



South West London
Academic, Health and Social Care
System

Case Studies- Series 3

Communicating Bad News to People with Learning Disabilities

Despite existing guidelines on breaking bad news to people with learning disabilities, research suggests many staff and carers still avoid the issue. Funded by a Small Grant from SWLS, Dr Irene Tuffrey-Wijne, Associate Professor in Intellectual Disability & Palliative Care, set out to identify and overcome the obstacles to these difficult, but crucial, conversations.

"I'd already seen the issue with staff wasn't that they didn't know how to do it, it was that for some reason they simply wouldn't or couldn't do it. So I wanted to talk in-depth to these groups about death and dying, and try to address the problem from their perspective."

Dr Irene Tuffrey-Wijne, PhD, RN, Faculty of Health, Social Care & Education, St. George's, University of London & Kingston University

Identifying Obstacles

In December 2015 Dr Tuffrey Wijne began three months of interviews with support staff and people with learning disabilities, mainly in care home settings, about their experiences around bereavement. The findings from this first phase would then shape development and delivery of training for relevant social care and acute care staff.



"My opening question was to what extent professionals talked to people with learning difficulties about people who were expected to die. There is a tendency to 'protect' this group; which can actually have a negative impact on their mental health."

The team were quite surprised by the widespread degree of reluctance learning disabilities staff had about discussing these issues; both with clients and in their own lives. And even those who felt that they had broached the subject often used vague language or side-stepped key elements. They also found that a staff's openness and ability to talk about death and dying was often role-modelled, for better or worse, on the example set by their service manager.

'Making best practice accepted practice'

Training Days at the Death Café

“Mostly we found it was about fear. Fear about doing or saying the wrong thing. So instead of giving another talk on death we wanted to simply enable conversations.”

Steered by this research, the team opted to open their newly devised training day with an informal ‘Death Café’. This coffee morning-style setting put attendees at ease and encouraged open and wide-ranging discussions around death. This was followed by a woman with learning disabilities sharing her own experiences, feedback on discussions from a panel with learning disabilities, and a group storytelling section to apply lessons learnt.

“By taking the group through questions like, ‘John is dying, do you think his friends should know?’ or ‘what words should we use?’ I think the storytelling format had a valuable role modelling function, and feedback was amazing.”

Dr Irene Tuffrey-Wijne

Feedback and Reflections

The sessions were held in March 2016 and attended by 114 professionals over the course of three days, including care home and service managers, learning disability teams, social workers, support workers, and trainers from the social care sector. Feedback on the day was overwhelmingly positive, “Today has been an eye opener. It’s made me aware not only about breaking bad news to people with learning disabilities, but breaking bad news to anyone.”

The team also gave all attendees a questionnaire, to assess their skills before, immediately after, and three months after training:

- *“I now find it easier to talk to service users, not avoiding the subject as I may have done in the past, but instead encouraging them to express their feelings.”*
- *“I have more knowledge and confidence about how to approach this subject and how to access all the tools that are available. We also presented the information to the rest of our Trust at a workshop event.”*

For Dr Tuffrey-Wijne highlights included working with advisors with learning disabilities and watching them gradually grow in confidence throughout the project, “by the end one of them was talking to dozens of staff about bereavement. So that in itself was really good for the staff to see” and hearing their feedback on the sessions, “Smashing! I really enjoyed it.”

Next Steps

Keen to capitalise on project momentum, Dr Tuffrey-Wijne has submitted several papers on the effectiveness of the death café format; suggesting rolling out shorter, one hour versions to hospices and hospitals across the country. She is currently developing ways to springboard the learning from one-off training sessions into something more widely accessible and sustainable, such as a DVD or website, and has also secured a grant from Baily Thomas Charitable Fund to do UK-wide research.

“The small grant from SWLS definitely acted as a stepping stone to larger work. We’ll now get a wider picture of where this is happening and be able to help staff develop a culture of being more open. So upwards and onwards!”

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