

Possibility and passion at learning disabilities and palliative care conference

22 May 2013
News | Care



The learning disabilities and palliative care conference was held at House For An Art Lover in Glasgow yesterday

An "incredibly rich day" of inspiring presentations related to learning disabilities and palliative care brought together professionals from each field, and those working to bridge the gap between them, yesterday in Glasgow.

The Learning disabilities and palliative care: Building bridges - supporting care conference, was organised by [The Prince and Princess of Wales Hospice](#) in Glasgow and attracted 80 delegates from throughout the UK. The venue was at House For An Art Lover, which is situated right next to where the new site for the hospice will be built (building expected to start in 2015).

*"We can get this right!
We can make it a lot
easier."*

The event was brought about by the partnership between Liz Smith, practice development facilitator at The Prince and Princess of Wales Hospice, and Allison O'Donnell, joint lead with Liz on the Learning disabilities and palliative care: Building bridges - supporting care project and with a background in learning disabilities. Having been running for the past nine months, the day celebrated what has already been achieved through the project, and discussed what more can be done.

Liz and Allison were described as a "powerhouse, fuelled by passion" by chair of the event, manager of family support services at The Prince and Princess of Wales Hospice and social care lead for Help the Hospices national care and support team Linda McEnhill. "They are a force to be reckoned with and I am proud to be associated with them," Linda said.

Presentations came from both researchers, professionals and users and showed the breadth and

depth of the work being carried out throughout the UK by people involved in both learning disabilities and palliative care. According to Linda, the presentations that featured service users "helped us to really understand how to get things right and how difficult it is when we get it wrong".

"They highlighted the necessity for participation of users of services," Linda said. "Things can be reformed - out of loss, other things can be changed and will change people's lives in ways that can be very significant."

Collaboration and partnership were the key words of the day, resonating with people from all professions.

"We are a partnership and that's what we endorse in this project," Allison O'Donnell said about her and Liz Smith. "We're both driven by the project...and we have certainly raised the profile of learning disabilities services.

"We also recognise there is still a lot of work that needs to be done. But together we are making a difference."

One of the presentations that had a massive impact on delegates was that featuring Amanda Cresswell, who has a learning disability, has lost her mother to a brain tumour, and has had cancer herself, so has a unique and highly valuable user perspective.

Amanda told the audience that communication is key and that listening to the person, avoiding using jargon, using simple words or picture, makes a big difference.

"My advice would be, let people know that they've got cancer - don't hide it from them. Even though it might be difficult to tell someone with a learning disability because of communication problems. I wanted to know. And I wanted to tell my family, not the doctor," Amanda said.

The day also included informative and inspiring talks from Marie Cooper from Help the Hospices, Jean McLelland from the Scottish Government, Irene Tufrey-Wijne on breaking bad news, dementia education and training expert Karen Watchman speaking of dementia and people with learning disabilities, Dr Noelle Blackman discussing her study into bereavement and people with learning disabilities, and interviews with key practitioners.

Another user perspective session dealt with palliative care and people with profound and multiple learning disabilities (PMLD) and included a parent's perspective of end of life care, via Jenny Whinnett and her experience during the death of her son Craig.

Jenny gave an open and honest account of her experiences. She called for earlier connection with palliative care teams, more information and support for family members and carers and training for staff to understand people with PMLD better.

She said, in their case, palliative care should've been involved up to a year earlier than it actually was. And that she wished she had've known more about the dying process and details related to that such as palliative medications, breathing difficulties, when to stop feeding and more.

"I didn't have the knowledge around the dying process... And it heightened my distress," Jenny said.

"Families deserve to have that knowledge. It can help the bereavement process later if family and carers have that information."

Jenny said there should be contact with palliative care professionals for all people caring for people with PMLD.

"This was the last thing I did for my son and I wanted his going out to be as good as his life had been.

"We can get this right! We can make it a lot easier."

Keep visiting ehospice to read further articles in coming weeks about learning disabilities and palliative care following this conference.

[See more articles in Care](#)