



PCPLD Network

Palliative Care for People with Learning Disabilities

TRUSTEE ANNUAL REPORT 2017

Jason Davidson (Chair), Dr Irene Tuffrey-Wijne, Dr Annie Stewart (Secretary) and Steve Mitchell (Treasurer)

Introduction

In February 2017, the PCPLD Network officially became a registered charity – this will give us a greater advantage in being able to obtain funds, claim gift aid on personal donations and give the public confidence in how the organisation operates.

In August 2017 exactly one year after representatives first had a meeting with NHS England we were thrilled to announce to our members the release of the following document: ***Delivering high quality end of life care for people who have a learning disability - Resources and tips for commissioners, service providers and health and social care staff.*** This was the outcome of a great collaboration between the PCPLD network and NHS England. This progression can also be seen in Scotland, Ireland and Wales and in March 2017 the network re-launched our Welsh regional group at a major conference led by the University of South Wales.

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

- We were delighted to be able to launch our new look website www.pcpld.org back in July 2017. Although this was a financial cost to the Network, it was something we viewed as a high priority and a great way for us to continue and expand on our core business in the future which is widening the network. Our website is at the heart of the Network and continues to be well used and we are seeing an increase in hits from all over the world. Alice Parkinson continues in her role as communications lead and manages not only the website for the Network but all of our social media. Alice's role is the only paid role in the PCPLD Network. We have seen a growth in our use of social media and we continue to plan to expand on our use of twitter and think more creatively about these and other forums in which we can continue our conversations and networking.
- 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.
- 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. Over the last five years, the Network has generated approximately £25k in income, mainly from the successful conferences, but there is a need to look further afield for core funding. The management 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. Therefore the management group agreed that rather than have an annual conference this year we will instead put our energy into organising an away day that we will all attend. The focus of the away day will be the designing of a business strategy to ensure we are fit for the future (next 3-5 years).

Membership

We have always kept a simple, informal data base of members in the form of an email list. Last year, this contained over 600 addresses, but many of these were out of date. As part of our legal obligations as a registered charity, we have asked all those on the email list to formally sign up as a member, using a simple electronic survey tool. In September 2017, membership of the Network is 273 people not only from the UK but from overseas. We will now discard the “old” email list. Membership of the PCPLD is free of charge and simple to do. You can register as a member via our website. Members are informed of events and items of interest through occasional emails.

Conferences

There has been a lot going on in 2017 and the network has been transitioning through a period of change which has been building for over two years. The trustees and management group all decided to use our time, energy and resources differently this year and arrange an away day as mentioned earlier) rather than have a conference.

However, we are very excited to announce that on June 13th 2018 we will be holding our biggest ever conference to date at Friends House, London. 2018 is a very special year for us as it will be the 20th anniversary of the Network and the 10th anniversary of the Linda McEnhill Award.

Save the date!

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 Sarah Jane Price's team, winners of the 2016 award. Sarah Jane died in 2015 at the age of 21. The care and support she received from her foster family, carers and professionals was truly inspirational.

Area Groups

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	Vacant

PCPLD NETWORK

Financial report

PCPLD became a charity earlier this year and it was decided to move the year end back to March so the accounts to be presented are for a 15 month period to March 2017.

Income for the year was £4600 and came mainly from the 2016 conference in Huddersfield. Expenses at £6800 included a 'one off' item of £318 in respect of costs incurred in setting up the charity.

The Network carried forward £4439 to the new financial year. This amount has since been reduced by £1000 due to the cost of the new website.

The role of the Treasurer is to keep the rest of the Trustees update with the financial position of the Network and to make sure that all financial protocols are adhered to.