



PCPLD Network

Palliative Care for People with Learning Disabilities

CHAIR ANNUAL REPORT 2015

Jason Davidson

Introduction

It's hard to believe that it's already just over one year since I was nominated as Chair of the network and here I am putting together my first Chair's report.

One of the first things the chair does in sitting down to write their report is gather information from all of the local area groups to find out what has been happening. And what a year it's been! You will see later in the report what has been going on locally but I must say I'm quite blown away by the continued networking and sharing of good practice and shared learning that has been going on across the whole of the UK since November 2014. I would like to say a huge thank you to all of the Area Coordinators for such incredible work and as coordinator myself; I know this is never an easy task. We are lucky to have you all on board. I would also like to thank each and every member and supporter of the network and urge you in the year ahead to keep networking, sharing and having these important conversations.

The following list summarises what our network steering group has been up to over the last year:

- We realised that we needed to get better at supporting our Area Coordinators. I am pleased to say that we devised a new volunteer role within the steering group of *Area Coordinator Support*. Amanda McKie took up this role and has been making headway in mapping out all of our area groups across the UK, improving our connections with all of the area leads and finding out from them what they would like from us as a network. This role has been a valuable addition to the network and I know will help us strengthen our groups nationally for the future.
- Our website continues to be well used and we are seeing an increase in hits from all over the world. We are aware that the technology our website works off is fast becoming out of date and so our plan for the next twelve months is to improve on this and have it updated. We have also seen a growth in our use of social media and we plan to expand on our use of twitter, LinkedIn and Facebook and think more creatively about these and other forums in which we can continue our conversations.
- As mentioned in our 2014 report the PCPLD Network has no formal status as a company, charity, social enterprise, community interest company or

otherwise. This continues to be unsustainable. Over the last year the steering group have worked really hard, gathering information, exploring options and discussing the pros and cons. We have enlisted independent professional advice which has been invaluable and we are getting closer to making a final decision. As a steering group of individuals who are dotted all over the country it has been a real challenge to carry out this work and we realise it takes time. The whole group are committed to this and we hope that we will be in a position to include the whole PCPLD network membership in the next steps by spring 2016.

Membership

Membership of the PCPLD is free of charge and simple to do. You can register as a member via our website. A simple email list is kept and members are informed of events and items of interest through occasional emails.

Conferences

Last year's conference was held at the Radison Blu Hotel in Glasgow, Scotland in November 2014. The feedback from the conference was really positive and the event certainly helped our Scottish group put the PCPLD network further up on the map (literally!). This year our 2015 conference will be held in London on Monday 16th November and the focus of the day will be carers and family carers. We hope to see you all there. As soon as this conference is over we will begin planning our 2016 conference and we already have a range of ideas so watch this space.

Linda McEnhill Award

The Linda McEnhill award has been running now every year since 2008. There are two categories for the award. One category recognises the work of an individual or team who have improved end of life care for people with learning through their practice and/or service development and the other category recognises the outstanding care of an individual.

Congratulations to the winners of the 2014 award:

- Jean Willson OBE (family carer) and Victoria's team: Centre 404 housing service, Islington ELIPSe and Camden palliative care team, London, England.
- Brenda Garrard - PAMIS bereavement and loss project team, Dundee, Scotland.

Both sets of winners will present at our conference in November 2015. In fact the theme of this year's conference was inspired by the work of our 2014 award winners. The 2015 award winners will be announced at this conference.

Area Coordinators report

By Amanda McKie – PCPLD Area Group Coordinator Lead

The PCPLD network has groups in the following areas:

Area:	Coordinator
1) Scotland	Allison O'Donnell
2) Yorkshire	Amanda McKie
3) North West	Carol Beaumont
4)Leicestershire	Ameila Boulton and Louise Hammond
5) Hertfordshire	Louise Jenkins
6) west Hertfordshire	Barbara Sayers
7) Oxford	Maggie Coombes
8)London	Jason Davidson
9)Kent	Helen Filmer and Sue Marsden
10) Sussex	Jackie Windsor and Corrine Nikolova
11) North Somerset	Tracy Bartholomew
12)Dorset	Val Cope and Jill Mildon
13)Republic of Ireland	Lasarina Maguire
14)Northern Ireland	Dorry Mcloughlin

The annual report from each of these areas is as follows:

Scotland

The Scottish group hosted the 2014 Annual Conference and were delighted that there was a lot of Scottish support for the event. Scottish members told us that they have never had the opportunity to attend the National annual conference due to cost restraints and evaluations were generally very positive. Consequently membership numbers in Scotland have continued to grow and the profile of the Network has been further highlighted by local coordinators whilst they have also led in the Learning Disability and Palliative Care: Building Bridges- Supporting Care Project, at both local, national and strategic levels.

This year most of our contact has been through the mailing list. We have had no formal meetings since the event due to Allison being unavailable due to surgery. We look forward to the new year when Allison returns to work and plan to hold a half day event in Edinburgh, with support from St Columba's Hospice, following the main themes from this year's annual conference.

Yorkshire

They are over 50 people on the email circulation list, the group held a very successful conference in October 2014 with over 70 people attending. The hope was that the regional meetings twice a year would have new membership. However the two meetings were only attended by few numbers 14 in March and 8 in October. The group is still networking via email throughout the year and share best practice at the

meetings. Bradford and Leeds remain very active outside of the regional group working on projects which they share when they attend.

North West

Unfortunately since the successful joint conference with Yorkshire in October 2014 the regional group as not met this year. The area coordinator would welcome support from within the region to have a joint chair to help get the once very successful group up and running again.

Leicestershire

Leicestershire have been running a group since the beginning of last year. They are currently meeting once a month, sometimes more. This is because they have had some funding secured to deliver a support group to people with learning disabilities who have been through cancer and who are now in recovery. They had their first session recently and it worked really well. The current area coordinator is on maternity leave.

Hertfordshire

Hertfordshire have 66 members on the circulation list, they meet three times a year and have on average 10-15 people at each meeting.

West Hertfordshire - No Update

Oxford

Oxford area group meets four times a year as a network, on average 2-10 people attend each time. In November 2014 they held a conference and over 30 people attended locally. The Oxford Area has held another study morning in September around bereavement and included sensors which went well and we have another planned for March 2016 around sudden death.

London

The London area group has continued to attract new members over the last 12 months. We are also continuing with our bi-annual learning events. The last learning was in May 2015 and attracted approximately 15 people. It was held at the Marie Curie Hospice in Hampstead, London. We have made the decision to not host an Autumn event as the annual conference will be in the autumn in London, so our next event will be in spring 2016.

Kent

There are 114 people on the mailing list but most people do not attend the quarterly meetings. They are now offering an education session once a year, which is better attended and appears to meet the local networks need.

Sussex

There are about 40-60 people within the area network which covers West Sussex, East Sussex and Brighton and Hove. The group meets three times a year. They hold a conference every year in May across Sussex, recent themes have been Bereavement assessment (2013), Death, Dying and Bereavement (2014), and this year it was in Dementia.

North Somerset - No update

Dorset

Dorset has 49 people on the network distribution list and a core group meets every three months. They had a local conference/workshop that was attended by about 70 people in April of this year which received good feedback. They have developed a Dorset LD and End of Life Care resource pack which is on the Dorset County Council website. The resources can be downloaded directly from the website by anyone. This is the link <https://www.dorsetforyou.com/article/407388/Resources---End-of-Life-Care>

Republic of Ireland

Republic of Ireland is a virtual group of about 55 people who do not meet regularly. This year 8 email updates have been circulated to all members, of which feedback from members is encouraging. It is hoped to hold an "All Ireland" event with Northern Ireland in 2016

Northern Ireland

Northern Ireland has had historically around 30-40 people on the circulation list, but this currently requires updating. PCPLD Network meetings do not take place regularly, but an all-Ireland Event with the Republic of Ireland may take place in 2016. A recent workshop took place at Queen's University, Belfast at which a number of people in Northern Ireland with an interest in end of life care for people with learning disabilities attended. The workshop focused on Dementia and people with learning disabilities and the speakers were Dr Irene Tuffrey-Wijne and Dr Karen Watchman-PCPLD Network Steering Committee Members.

As mentioned earlier in the report, the local area coordinators are now offered support from the Yorkshire area coordinator who is the lead coordinator for the local groups. She can offer advice and support, make sure the area groups are linked into the PCPLD steering group. This is a new role for the network and one that we hope will grow and support the sustainability of current groups and hopefully develop new area groups in the future

Financial report for AGM 16/11/2015
by Irene Tuffrey-Wijne (Treasurer)

Having stepped down as Chair last year, I continue the task of administering the organisation's finances, dealing with in- and outgoings, and keeping accounts.

Steve Mitchell, our external scrutiniser of accounts, has checked our accounts for 2014 (calendar year). See attached financial balance sheet and breakdown. Further details and breakdown of finances are available on request.

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 pay for a website coordinator in recognition of the workload involved.

Our only income is through our annual conference. This is unpredictable, as we always try to keep delegate fees as low as possible, aiming to break even. Therefore, our outgoings have been exceeding our income for the past few years. This has been sustainable because of generous one-off donations from Macmillan Cancer Support and Mencap in the past. However, it is of concern for the future. The Steering Group is aware of this. One of our hopes is that once we obtain charitable status, it will be easier to raise donations.

Our largest expenditure posts are (a) annual conference and (b) website and social media maintenance.

The Steering Group decided that maintenance and development of the website and social media remains a priority. We also continue to pay expenses for Steering Group members (travel to meetings), but in order to keep within our means (and to help logistics) we have had several meetings via telephone conference.

This year, we have decided not to give financial support to area groups.

Our bank balance for 2015 (so far) is as follows.

Opening balance on 01/01/2015: £4,611.22
Closing balance on 25/10/2015: £5,496.42

Income: £2,800 delegate fees, Glasgow Conference, Nov 2014
£ 900 delegate fees, London Conference, Nov 2015
Total **£3,700**

Expenditure: £2,057.77 Website and social media
£ 511.65 Outstanding payments for Glasgow Conference in Nov 2014
£ 345.38 Travel for steering group members
Total **£2,914.80**

NB Bank balance figures are deceptive at this time of year, as we have not yet paid all expenses for our November 2015 conference, but we have received some of the delegate fees

PCPLD Network

Balance Sheet

	2014 £	2013 £
Fixed Assets	<u>0.00</u>	<u>0.00</u>
Current Assets		
Cash at Bank	5,954.19	8,027.45
Debtors	1 <u>400.00</u>	<u>1,680.00</u>
	<u>6,354.19</u>	<u>9,707.45</u>
	<u>6,354.19</u>	<u>9,707.45</u>
Represented By		
Unrestricted	<u>6,354.19</u>	<u>9,707.45</u>
	<u>6,354.19</u>	<u>9,707.45</u>

Note 1

The 2014 conference attracted 86 paying delegates and income has been received from 78. An assumption has been made that PCPLD will receive 50% of the outstanding delegates fees.

Signed

I. Tuffrey-Wijre
16/3/15 I. Tuffrey-Wijre

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

Steve Mitchell
4th March 2015