



NNPCPLD

National Network for Palliative Care
of People with Learning Disabilities

Network News

Volume 1, Issue 1

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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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Welcome

Welcome to the new-look newsletter! I have taken over from Linda McEnhill as chair of the NNPCPLD from November 2008. Thank you to those who trusted me with this important role. It was meant to be a job share at first: both Amelia Jones (known as Milly) and myself were elected to chair the Network together. However, Milly has since been landed with a wonderful but demanding new job (congratulations Milly!), and she has had to withdraw.

It is a privilege and a challenge to be at the sharp end of this Network, which I joined right at the start (some may remember the newborn baby I brought along to a study day; she is now a strapping 9 year old!). A short introduction: I work as a research fellow at St George's University of London. My career so far has moved from nursing college in the Netherlands, to supporting people with learning disabilities in a residential care service, to palliative care nursing in a hospice, to researching the cancer and end-of-life care needs of people with learning disabilities. Hopefully, these varied experiences will help me understand the issues you all face.

Most of you will have met Linda, and I'm sure you agree that she is a hard act to follow... The only reason I decided to take on the responsibility of chair on my own is that so many of you out there are tremendously supportive of the Network, so if I feel lost, I know there will be others to help me. I am very grateful to Noëlle Blackman who has agreed to continue as vice chair for the coming year; her experience and commitment will be invaluable.

These are exciting times for the Network. We are celebrating our 10th anniversary at a time of growing national interest in the end of life care needs of people with learning disabilities. Mencap's 'Death by Indifference' report (2007) has made people sit up and take note. The Independent Inquiry into access to health care for people with learning disabilities (2008) confirmed that there is still a long way to go before people with learning disabilities get a good deal from hospitals. There are a lot of wonderful initiatives around the UK, many by members of the Network. It is more important than ever that we share our experiences and take things forward.

I will distribute this newsletter at least three times a year. It will contain news of what is going on in the Network, including study days. But there will also be space for special features: on regional groups, on individuals within the Network, on case studies, on new research and publications. We could provide a space for members to network – so if there is anything you would like to share with other members, or if you need their help or advice, let me know.

In this issue we will focus on the wonderful work Linda has done in promoting good palliative care for people with learning disabilities. Look out for the announcement of the annual Linda McEnhill Award! There is feedback from the national study day held in November 2008.

Do let me know what you think of this re-launched newsletter... and get in touch if you would like to contribute! I look forward to meeting as many of you as possible in the months and years ahead.

Dr Irene Tuffrey-Wijne (Chair, NNPCPLD)



A message from Linda



I am a great believer in serendipity; it's certainly stood me in good stead and no more so than in the development of the Network. In 1997 I found myself, by an unusual and not altogether pleasant turn of events, working as a bereavement counsellor in the newly formed bereavement service of a Hertfordshire learning disability trust. It was there that I met Noëlle Blackman whose brainchild the service was. The trust's three hospitals were all contracting and consequently resettling their residents into the community which was all to the good except that when someone became seriously ill the only option, given the unpreparedness of mainstream palliative care, was to readmit them to die in the hospital; so much for a 'Home for life'.

Room does not permit a detailed explanation of the many 'serendipities' that found Noëlle and I tentatively launching the NNPCPLD in 1998 along with a small group of equally impassioned practitioners, some of whose names you now know well.

Ten years on I am proud to say that we are a much larger (though still enthusiastic) group spanning the UK and the republic of Ireland. Members have individually and collectively achieved a great deal and now there is a body of knowledge and good practice which practitioners can turn to. However, things are far from sorted and many people with learning disabilities still do not get adequate palliative care so there is just as urgent a need to network and collaborate as ever there was.

Sadly, though I am very grateful, there is no room to acknowledge here the many things that I have learned from you nor the support that I have received and how much it has meant. I hope that you will continue to support the Network and Irene as she leads us into the next stage; here's to what Serendipity has in store next! With every good wish

Linda McEnhill (former chair, NNPCPLD)

Thank you Linda McEnhill

Linda founded the Network some ten years ago, which now has an established voice within the worlds of palliative care and people with learning disabilities. At the NNPCPLD annual conference (see page 3) tributes were made to Linda to mark what has been a remarkable achievement.

Over the last ten years Linda has held significant roles as a social worker, bereavement counsellor and head of family support and more recently as senior lecturer at St Christopher's Hospice and currently as project manager on widening access at Help the Hospices. It has been from this background that Linda's desire to improve care at the end of life for those with learning disabilities has been fuelled. In a nutshell Linda has helped to 'mainstream' people with learning disabilities into palliative and end of life care services by successfully raising awareness, working with key stakeholders, never taking no for an answer and yet being unendingly pleasant. Her driving motivation and vision for the network has been to link professions and carers from palliative care and learning disability so that they are no longer working in isolation and that their skills and experience can be shared. As a result the network of people taking an interest in the palliative care of people with learning disabilities has grown enormously over the last decade. In recognition of her achievements, Linda was awarded a Hambro-Macmillan Associate Fellowship in 2003.

Linda has achieved so much with her honest and open approach and her ability to provide national leadership in bringing together two complex and demanding areas – that of end of life care and people with learning disabilities. Linda has been able to address and articulate the complexity of equality and diversity to an equally diverse set of stakeholders, such as government, palliative care professionals and national charities. Her driving passion and motivation has been to bring justice for those who cannot easily speak for themselves and support to those who tirelessly care for them.

Sue Hawkett OBE (former nursing advisor, supportive/palliative care, Department of Health)
This is an edited extract from an article in Hospice Bulletin



Linda and Peggy Fray at the Kathleen Study Day, 2006

"Linda has achieved so much with her honest and open approach and her ability to provide national leadership"

The 10th Anniversary Conference

We gathered in Gateshead on 3rd November 2008 to celebrate the 10th anniversary of the NNPCPLD. Listening to the speakers, it was amazing to see just how far we had come in those 10 years.

Isabel Quinn, national manager of the End of Life Care Team, kicked off the day with a keynote address. This was followed by Lynn Gibson, Dorothy Matthews and Claud Regnard, who described how they developed their palliative care services for people with learning disabilities in Northgate. They hold a wealth of experience we can all learn from: not only the successes (gaining Beacon status in 2000; developing the DisDAT tool) but also the 'threats along the way'. Their story shows how important it is to stay committed and keep going, to champion the needs of vulnerable people, and to work together.

Steve Willis and Sharon Splaine from the Manchester Learning Disability Partnership explained how they developed a palliative care pathway. The pathway is available in the form of information booklets, including one in accessible format. For details, contact Steve (0161 998 7424) or Sharon (0161 223 9901).

Gavan O'Sullivan, a palliative care nurse with Westminster PCT (London), presented his Masters Study. He conducted focus groups with direct care staff in learning disability settings, and asked them about their experiences of supporting someone at the end of life. It was clear that such staff needed a lot of support themselves, and the audience identified with their experiences.

Irene Tuffrey-Wijne and Jane Bernal presented their research. Irene spent 3 years following the experiences of 13 people with learning disabilities who had cancer, most of whom died. It was very moving to listen to the voices of the people with learning disabilities. Irene asserted that it is essential to understand people's life story in order to understand their experience of dying. There have been several published papers on this study. For details, contact Irene (ituffrey@sgul.ac.uk).

The final presentation, fittingly, came from Linda McEnhill who looked back on the first decade of the NNPCPLD, and looked forward to what is yet to come...

The most immediate events that were yet to come were a wonderful tribute to Linda by Sue Hawkett, and the presentation of the first Linda McEnhill Award (see below), followed by a spectacular birthday cake!

If you missed this conference, you still have a chance to come to our conference in Northern Ireland on 24th March, which promises to be just as good (see page 4)

The Linda McEnhill Award

In recognition and celebration of Linda's wonderful contribution to the palliative care of people with learning disabilities, we are launching the Linda McEnhill Award. This prestigious annual award will be given to an individual or team who has made a positive difference to the end of life care of people with learning disabilities.

The first Linda McEnhill Award was given to Linda herself during the 10th Anniversary Conference. For once, she was speechless!

Look out for further details on the award, including how to nominate (which will be emailed to members, and published in the next issue of the newsletter).



Quote of the day

"I couldn't care less whether the person looking after me has a load of qualifications or gone to university. What matters to me is whether they listen to me."

Pat Charlesworth,
delegate



Delegates at the conference



Noëlle Blackman
presents Linda with the
Linda McEnhill Award

Your space

Do you have something you would like to share with other members? Telephone or email Irene!

It could be...

An inspiring example of good practice (or an example of less-than-ideal practice that we could all learn from)

Your reasons for joining the Network

A question for help or ideas from other members

News from where you are...

I look forward to hearing from you!

Telephone advice on caring for people with learning disabilities who have cancer or palliative care needs (including support to carers and advice on resources and training) is offered by the **Macmillan Network Information and Support Service**. Telephone helpline 020 7387 3976, email info@mniss.co.uk.

Forthcoming events

24th March 2009, 9.30-16.30

Antrim, Northern Ireland

Death with a difference? Researching death, dying and learning disability

A one day conference as part of the 10th Anniversary celebrations of the NNPCPLD. The focus will be on research conducted, in progress, and areas for future investigation. Areas covered: mortality; end-of-life-care; bereavement; remembrance. Chair: Prof R McConkey. Keynote address: Prof S Hollins. Cost £60.

To register, contact Sue Read

Tel 01782 556657

Email s.c.read@nur.keele.ac.uk

Regional meetings

London & Home Counties:

11 March, 2-4pm, London NW1.

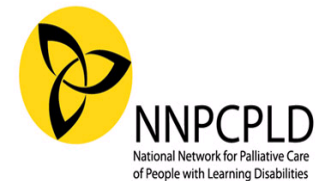
Contact:

noelle.blackman@respond.org.uk

North West: 18 Feb, 11am-2pm, Rochdale; and 1 July, Huddersfield.

Contact: sue.smith@hmrpct.nhs.uk

Scotland: 23 Feb, 11am-1pm, Glasgow. Contact: josephine.mcculloch@lanarkshire.scot.nhs.uk



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)

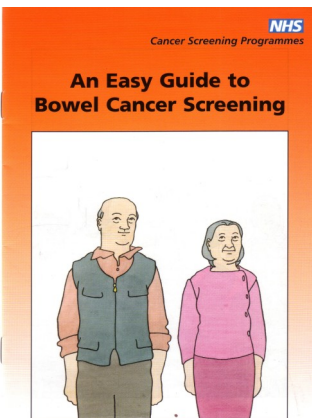
£65 (group of 3 members at the same address)

Unwaged: free

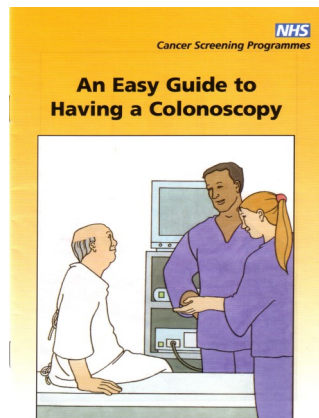
Contact Irene Tuffrey-Wijne for a membership form:

chair@natnetpald.org.uk
07977 260967

New Publications



A leaflet by and for men and women with learning disabilities



A leaflet by and for men and women with learning disabilities

These two new leaflets from the NHS Cancer Screening Programme have been designed for and with people with learning disabilities, using pictures and easy language to explain bowel screening and colonoscopy. Available free of charge. Email dh@prolog.uk.com, tel. 0300 1231002, or download a copy from the website: www.cancerscreening.nhs.uk/bowel/publications/information-leaflets

Dementia and People with Learning Disabilities

This invaluable training pack has been devised by Respond in partnership with the GOLD group—a group of older people with learning disabilities who have been working together for the past decade on helping others to understand what it means to grow older with a learning disability. The focus for this training pack is the importance of supporting relationships for people with learning disabilities who develop dementia. It has been designed primarily with the staff team of a

residential home in mind, but is flexible for other training situations. Contains 2 DVDs, training and action cards, and a resource list. Cost £75. To order: Tel. 020 78745481, email admin@respond.org.uk, or on the website: www.respond.org.uk/shop

