



NNPCPLD

National Network for Palliative Care
of People with Learning Disabilities

Network News

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The National Network for Palliative Care of People with Learning Disabilities

was established in 1998. It brings together service providers and carers working for the benefit of people with learning disabilities who have palliative care needs. It is based on the belief that people with learning disabilities should receive all the co-ordinated help they need in living their lives to the full until the end of their lives.

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Editorial

Sometimes I live in hope that things have really changed for people with learning disabilities. That they are listened to and heard; that they are able to participate in the care they receive at the end of life; that they are included, involved, and treated equitably.

At the NNPCPLD, we hear some truly inspiring stories and examples of outstanding support and care. Often, such care is thanks to one or two individual practitioners who go out of their way to make this happen, who take time, who make links, and who are sensitive enough to listen to the person's wishes. I am always impressed with the commitment of many of our members to be just such a practitioner. They can make a huge difference to people's lives. Increasingly, we also hear of collaborative initiatives: different professionals and carers getting together to think through the issues for people with learning disabilities who need palliative care.

The nominations for the Linda McEnhill Award have uncovered a number of examples of excellent practice by individuals and teams. We will dedicate the next issue of this newsletter to these inspiring examples. The winner of the award will be announced at our conference in Glasgow on 10th November (there are still a few places available: see back of this newsletter).

However, there are other times when I hear stories that leave me shocked. I was recently told two very similar tales, totally unconnected with each other. They both concerned someone with learning disabilities who needed life-saving renal dialysis. In both cases, the person concerned had capacity to consent, and had refused the treatment, because they hated hospitals and therefore didn't want to go through with such invasive procedures. Their decision was accepted by the medical teams, who were undoubtedly acting in the belief that they followed the Mental Capacity Act.

However, these individuals had not fully understood the consequences of their refusal, because these had not been explained to them clearly enough. Fortunately, the people who told me these stories were both skilled learning disability professionals, who then took the time to sit down with the person and spell out that without the dialysis, they would die. They explained clearly what the treatment would involve. Both people then decided to accept the treatment after all, and coped well with the dialysis. It is chilling to think that if their professionals had not stepped in, they would not have survived.

I hope you enjoy this issue of our newsletter, which includes the Chair Annual Report.

Dr Irene Tuffrey-Wijne (Chair)



Chair Annual Report 2009

Introduction

The NNPCPLD is now 11 years old.

This last year has been a year of transition, with Linda McEnhill, our founding chair, stepping down in November 2008 after a very successful decade. It has been a daunting but exciting challenge to follow in her footsteps. During this year I have tried to get a feel for the NNPCPLD, and in particular for all the work that members are doing across the Network.

Change is set to continue, as our vice chair, Noëlle Blackman, is stepping down in November 2009. Noëlle launched the NNPCPLD together with Linda in 1998, and has been a hugely supportive and very active presence ever since. I would like to record early in this report my gratitude for all her hard work. It has been invaluable to have her continued support and service to the Network during this past year. A new vice chair will be elected at our 2009 AGM. Noëlle will continue in her role as representative for the London and Home Counties area.

I have been very impressed with the enthusiasm of so many members, and their commitment to improving the palliative care, end of life and bereavement experiences of people with learning disabilities. That commitment and enthusiasm is what keeps the NNPCPLD going.

Membership

We are a membership organisation. Membership fees were waived during our 10th anniversary year (2008). Fees were raised slightly in 2009: they now stand at £25 for individual members and £65 for group membership (3 members at the same address/organisation). Membership is free for the unwaged.

Members benefit from (1) linking in to area groups (area representatives are given the details of new members, so they can be invited to area meetings); (2) reduced fees at our national conferences, and (3) the newsletter.

Anyone is welcome to attend area meetings, but after one or two meetings, people are expected to become members if they wish to continue to benefit from these meetings.

By the end of October 2009, there were exactly 100 registered members.

Geographically, these members are not spread equally. One quarter of all members are located in London & Home Counties; another quarter in Yorkshire and the North West. Some areas of the UK have hardly any members at all.

Area groups

The area groups are a fundamental part of the NNPCPLD. They provide regional opportunities for networking, collaboration, and development of local 'best practice'. Each group is coordinated by an area representative (some areas have two representatives who share the role). Some groups have around three meetings a year; some have not been active during the past year; and some are only just beginning, and have not yet held any meetings.

The area representatives are supported by the NNPCPLD, and meet once or twice a year for mutual support and exchange of ideas.

The following area representatives have stood down in 2008/2009:

Lynne Gibson (Northumberland)
Sue Medley (East Anglia)
Sally Radford (Hertfordshire)
Sue Read (Staffordshire)
Sue Smith (North West)

I would like to express my sincere thanks to them all for their work over the years.

The following area representatives are new, either taking over from existing representatives or starting/re-establishing an area group:

Carol Beaumont and Sharon Dewhurst (North West)
Maggie Coombes (Oxfordshire)
Louise Jenkins (Hertfordshire)
Rachel Lucas (Northumberland)
Josephine McCulloch (Scotland)
Dorry McLaughlin and Mary Bogue (Northern Ireland)

A warm welcome to all of them, and very best of luck in supporting the work of the NNPCPLD in their local areas.

We now have the following area groups and representatives:

Derbyshire (Debra Cooper)
Hertfordshire (Louise Jenkins)
London & Home Counties (Noëlle Blackman)
Northern Ireland (Dorry McLaughlin and Mary Bogue)

Northumberland (Rachel Lucas)
North West (Carol Beaumont and Sharon Dewhurst)
Oxfordshire (Maggie Coombes)
Scotland (Josephine McCulloch)
Staffordshire (situation vacant)
Wales (Stuart Todd)
Wiltshire (Amelia Jones)
Yorkshire (Amanda McKie)

Steering Group

The area representatives met together in London for our Steering Group Meeting on 17th February 2009. They will meet again in Glasgow on 9th November 2009.

The Steering Group includes :

Irene Tuffrey-Wijne (chair)
Noëlle Blackman (vice-chair)
Stuart Todd (treasurer)
Pat Charlesworth
Beverly Dawkins
Peggy Fray
David Oliver

In addition, all area representatives are also part of the NNPCPLD Steering Group.

Newsletter

The newsletter was re-launched in February 2009. The aim is to produce three issues a year, and so far, we have managed that! It has proved to be an effective means of communication with members and inspiring interest.

The newsletter is edited by myself. I have written most of the features, but there have been some contributions from other members. Any feedback, contributions or ideas for future issues will be most welcome!

Conferences

The NNPCPLD aims to organise two conferences each year, in different locations across the UK. We organised two successful conferences during the past year.

The 10th Anniversary Conference was held in Gateshead on 3rd November 2008. It was an opportunity to look back, and to look forward to what is yet to come. It was clear throughout the day's conference just how far things have moved on during the past decade. The conference saw the launch of the annual Linda McEnhill Award (see below).



10th Anniversary Conference, Gateshead, November 2008

Our first Research Conference was held in Antrim on 24th March 2009. Over 100 delegates attended. A range of eminent researchers in the field of death, dying, bereavement and learning disability presented their work. It was a truly inspiring event, and an important opportunity for researchers in this area to get together. There are relatively few people who carry out research in this field, and therefore this was an important occasion for mutual support and sharing of ideas. It was also good for practitioners to hear about recent developments and new insights.

Our next conference will be held in Glasgow on 10th November 2009. We will hold our AGM during this conference.

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. The 2008 award was presented to Linda McEnhill herself.



Nominations for the 2009 award closed on 31st August 2009. The judges (made up of six members of the steering group

representing a range of backgrounds and experiences) were impressed with the high number and standard of nominations received. The winner will be announced at our conference in Glasgow on 10th November 2009.

During the coming year, the NNPCPLD will support the dissemination of the important and exciting work that this award has uncovered – watch this space!

Change of name

The Steering Group has often talked in the past of the need to change our name. Not only is “The National Network for Palliative Care of People with Learning Disabilities”, or “NNPCPLD” for short, rather cumbersome; it is also inaccurate, as there have been members outside the UK. Therefore, the word “National” will be dropped from our name. Members have been voting for their preferred new name. Voting will close, and the outcome announced, during our AGM on 10th November.

Financial report

In April 2009, I took over (from Linda McEnhill) the task of administering the organisation’s finances, dealing with in- and outgoings, and keeping accounts.

Balance on 09/04/2009: £1,385.32

Balance on 02/10/2009: £2,986.07

Most of our income is through membership fees and conference fees.

Most of our expenditure is for steering group/area rep meetings (mostly travel cost, plus accommodation when the meeting is held the day before an NNPCPLD conference) and conference costs (venue hire, speakers’ fees, speakers’ travel and hotel costs).

It must be noted that the conference held in Antrim (March 2009) broke even.

The balance in October 2009 includes income from membership fees and some conference fees; but none of the expenditure for the November 2009 steering group meeting and conference is showing in the accounts yet.

A full financial statement of the accounts since April 2009, with breakdown of income and expenditure, will be sent to all members in December 2009.

Worryingly, one of the chequebooks got lost in the post, which I discovered when person(s) unknown tried to cash 15 cheques totalling over £84,000! Luckily, I spotted this just in time to save us from bankruptcy... Vigilance is everything!

The future

It is now time to begin thinking about the direction the NNPCPLD should take in the years ahead. These are exciting and crucial times. The health care needs of people with learning disabilities, including the care they receive at the end of life, has gained national prominence. There have been various reports and new legislation that brought these issues to the attention of practitioners and policy makers.

At the NNPCPLD, we have noticed an increasing interest from practitioners to collaborate and improve things for people with learning disabilities who need end of life care. To name but a few live issues: More practitioners are beginning to work on and ask about Care Pathways and advanced planning documents. There is also a growing concern about the needs of young adults with learning disabilities who have palliative care needs, and who are making the transition from children’s to adult services.

Our challenge ahead will be to facilitate networking and sharing of information across counties and countries. We may well need to re-think the structures of the NNPCPLD in order to keep up with a changing landscape.

One of the priorities for the year ahead will be to set up a website for our organisation.

Conclusion

This has been a year of transition, taking stock, and new growth. I am acutely aware that it is the enthusiasm of our members that keeps our work going. Most of us who have a recognised role in the NNPCPLD (whether it is as a member of the steering group, or an area representative) have busy jobs, and carry out much of this work in their own time.

I hope that this report has given you enthusiasm to become (more) involved in our Network. This is very much a *network*. Everyone is most welcome to join us, and be inspired as well as inspiring!

Irene Tuffrey-Wijne

Chair

National Network for Palliative Care of People with Learning Disabilities

29th October 2009

In the spotlight

In each newsletter, we will put one of our members in the spotlight. This time it is the turn of Sue Smith, who has just stepped down as area representative for the North West Branch of the NNPCPLD. She tells Irene Tuffrey-Wijne how it all started.

Sue Smith (45) trained as a learning disability nurse in the days of the large residential institutions for people with learning disabilities. In 1994 she started work in smaller community homes for supported living, gradually moving up to become the manager of 14 houses.

Starting a new group

A long-standing interest in health prompted her and her colleague Carol Beaumont to attend an NNPCPLD conference in Cardiff, back in 2004. 'It started from there,' she remembers. 'We were so fired up, we didn't stop talking in the car on the way back: "We could do this... and that..." It was a very relevant issue, we had so many older people with learning disabilities in the North West. But there was absolutely nothing going on for people who needed end of life support.' Sue linked up with other NNPCPLD members who ran local groups elsewhere in England, to see how they did things. She put out announcements of a forthcoming meeting, and the North West group of the NNPCPLD was born. It covered a huge area, all the way from Liverpool to Yorkshire (which has since developed its own group). 'Because I was a manager, at the time, I was in the fortunate position that I could get new things up and going. There was lots of interest. We said that anyone could come to the meetings, but made it a condition that after they'd been to a few meetings, they had to contribute and share something. People couldn't just sit back and take everyone else's work away. It is important to share. It is a network, after all.' Attendance has fluctuated, but the group has continued to meet regularly.

New developments

Since those simple beginnings, the North West group has come a long way. Sue ran the North West group in close collaboration with her colleagues, and encouraged them to take a special interest in specific issues, such as dementia. In 2004, the group surveyed palliative care providers in Rochdale to see how many referrals there were for people with learning disabilities ('None!'). Group members have been instrumental in a range of developments, including a dementia pathway and other pathways within learning disability services. 'A pathway was set up within supported living services so that as soon as someone was diagnosed with a terminal illness, we link in with the learning disability nurse who could bring in the right services and set up training for staff groups. We also developed bereavement training for people with learning disabilities.'

Sue herself has also developed. 'I did a 3 year secondment as health facilitation lead. I'm currently writing up my PhD about the effectiveness of health action plans. But when supported living services went out to tender, health was taken out of our roles, and I had to focus more on being a manager again. I am now back in the PCT where my responsibilities include Research, Development and Training. I just about kept the Network ticking over, and there are ways of keeping the issue of end of life care alive, if you want to. We put on a training day in the hospice, and set up a working group to make links with palliative care across Rochdale. Our branch of the Network also held two conferences about palliative care and the work that had been developed as part of the North West Network since it started.'

Moving on

Sue has now decided that it is time to hand over the running of the North West group to some of her colleagues. Carol Beaumont and Sharon Dewhurst will share that responsibility from now on. It is a tribute to Sue's enthusiasm and inspiration that the group continues to thrive, and has found others to carry on. Will she still be involved? 'Oh yes! I don't want to give up on all the work we have done. When people at work see me marching down the corridor, they say, oh my god, here she comes again! She'll find me something to do!' she laughs, adding, 'My glass is always half full. There are always new ideas to develop. I don't give up that easily!'



Sue Smith: *"There was absolutely nothing going on in the North West for people with learning disabilities who needed end-of-life support."*

News from area groups and members

Amanda McKie, area representative for the Yorkshire branch of the NNPCPLD, reports on a successful conference

On the 1st of July the two area groups Yorkshire and North West came together to hold a joint conference sharing the best practice that has been developed within their areas. It was a well attended event with 80 people attending and more on the reserve list. We had presentations of many subjects and the feedback was very positive. One delegate stated that it had been a very thought provoking and

interesting day. Everyone who attended received a copy of Living and dying with dignity, the best practice guide available on the Mencap website. The day was summed up by Sue Smith who stepped down from her post as chair in the North West. She was presented with well earned flowers and a bottle of bubbly, and will be sadly very much missed.



Sue Smith and Amanda McKie at the conference

Care Pathways

Have you been involved, or are you interested, in developing a Care Pathway for people with learning disabilities who need palliative care?

We are aware that there are several groups across the UK who are thinking about or working on this; some have already produced a pathway.

It seems important that we share good practice in this area, rather than have people re-inventing the wheel!

If you are interested in publishing your work around Care Pathways, in collaboration with other members of the NNPCPLD, do get in touch with Irene Tuffrey-Wijne (chair@natnetpald.org.uk).



Helen Dudley

is leaving her post at Kirkwood Hospice in Huddersfield as tutor. Helen was one of the co founders of the Huddersfield group, which was formed to improve palliative care for people with learning disabilities locally. They devised a pain tool, put on educational sessions for people with learning disabilities, care staff from learning disability homes and for palliative care staff. Helen was very supportive of the start of the Yorkshire group and has been an inspiration to all who meet her. She has been an excellent resource of knowledge and practical skills in this area and will be dearly missed.

Amanda McKie

Stuart Todd reports on a new development within IASSID

The NNPCPLD has several members who play an active and interested role within IASSID (The International Assoc for the Scientific Study of Intellectual Disability). IASSID is one of the foremost, international associations in this field.

For some time, Network members have been promoting issues around and raising awareness of death and dying as they relate to people with learning disabilities. This would include issues of bereavement and end-of-life. They have worked as a small and informal grouping ensuring that these matters were discussed at key international gatherings.

Recently, this work was given a more formal footing when IASSID brought their work within one of the Association's research and special interest groupings. This gives matters close to our

concerns a platform on which to build more regular dialogue with colleagues around the globe.

The next meeting of this group will be at an international conference in Rome next October. There will also be regular smaller meetings held annually and where some of the key messages and work of the Network can be shared.

For anyone interested in more information about this please contact Stuart Todd, stodd@glam.ac.uk



Final chance to register:

Forthcoming conference

10th November 2009, 9.30-4.00

The Renfield Centre, Glasgow

Quality transitions in end-of-life care for people with learning disabilities

There are still a few places left for this one-day conference, but do hurry!

The conference will address a range of issues around the end-of-life care for people who have learning disabilities. The conference is suitable for professionals from primary and secondary health care settings, learning disability services, carers and families. Topics will include: Dementia; Transitions of young adults into palliative care; Pain and symptom assessment; Bereavement. Cost: £65 (NNPCPLD members: £50).

To register: tel 020 7387 3976, email lindamcenhill@natnetpald.org.uk

Please note: the Annual General Meeting for members will be held during this conference.

Regional meetings

London & Home Counties: 9 December 2009, 2-4pm, London NW1. Contact: noelle.blackman@respond.org.uk

Yorkshire: 3 February 2010, 10am-12.30pm, venue to be confirmed. Contact: amanda.mckie@cht.nhs.uk

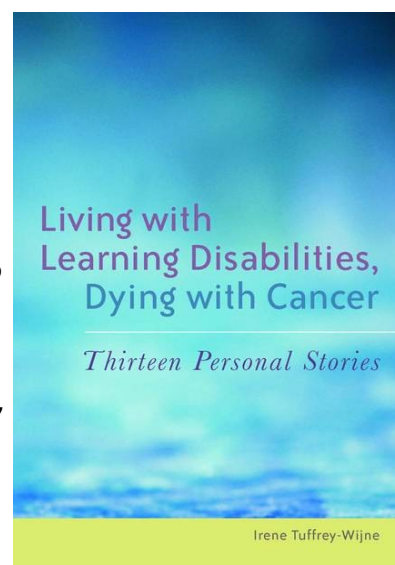
New Publications

Living with learning disabilities, dying with cancer: Thirteen person stories

By Irene Tuffrey-Wijne, foreword by Sheila Hollins
 Publisher: Jessica Kingsley, ISBN 9781849050272,
 272 pp, £19.99

This book is a powerful and moving account of the experiences of 13 people with learning disabilities who were living with cancer. The author followed their lives as part of a 3-year research study, during which 10 people died. She spent extensive periods of time with them at their homes and day centres, in hospitals, hospices and nursing homes. In this way she gained a unique understanding of what it is like for individuals with learning disabilities to live with deteriorating health and how this may impact upon their families, friends and carers. How was each person's cancer diagnosed? How was their cancer and its implications explained to them? How much did they understand and how did they cope with treatment? What happened when they were dying? In answering these questions, the book exposes the suffering of people with learning disabilities at the end of their lives, but also their remarkable resilience and strength. In an optimistic final chapter, the author demonstrates how people with learning disabilities can best be supported at the end of life.

This book will be an invaluable resource for anyone involved in the care and support of people with learning disabilities who have cancer and who are dying, including health and social care professionals, families and friends.



How to join

Members of the NNPCPLD can attend meetings of regional groups. They receive a regular newsletter and reduced fees to UK study days, and they have voting rights within the NNPCPLD.

Annual membership costs:
£25 (individuals)
£65 (group of 3 members at the same address)

Unwaged: free

Contact Irene Tuffrey-Wijne for a membership form:

chair@natnetpald.org.uk
07977 260967

Training and advice service

ENFOLD c.i.c. provides bespoke courses and interventions to support the End of Life Care (EOLC) of people with learning disabilities. From diagnosis through treatment or into bereavement the training is based on both the most up to date research and significant hands on experience of caring directly for people with learning disabilities who are ill or bereaved, their families and the professionals who care for them. A range of stand-alone courses are also on offer, including communication, end of life care and bereavement. The service is co-ordinated by Linda McEnhill.

Contact details:

Tel **01223 573173**

Email **info@enfold.org.uk**

Please note that the Macmillan Network Information and Support Service (MNISS) no longer exists.

Journal Watch: newly published papers

McLaughlin, D., Barr, O., McIlfatrick, S. (2009) Palliative care and learning disability: context and challenge. *European Journal of Palliative Care* 16 (6), Nov/Dec.

Tuffrey-Wijne, I. (2009) The preferred place of care for people who are dying. *Learning Disability Practice* 12 (6), 16-21.

