



PCPLD Network

Palliative Care for People with Learning Disabilities



ANNUAL REPORT 2021-2022

Registered Charity No: 1171355

www.pcpld.org

Twitter: @PCPLDNetwork

A message from the Chair of PCPLD Network

I am delighted to share with you the Palliative Care for People with Learning Disabilities (PCPLD) Annual Report on behalf of the Board of Trustees.

The year under report commenced with the UK gradually easing back to a semblance of normality whilst continuing to experience and navigate the impact of Covid-19. Our health and social care workforce has continued to be under unrelenting pressure and the cost-of-living crisis is undoubtedly affecting many of our members, including family carers, colleagues and people with learning disabilities.

It has been a quieter year for PCPLD Network following the whirlwind of 2020-21. During this period, we have taken time to reflect and focus on the future direction of the charity, collaborate with others and signpost people to advice, services, and support. Collaboration with others included the End Of Life Care Think Tank Partners Impact Report and as advisory members on a National Institute of Health and Research funded study 'The Victoria and Stuart Project' with Kingston University, London.

As from the 28th February 2023, I will be stepping down from my duties as Chair and Trustee of PCPLD Network. Whilst this decision has been an extremely difficult one for me to make, it has been a privilege to lead and see PCPLD grow during my time with the charity. I will continue to support and champion PCPLD for many years to come and I would like to express my thanks to all the Trustees, Website Manager, Specialist Advisory Group and PCPLD members for their hard work, commitment, and support. I leave in the knowledge that the charity remains in the safest of hands and the warmest of hearts. A new Chair will be appointed at the next AGM on Tuesday 28th February 2023, I wish my successor all the best in what is the most rewarding role.

Gemma Allen

PCPLD Network



Current Trustees

The board of trustees consists of nine individuals who are mostly from healthcare backgrounds.

- Gemma Allen (Outgoing Chair)
- Dr Annie Stewart (Secretary)
- Steve Mitchell (Treasurer)
- Dr Sarah Yardley
- Professor Irene Tuffrey-Wijne
- Carol Gray
- Dr Valerie Potter co-opted October 2022
- Dr Jo Elverson co-opted October 2022
- Louise Jenkins co-opted October 2022
- Sarah Swindells (co-opted December 2022)
- Sue Marsden (co-opted January 2023)

Current Specialist Advisory Group

The Specialist Advisory Group advise the trustees and are people with a wealth of experience, including lived experience, and knowledge about palliative care and learning disabilities. We welcomed two new members to the Specialist Advisory Group during this period, James Benfield and James Elsworthy both of whom represent people with learning disabilities.

- Pat Charlesworth (representing people with learning disabilities)
- Peter Allum (representing people with learning disabilities)
- James Benfield (representing people with learning disabilities)
- James Elsworthy (representing people with learning disabilities)
- Louise Heatley (Retired support worker. Works in special educational needs)
- Kumar Cithambaram (Lecturer at School of Nursing and Midwifery,

Queen's University, Belfast)

- Sharon Prowse (Senior Manager, Freeway Bristol)
- Catherine Wood (CEO. Representing family carers)
- Sian Mair Owen (Independent advisor in autism, learning disabilities and inclusion. Representing family carers)
- Jean Willson (Representing family carers)
- Dr Claud Regnard (Honorary Consultant in Palliative Medicine at St Oswald's Hospice, Newcastle.)

Membership

The latest figures show PCPLD Network membership stands at 1687 individuals and organisations. Membership continues to be free of charge.

In September 2021, PCPLD Network successfully hosted a second online conference 'Finding the gaps and closing the gaps. Death, dying and bereavement' with keynote speakers including Professor Mark Taubert, Dr Kathryn Mannix, Dr Jo Elverson and David Harling and chaired by Professor Irene Tuffrey- Wijne and Peter Allum.

A high volume of outstanding quality abstracts for oral and digital poster presentations were submitted and delegate feedback following the event was extremely positive. The conference was a paid event, with the exception being people with learning disabilities and family carers who received free places. The conference was recorded and made available to delegates for a short time afterwards. Thank you to everyone involved, including abstract reviewers, technical support and speakers. Due to the trustees' other work commitments and illness, no further webinars or conferences took place during 2022.

Just wanted to say a few words about the excellent Conference and Linda McEnhill award evening. Both were absolutely riveting, informative and very moving. What a long way the PCPLD Network has come."

Linda McEnhill Awards 2021

The Linda McEnhill Award is a biennial award that showcases excellent practice in palliative and end of life care, including bereavement support, for people with learning disabilities. We received a record number of inspiring nominations, eighteen in all and several awards were presented during an online ceremony hosted by BBC disability news journalist Nikki Fox.

The 'One to Watch' Award:
James Channon and Simon Cox at St Giles Hospice, Lichfield.

Outstanding Bereavement Support Award: The Dell House Team at The Lantern Community, Hampshire.

Inspirational Individual Award: Liam Canfield, Mental Health Student Nurse, Swansea University.

Unsung Hero Award: The Beau Sejour Care Team, St Albans.

Providing outstanding end of life care award- Highly commended: Dolphin Court, Royal Mencap Society, Hampshire.

Providing outstanding end of life care award- Highly commended: Chandon Team, Achieve Together, Surrey.

Winner of the outstanding end of life care and The Linda McEnhill Award 2021:

Stuart Hasler and his Circle of Support in Enfield and North London. This includes professionals from North Middlesex Hospital, Enfield Integrated Learning Disability Service, the Community Respiratory Team, Rapid Response Nurses, North London Hospice Palliative Care Team, as well as Stuart's personal assistant, Evendale Care, and Stuart's family.

Stuart's award was a posthumous award. We wanted to recognise the healthcare professionals involved in his care and that at the heart of it was Stuart himself. Stuart not only talked about his death, but he planned ahead ensuring everyone knew his wishes, including fundraising for his funeral.

PCPLD Writing Group

A PCPLD writing group was formed during the time under report, led by Dr Jo Elverson and consisting of Dr Valerie Potter, Dr Sarah Yardley, Gemma Allen and Louise Jenkins following interest in a Royal College of General Practitioners journal article.

Away Day

A trustee away day was planned for both 2021 and 2022 but unfortunately these were postponed due to Covid and trustee illness to February 2023. During this period, trustees continued to communicate via email and online meetings.

Assisted Dying bill

With the Assisted Dying bill introduced in the House of Lords by Baroness Meacher, a group of trustees and Specialist Advisory Group members met to discuss the impact of this on people with learning disabilities and to write a response on behalf of the network, namely, PCPLD does not support the current Meacher bill. Specialist Advisory Group member, Dr Claud Regnard, prepared a statement that is available on the website.

We believe that everyone with a learning disability has the right to be valued in life and to have excellent palliative and end of life care, whatever that might be

Annual General Meeting 2021

The Annual General Meeting took place online during November 2021. Following an update from the chair and treasurer, Steve Mitchell and Gemma Allen were re-elected as trustees.

Financial Report – April 2021/March 2022

During the year under review, total income was £7,598 of which the online conference had a gross income of just under £6,000. A further £1,200 was generated from donations and £334 derived from people logging on to the PCPLD webinars.

Expenditure for the year was £8,428 of which £7,170 was paid to the website manager. This was partially funded by a £3,000 grant received in the previous year from the Bailey Thomas Trust. All other expenses related to the running costs of PCPLD including the costs associated with the conference and the webinars. The expenses also benefited from a reversal of an expenditure and relates to an underspend on the lottery fund which was expected to be repaid, this was not required.

Overall, PCPLD had a net deficit of £830 for the year leaving £11,911 carried forward to the new financial year.

At the start of the new year, there were no significant projects planned although since then, the Trustees have agreed to relook at updating its website.

