



PCPLD Network

Palliative Care for People with Learning Disabilities

CHAIR ANNUAL REPORT 2016

Jason Davidson

Introduction

In August 2016 I attended a scoping meeting organised by NHS England along with another network colleague. The focus of the meeting was to share knowledge of good practice around end of life care in learning disabilities and autism services and explore how this work could be developed more strategically and think about how NHS England could raise the profile of this work nationally. It was inspiring to see such commitment from senior health and social care professionals and reminded me how far things have moved on over the last fifteen years. This progression can also be seen in Scotland, Ireland and Wales and we look forward to March 2017 where the network will be re-launching our Welsh regional group.

However, as a social care professional working in end of life care I still hear stories of those times when it doesn't go well. This is also evident on many social media platforms such as twitter where families are reaching out for support and calling for change. The work of our network is as relevant today as it was in 1998 when it was founded.

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

- Our website continues to be well used and we are seeing an increase in hits from all over the world. The aim to update our website over the last year wasn't achieved mainly due to having three different people carrying out the role of communications lead. Our previous communications lead, Karen Watchman resigned in November 2015 and we now have a great team on-board. Alice Parkinson who is currently on maternity leave and Liz Kinder who has been helping us out. We have 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.
- Amanda McKie continues in her role as *Area Coordinator Support* 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. In addition to this role Amanda has also taken the lead in organising our upcoming conference this year alongside Allison O'Donnell and Dorry McLaughlin. Our conference will be held in

Huddersfield on Friday 4th November 2016 and further details can be found on our website www.pcpld.org

- Looking to the future - The PCPLD Network started in 1998 with a group of like-minded health and social care professionals coming together to promote best practice in end of life care for people with learning disabilities. In the intervening 18 years the network has grown significantly in size and status. We have members from all over the UK and abroad and our annual turnover is currently £5,000-£10,000 per annum. The steering group has recognised the need for greater transparency and accountability in the workings of the PCPLD Network, by having a clear organisational structure. We would also like to be in a better position to attract donations and grants. The steering group has investigated and discussed this extensively over the last couple of years, and has also engaged a charity law expert. We have concluded that the best way forward is to become a Charitable Incorporated Organisation (CIO) and this will require a new constitution.
- In order to proceed, we need the approval of yourselves. We will therefore ask members **to vote on the new constitution** at the next Annual General Meeting on 4th November 2016 (at the national conference in Huddersfield). It is possible to vote via email or by proxy. The new constitution will allow us to become a CIO. Again, for more information please go to www.pcpld.org

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 St Joseph's Hospice, Hackney, London on 16th November 2015. The feedback from the conference was really positive and it was interesting hosting the conference in a hospice again rather than a hotel. The generosity of St Joseph's Hospice was very much appreciated. This year our 2016 conference will be held in Huddersfield on Friday 4th November and the focus of the day will be the latest research, developments and innovation in end of life care for people with learning disabilities. We look forward to seeing you there.

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 disabilities, through their practice and/or service development and the other category recognises the outstanding care of an individual.

Congratulations to the winners of the 2015 award:

- St Anne's Community Service, Oxfield Court Nursing Home and Nicky Lyall from the Learning and Development Department, Huddersfield, West Yorkshire, UK.

And a highly commended award for outstanding care of an individual went to:

- Gerard Wainwright from Heatherstones Nursing service in Halifax, UK and Marnie Walker from 8 Oxfield Court, Huddersfield, UK.

Both sets of winners will present at our conference in November 2016 and the 2016 award winners will also be announced.

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	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 McLaughlin

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

Yorkshire

The regional group remains active and circulates information via email and continues to promote good practice and support individual practitioners as required. The group is proud to host the annual conference this year and the winners and highly recommended categories are all from the Yorkshire regional group. We continue to work closely with the local Bradford palliative care group, again sharing best practice. The group intends to meet again regularly next year in 2017 to continue to network with professionals from a palliative care background and learning disability background to promote best practice in end of life care for people with a learning disability.

North West

The steering group covers Rochdale, Bury, Oldham and surrounding Areas

Some of our members led on the Dementia steering group and they meet regularly. We have had local meeting within Pennine Care to look at our own pathways and the support that we provide to our patients carers and families, this work remains on-going.

The regional representative and her colleagues are holding a one day awareness course with the local Hospice on the 9th December 2016 to promote and share good practice and to re-launch the steering group and hopefully promote the network and recruit new members - details will be circulated shortly.

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

A regional event has not taken place this year however there are several initiatives within the county that the regional representative has been sharing with members as follows;

- Joint bid to Graham Rowlandson Fund between Hertfordshire County Council, Palliative care services & Help the Hospices successful. A joint bid of almost £10,000 has been awarded to deliver specialist End of Life and Learning Disability training to care providers within the county. This project will bring together palliative care and learning disability professionals to support care providers to enhance their skills, knowledge and confidence in providing end of life care to the service users they support.
- “Leaving Life” workshops – Using the Change model the Community Learning Disability Nurses are delivering some workshops for service users and carers to help find out key information that would inform a service users end of life care plan.
- The surprise question – The Community Learning Disability Nurses are actively working with social care colleagues to raise awareness of service users that may be in the last year of their life. This is to ensure that effective co-ordinated care is delivered to service users and carers in a proactive way in their last year of life.

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 event was in May 2016 and attracted approximately 15 people. It was held at St Joseph's Hospice in East London.

Some of our new members in the last year include a team of nurses from St Christopher's Hospice in Sydenham who are leading on a project to improve end of life care for those people with a learning disability who live in residential care. Similarly, we had new members from the Royal Marsden Hospital, Chelsea, London which is also funding a similar project which the network were consulted on.

Republic of Ireland

In view of the geographical spread The Republic of Ireland Area group is fuelled by e mail contacts. On a monthly basis I issue an update regarding what is happening in the area of Palliative care/ Intellectual Disabilities. It was a great support to have the Newsletter. I link in with other bodies such as the All Ireland Institute for Hospice & Palliative Care & the Irish Hospice Foundation to promote PCPLD. I keep in regular contact with the Area Rep for Northern Ireland Dorry McLoughlin. We are both hopeful that Dublin will be considered as a venue for the 2017 conference.

Scotland

They had a large full day event in March in St Columba's Hospice in Edinburgh with almost 80 people attending. It evaluated very well and consequently the regional group lead Allison O'Donnell has been asked to chair a reference group looking at the National palliative care and end of life education framework, from a learning disability and mental health perspective.

Allison was also asked through the Network to support a conference in Oxford. She recently attended the Odyssey Conference Cancer Survivorship at Oxford University speaking about the challenges of a cancer diagnosis for people with learning disabilities. Allison presented 5 peoples stories and showed a DVD of service users and staff within GG&C. Allison will be speaking at a Lymphoma Nurse Study Day in Stirling in November. Spreading the word!!!

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 support the development of new area groups in the future

PCPLD NETWORK
Financial report for Annual General Meeting on 04/11/2016
by Irene Tuffrey-Wijne (Treasurer)

I continue the task of administering the organisation's finances, dealing with in- and outgoings, and keeping accounts. If the membership approves the application of the PCPLD Network to gain charitable status, I am standing for Treasurer of the Board of Trustees.

Steve Mitchell, our external scrutiniser of accounts, has checked our accounts for 2015 (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 is of concern for the future. 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 only met in person once a year (linked to our annual conference), and held other meetings via telephone conferencing. Unfortunately, the telephone conferencing bill from British Telecom was much higher than we anticipated. We have now changed to "WHYPAY?" which is a free teleconferencing service.

Our bank balance on 20/10/2016 was as follows.

Opening balance on 01/01/2016: £7,946.42
Closing balance on 20/10/2016: £3,293.32

Income: £200 delegate fees, Glasgow Conference, Nov 2015
£400 delegate fees, Huddersfield Conference, Nov 2016
Total **£600**

Expenditure: £1,006.80 Website and social media
£1,406.10 Outstanding payments for London Conference in Nov 2015
£2,270.40 Conference venue Huddersfield Conference Nov 2016
£ 569.80 Steering group meeting costs
Total **£4,953.10**

NB The bank balance is deceptive at this time of year. We have not yet paid all of our conference costs, and have not yet received the bulk of the conference delegate fees.

PCPLD Network

Balance Sheet

	2015 £	2014 £
Fixed Assets	<u>0.00</u>	<u>0.00</u>
Current Assets		
Cash at Bank	7,240.32	5,954.19
Debtors	1 <u>7,240.32</u>	<u>400.00</u>
	<u>7,240.32</u>	<u>6,354.19</u>
 Represented By		
Unrestricted	<u>7,240.32</u>	<u>6,354.19</u>
	<u>7,240.32</u>	<u>6,354.19</u>

Note 1

The 2016 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-Wijne

*I. Tuffrey-Wijne (Treasurer)
4/3/16*

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
9th February 2016