshire Learning Disability Services)
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. **Vacant**

The first 4 positions are up for re-selection in autumn 2013. My position as chair could be extended by the Steering Group for a final year (up to November 2014), when I will have served the maximum 6 years as chair; therefore, nominations for the position of chair are only open next year if I chose to stand down (and if I do, I will inform the membership in due course). Therefore, next year, there will be 3 places open for nominations. This includes both the representative with learning disabilities and the carer representative; these places must be filled as such. As we only have very few carers and people with learning disabilities amongst our members, I would ask all members to help us think about possible people who may want to fill those positions. Please speak to any member of the Steering Group if you have any ideas or suggestions.

Newsletter

I'm afraid I haven't managed to write any newsletters this year! It is quite a time consuming task (however enjoyable). I will do my best to produce another one this year. Any help is most welcome!

Website

Our website (www.pcpld.org), launched in 2010, continues to be 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. We would like to see an interactive area for on-line networking and a presence on Facebook and Twitter, as well as more regular website updates.

Thanks to some generous donations, we now have some funding to support the development of the website. We are looking for someone who is able and willing to work on this, maybe for a couple of hours every week; hours and remuneration will need to be negotiated. If you, or someone you know, is interested, please contact me.

Conferences

In June 2012, held a very successful conference in Antrim (N.Ireland), with the theme "New developments in palliative care for people with learning disabilities". It was extremely well evaluated. The highest ever evaluation scores were received by the group of singers at the close of the conference (all with learning disabilities), with some delegates trying to give them 11 or even 100 out of 10!

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.

We have received invaluable support from Help the Hospices in organising our recent conferences; without them, it would have been difficult for us to put on such a successful event. Thanks to Anne Garley, Ruth Reid and Irina Orlova.

The cost of our conferences has been low compared with similar events, £80 with a concessional rate of £40.

Future conferences

Despite the wonderful help from Help the Hospices, organising a national conference is quite a lot of work. The Steering Group has decided to focus our efforts on one, not two, major conferences each year, to be held in the autumn. This is partly in recognition that there is now so much expertise and local activity, that we are beginning to see some excellent local conferences. The PCPLD Network will support Area Groups who wish to put on a local event, both financially and through sharing resources.

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 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. Five of these judges have been on the panel since the start of the award. They have been struck by the quality of nominations. The benchmark seems to be set higher every year. It is wonderful to see how previous winners are helping to set this benchmark.

Congratulations to the winners of the 2011 Award:

Sharon Hicks, staff nurse, Severn Hospice Shropshire and Telford & Wrekin in the category "Practice and service development": *Widening Access to Severn Hospice for people with a Learning Disability*

Staff from **Fallstaff House** in the category "Outstanding end of life care of an individual" (*Tim's Story*). Both will present at our conference in Nov 2012.

The winners of the 2012 Award will be announced at this conference.

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 is currently reviewing how they support organisations like ours, and I will keep members informed of any changes.

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 very healthy at present. This is mostly due to some very successful recent conferences, and to a generous £5,000 donation from Macmillan Cancer Support, for which we are most grateful. 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. The Steering Group has 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	9,751.63*
Closing balance	17,263.96

INCOME

Conferences	6,203.00
Donations	5,000.00**
TOTAL	11,203.00

EXPENDITURE

Conferences	2,618.53
Steering group	304.45
Website	221.76
Other	341.00***
TOTAL	3,485.74

*Includes previous ring-fenced £5,000 donation from Mencap for Website, of which there is around £1,700 left for website maintenance

**Donation from Macmillan Cancer Support – for non-specified expenditure

***includes £250 for consultancy (constitution writing)

Finally

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!



Irene Tuffrey-Wijne
Chair, PCPLD Network



7th November 2012