



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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Welcome

Getting ready for our 'Death with a Difference?' conference in Antrim early one morning in March, I turned on the news and found that the appalling care of some people with learning disabilities in hospitals was making headlines once again. The health ombudsman had published its findings after investigating the claims made by Mencap in their 'Death by Indifference' report that six people with learning disabilities died unnecessarily while in NHS care.

These terrible stories will be well-known to many of you. They include the case of Martin Ryan, 43, who went without food for 26 days while he was in hospital following a stroke. By the time staff realised what was happening, he was too weak to be helped. Martin died. He had severe learning disabilities and no speech.

The health ombudsman agreed that Martin's death had been avoidable. She found that in several cases, people were treated less favourably because of their learning disabilities. There was a failure by several organisations to live up to human rights principles, particularly those of dignity and equality. The ombudsman also found that hospitals failed to make 'reasonable adjustments' to meet the needs of people with learning disabilities.

All this is rather depressing. The headlines were a poignant reminder that the NNPCPLD is as relevant today as it was when it was founded 10 years ago. We desperately need to share best practice, and to learn from situations that have not gone so well. We also need to have the courage to stand up and be champions for people who may not be able to let those around them know what they need. The NNPCPLD is a place where we can find inspiration and support for

the work we do with people with learning disabilities at the end of life.

As part of the NNPCPLD's mission to share our practice, one learning disability nurse reflects on his experiences with a client who died of oesophageal cancer (page 2).

From the gloom of the early morning news I went to feel more and more heartened, even excited, as the day of the Antrim conference wore on. The conference had a research focus, giving an overview of what researchers had learned and achieved over the past few decades. We may think there is still a huge mountain to climb (and there is!), but at least we have left the valley behind, and are on our way up. You can read more about the research day on page 5.

This newsletter launches the new 'In the Spotlight' feature, focusing on one of our members. We start with Josephine McCulloch in Glasgow, who is getting network meetings off the ground in Scotland (page 4).

We know that there are many people out there who do wonderful work to make sure that people with learning disabilities receive excellent end of life care. If you think someone (or a team) deserves to have their achievements recognised, why not nominate them for the Linda McEnhill Award (page 2)? It isn't all doom and gloom, and our positive achievements surely deserve to be in the headlines, too!

Dr Irene Tuffrey-Wijne (Chair)



The Linda McEnhill Award

Have you, or anyone you know, made a positive difference to the end of life care for people with learning disabilities? This could be, for example, a clinical development, an educational project, a piece of research, or an

example of outstanding support of an individual.

If so, why not consider putting the achievement forward for recognition through the Linda McEnhill Award?

Anyone involved in the end of life care for people with learning disabilities can be nominated. Nominations can be made by anyone: health or social care professional, person with learning disability or carer. Self-nominations are also invited.

The winner will receive a free place at the NNPCPLD Conference in Scotland (10th November 2009) and the opportunity to promote their achievement through the work of the NNPCPLD. The name of the recipient(s) will be added to the award trophy and the winner will receive a framed certificate.

Nominations should be received by 31st August 2009. The winner will be informed in October 2009. The award will be presented at the NNPCPLD National Conference in Scotland.

For more information and nomination forms, contact:

Noëlle Blackman

Email: noelle.blackman@respond.org.uk

Address: **RESPOND, 24-32 Stephenson Way, London NW1 2HD**

Lost in cyberspace

If you have had difficulties getting through to the NNPCPLD by email, our apologies. Hiccups with the email system meant that emails sent during a 5-week period earlier this year never arrived. It seems that the email system is now working properly again, so fingers crossed! Remember though that all postholders within the NNPCPLD are volunteers and many have busy day jobs, so please bear with us if you don't get an immediate response.



Sorting out Patrick's care

Mark Adams, a Community Learning Disability Nurse in Kirklees, shares his experiences with one of his clients.

Patrick Simmons (*not his real name*) had moderate learning disabilities and lived on his own. Patrick had no family, and relied greatly on professional supporters and a network of friends with similar disabilities. He was active in his local church and had made good friends there. With a robust system of tenancy support and day care, he managed well.

The cancer diagnosis

Patrick started losing weight, had difficulty swallowing and began vomiting. After a few months of this, his staff supported him to see his GP. The GP, looking at past medical

records that showed Patrick would not eat and lose weight when he was stressed, felt that the symptoms were related to his learning disabilities. The staff stressed that this was different, but no further action was taken until several weeks later. Patrick's symptoms had worsened, and a staff member took him to A&E. Further investigations revealed an oesophageal cancer, now in its late stages. Suddenly, lots of professional became involved. This included an urgent referral to our community learning disabilities team.

The first thing I had to do was to find out as much about Patrick as possible. I offered myself as a hub through which communications between other professionals could flow. It was quite a challenge to pull everyone together, because several of the different people

involved had not talked to each other, and some were not aware of each other at all.

Telling Patrick

Patrick had not been told of his diagnosis. People felt it was important



Mark Adams: "At the time I felt like I was a passenger in the back seat of a fast moving car."

to give him the news as quickly as possible, but in a sensitive way. Unfortunately, one Thursday evening his GP told him quite bluntly that he had cancer and was going to die. I wish his carers had known about this beforehand, so they could be with him. When I visited Patrick at home the following day, he was very upset and refused to discuss what the doctor had told him. I was concerned as the weekend was approaching and Patrick would have to spend the whole weekend on his own. We arranged with his social worker that he could have a weekend of Shared Lives support with a couple who knew him.

The couple had known him for years, but hadn't seen him for many months. They were shocked to see Patrick. They weren't really well enough prepared. Patrick was actually very ill that weekend. It was clear he couldn't stay at home on his own, and he agreed to accept a respite place on Monday night.

What to do about treatment?

In the meantime, there were hospital appointments and medical procedures to think about. Patrick hated hospitals and had a needle phobia. An IMCA (Independent Mental Capacity Advocate) assessed him and said that he did not have capacity to consent to investigations or treatment. She advised the hospital consultant that decisions had to be based on 'best interest'. The consultant decided to place a oesophageal stent to help him swallow better, and to do an ultrasound to see if the cancer had spread to Patrick's liver. There were huge problems with this. Patrick refused to go to hospital. When he finally went, the procedures had to be stopped after four hours because he didn't comply, although he had been given sedation to help him cope.

Where can Patrick go?

The respite unit wanted Patrick's bed back, so there was a desperate search for an alternative. There were only short-term beds, a few days at most. In the end, he was referred to a hospice and he agreed to move there.

The hospice was absolutely amazing. His



"It was clear he couldn't stay at home on his own"

care was exceptional. They looked after him so well. They even agreed that he could stay, although his prognosis was a couple of months and they don't usually keep people that long. They knew that the only alternative was for Patrick to move to a respite bed with different providers every few days. I visited the hospice most days and supported the doctors and nurses in communicating with Patrick, making sure the staff was comfortable working with him and ensuring his consent and co-operation for procedures. Despite his needle phobia, they managed to give him a syringe driver (*small machine delivering a continuous flow of drugs through a needle under the skin*), so his pain was controlled.

Patrick died six weeks later. The nurses were really upset when he died. They had built up a deep relationship with him.

Looking back

Supporting someone who was dying was all very new to me. It was the first time I ever had to deal with something like this. Looking back, we managed to sort things out for him, but at the time I felt like I was a passenger in the back seat of a fast moving car. Now, I accept that things can feel out of control and not ordered. Things just change so quickly when someone has end stage cancer. Maybe next time I would be a bit more proactive. I would want to make sure that everyone involved knows what is happening, and that we plan for the changes as much as possible.

Do you have a story or experience to share? Contact Irene on chair@natnetpald.org.uk

In the spotlight

In each newsletter, we will put one of our members in the spotlight. First up is Josephine McCulloch in Glasgow. Jo has just become an area representative, bringing new life to the Scotland Area Group of the network. 'We've moved on tremendously in the past 20 years,' she tells Irene Tuffrey-Wijne. 'Now, I want to push the agenda forward.'

Josephine McCulloch, 39, was working as a general nurse in a stroke unit when she decided it was time for a radical change of direction. Supported by her employer, she retrained as a learning disability nurse. Now, she is the Transitions Practitioner in a community learning disabilities team. 'That includes people moving from child to adult services, but also any other major change in people's lives,' she explains. 'We have to acknowledge that transition often begins with loss.'

A family experience

This momentous change was prompted by a very personal experience. 'I have a son with learning disabilities, and I felt I needed to gather more information. He is 14 now. He is just tremendous, and I feel privileged to be his mother. But when he was first diagnosed at the age of 2, I was devastated. The emotional impact has been huge. Medics give you the worst case scenario, saying that he would be like a 6 month old all his life and would never achieve anything.' Jo became aware that people can experience feelings of loss and grief, even if no-one has died.

Learning disability and loss

She has always been interested in end of life care. 'I don't know why, but it was an area where I felt I could make a positive contribution. I've experienced a number of deaths that were not good, and want to prevent it happening again. Respect for people is a big part of that.' She started reading learning disability legislation and literature around learning disabilities, bereavement and end of life care.

When she was re-training, her placement in a community team had a focus on physical health for people with learning disabilities. Jo found that loss had a big impact on some of her clients' health. 'When I addressed that for one man, the change was remarkable.'

Further training courses took her to St Andrew's hospice, and to London, where she took part in a 5 day bereavement training course run by Linda McEnhill and Noëlle Blackman. It was here that she first heard about the NNPCPLD.

Since then, she has set up loss discussion groups for people with learning disabilities, together with three colleagues. 'I've been lucky. My managers have really supported me in putting into practice what I've learned in these courses.'

Scotland Group

Jo is keen to promote collaboration in end of life care for people with learning disabilities. There have been attempts in the past to set up regional meetings of the NNPCPLD in Scotland, but it was hard to get off the ground in this large geographical area – a country rather than a region!

'I think it was hard getting people together. I hope it will be easier now, we are setting up meetings in Glasgow, quite central. And we are having them in the afternoons so

people can go to work first.'

At the initial meeting earlier this year, there was huge interest. 'I think the time is right. There's the new End of Life Care Strategy. And people are more aware of the need. Providers are keen to continue to support people at home, but need specialist support. Carers are looking for training. The local hospice wants to be involved, too, so that's great. What people wanted at that first meeting was putting resources together, find out what is available, share information and good practice.'

Jo has been supported in her task as Area Representative by Linda McEnhill, who previously chaired the NNPCPLD and lives in Glasgow. They are looking forward to hosting the next National Conference in November (see page 6).

What keeps her going? 'I just want to use my experience to help others, give them hope,' she says. 'It's not all doom and gloom.'



Josephine McCulloch: "I want to use my experience to help others."

Conference Report

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

Antrim, 24th March 2009

Over 100 delegates gathered in Northern Ireland for our first Research Conference. Part of our celebrations of the 10th anniversary of NNPCPLD, this was an opportunity to look back on the way research has contributed to good practice, and look forward to what still needs to be done.

The day kicked off with an overview by Prof Sheila Hollins of research around experiences of loss, bereavement, death and dying for people with learning disabilities. It was a sobering reminder of how only a few decades ago, there was little (if any) knowledge in this area. No researchers had ever taken an interest—in fact, most people believed that issues of death and loss were not relevant for people with learning disabilities.

What followed was an exciting and inspiring range of presentations by researchers and practitioners who have focused on issues of loss, death and learning disabilities during the past 10 years. Several presenters had turned this into the subject of their doctoral research.

Noëlle Blackman reviewed the available research on bereavement and people with learning disabilities. Her own work as a therapist with people with learning disabilities who have experienced trauma has clearly helped to advance knowledge and expertise in this area. Dr Phillip Dodd gave a fascinating insight into complicated grief for people with learning disabilities, based on his research.

A major research development during the past couple of years is the emergence of studies involving people with learning disabilities as participants and co-researchers.

Dr Sue Read talked about a study involving people with learning disabilities, listening to their ideas about death and what that means.

Dr Liz Forbat involved people with learning disabilities in identifying priorities for cancer research in Scotland.

Dr Irene Tuffrey-Wijne spent three years sharing in the experiences of 13 people with learning disabilities who had cancer, 10 of whom died.

Dr Stuart Todd and Dr Rachel Davies presented initial findings from studies into the end of life care received by people with learning disabilities in Wales.

Dr Stuart Todd took us through the history of death and learning disability in a 20th century institution—a grim reminder of how hidden and disposable the lives and deaths of people with learning disabilities were. Finally, Dr Jane Bernal helped us to think about “Why end of life research does not end with death”, and explored ways in which we remember and commemorate people with learning disabilities.

The day was chaired with skill and good humour by Prof Roy McConkey, who maintained just the right balance of seriousness and light relief.

All the presenters have been involved with the NNPCPLD, many of them since its foundation a decade ago. Through the NNPCPLD, members from across the UK have met regularly in the past, often presenting at the same conferences. They have inspired and supported each other in their work. The Research Conference was an inspiring day for delegates who had never been involved with the NNPCPLD before, and for those who had been involved for many years. It was a celebration of 10 years of inspirational research by some of our members. Much of the research presented has gained international recognition. As a network, we are very



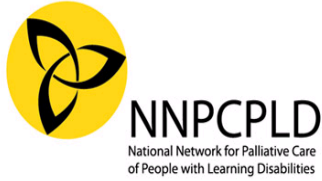
fortunate to bring together and nurture so many excellent researchers who have set an international standard.

The following day, a handful of members interested in carrying out further studies met to discuss future research possibilities. None of us have large research teams behind us; in fact, most of us work with limited resources, dependent on hard-to-get research grants. In the future, it will be important to collaborate—many of the important research questions cannot be answered by single researchers, and we need to begin to think about setting up larger national or even international studies (and, crucially, attracting funding for it!).

If you think research is not for you, think again—most of us started very small; in my case, as a hospice nurse simply wondering why I didn't see any patients with learning disabilities on the wards, and carrying out a small case study as part of a degree course. If you are interested in research, do share your ideas with other NNPCPLD members—you never know where it could take you, or what difference you could make!

Report by Irene Tuffrey-Wijne

If you missed this event, do consider joining us for our next conference, held in Glasgow on 10th November 2009. See page 6 for details.



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

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.

New training service

ENFOLD Training and Consultancy Service 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.

Further details: Tel **0207 387 3976** or email **Training@Enfold.org.uk**.

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

This one-day 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.

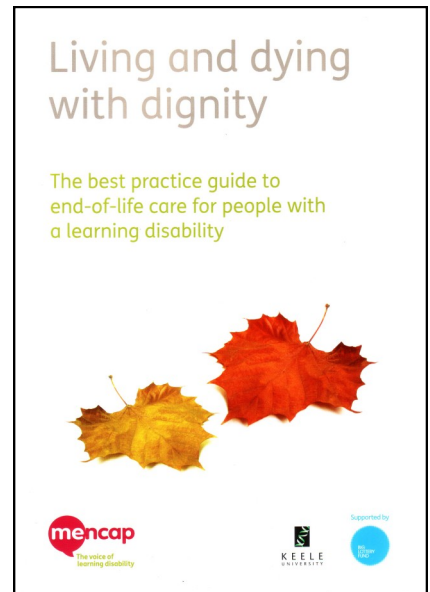
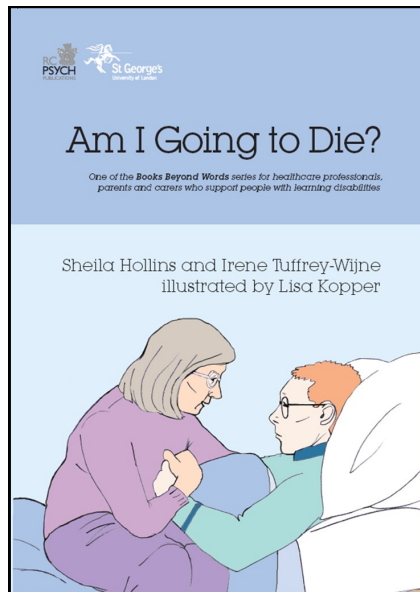
Regional meetings

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

Yorkshire: 4 November 2009, 10am-12.30pm, Kirkwood Hospice, Huddersfield. Contact: amanda.mckie@cht.nhs.uk

Scotland: 28 August 2009, 2-4pm, Glasgow. People from all areas in Scotland are encouraged to attend. Contact: josephine.mcculloch@lanarkshire.scot.nhs.uk

New Publications



“Am I going to die?” is a new title in the Books Beyond Words series. It tells the story of John, who has a learning disability. John is dying. The pictures follow him in his illness and his final days. They are designed to help the reader make sense of what is happening to them or someone they know who is ill. The pictures help them to ask questions or share their concerns. The book is based on “The Veronica Project”, a study of people with learning disabilities, 10 of whom were terminally ill. The story in the book draws on their experiences of what was important for them when they were ill and dying. “Am I going to die?” by Sheila Hollins and Irene Tuffrey-Wijne, illustrated by Lisa Kopper. Cost: £10 www.rcpsych.ac.uk/publications/booksbeyondwords, tel. 020 7235 2351 ext. 146.

“Living and dying with dignity” is a best practice guide to end of life care for people with a learning disability. It was developed by the North Staffordshire Palliative Care Project. The authors, Sue Read and Heather Morris, held conversations with people with learning disabilities, families and carers, advocates, and health and social care clinicians. An easy read version, and a summary of key messages, are also available. Copies can be downloaded from: www.mencap.org.uk/endoflifecare Tel 01159 827 022