

...with Sheila Payne

Help the Hospices Chair in Hospice Studies, Lancaster University

One moment that changed the course of your career

Over 25 years ago I worked as an agency nurse and was assigned to provide individual 'special' care for an older woman dying alone in a care home in Torbay, Devon. During her final days she taught me so much about the process of dying: what was not good enough (like her pain control) and the importance of emotionally being with a dying person. Her death imparted a feeling of great privilege of sharing that final part of her life. My fascination with loss, dying and bereavement and the desire to improve care has not left me yet.

One book that you think all psychologists should read

One I have returned to many times is Young and Cullen's 1996 book *A Good Death: Conversations with East Londoners*, a richly evocative account of narratives of loss and death from traditional East Enders. It shows that we

are *not* all equal in death. Instead our deaths are largely determined by how and where we have lived, and that end-of-life rituals and mourning behaviours are socially constructed.

One inspiration

Frances Sheldon, not a psychologist but a social worker, who died tragically young of breast cancer. I first met Frances when she was working at Countess Mountbatten House, the hospice in Southampton, in 1990. We then worked together at the University of Southampton where she set up the first master's programme in psychosocial palliative care. She was a pioneering international leader, and her fearless and spirited engagement in promoting psychosocial care for dying people has shaped and inspired my work.

One thing that you would change about psychology

I have a foot in two disciplines

– health psychology and nursing – and I think there are strengths in both. However, to generalise, I think that health psychologists could benefit from a greater understanding of pathology and disease processes and have a firmer grasp of the 'realities' of health care services, while nursing research could benefit from valuing theoretical concepts more and becoming more methodologically sophisticated. There, I have probably managed to insult both groups.

One particular challenge in working in palliative care

There are formidable ethical, methodological and practical challenges. Debates have raged over whether it is ever ethically justifiable to recruit dying people into research studies. My view is that collecting evidence on the experiences of dying people and their families is justified because not to do so is disempowering and negates them as adults. If we are to understand their needs better and improve services, we need more than assumptions or proxy data

from health professionals. However, research ethical review committees increasingly position these people as 'vulnerable', and 'gatekeeping' by health professionals means that recruiting reasonably sized samples is always challenging. We need to respect decisions made by patients and families: many will have more important things to do in their final days than research, while others like to contribute to research as part of a lasting legacy to others.

One nugget of advice for aspiring psychologists

Recycle. If your research proposal gets rejected for funding, request feedback, review, revise and resubmit to another funder. My record is eight times before the study



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got funded. Being a researcher is often more about resilience than brilliance.

More answers online at www.thepsychologist.org.uk

resource

Payne, S. & Haines, R. (2002). Doing our bit to ease the pain. *The Psychologist*, 15(11), 564–567. [See www.bps.org.uk/payne]
'It started to raise the profile of psychologists working in palliative care and demonstrated the contribution that psychology could make near the end of life.'

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