

# The experience of bereavement following a physician assisted suicide (PAS): what do we know about the needs of these bereaved?



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Many of us have watched television programmes or read about people who have decided to travel abroad to end their lives in countries that have a legal framework to support an assisted death or suicide. The programmes or articles concentrate on the needs and experiences of the person who dies. Sometimes we hear from, or about those people around them but, when we do their thoughts are about their relative's needs and not about what might be in the future for them after the death.

We know that between 1998 – 2012, 215 people from the UK travelled to Dignitas' clinic in Switzerland, including 33 people in 2012 (Dignitas, 2014). In an article in *The Guardian* article titled 'One person a fortnight' travels to Dignitas from Britain to end their lives, it was claimed that '292 Britons have gone to Dignitas since 2002. The largest number of people who have died came from the Greater London area – 57 – compared with just seven from the north-east' (Doward, 2015). There is a growing number of people from the UK who seek an assisted death (Badcott, 2010) and then go abroad as 'suicide tourists' (Gauthier *et al*, 2015, p611). Many of these people have networks of family and friends around them that are affected by the deaths.

Assisting the suicide of another person, in England and Wales, is punishable by up to 14 years in prison

which includes accompanying people travelling abroad to die in this way (Crown Prosecution Service, 2014). According to the Home Office *Statistical Bulletin*, 141 persons were registered by the police for assisting suicide between 1997 and 2012 (Gauthier *et al*, 2015). The current policy allows that assisting someone to commit suicide may be free from prosecution in circumstances where it is judged to be in the public interest not to prosecute. For example, if the decision to seek an assisted suicide was voluntary, clear, settled and informed and if the person assisting was acting out of compassion (Crown Prosecution Service, 2014). Until recently, there had been no prosecutions for the offence since the introduction of the 2010 policy, although in August 2013 the wife and son of a man who wanted to commit suicide in Switzerland with the help of Dignitas were arrested (Salkeld, 2013).

The language used to describe an assisted death is varied, with either physician assisted suicide (PAS) or physician assisted death (PAD), usually used to describe an assisted death in Switzerland (Fischer *et al*, 2008). In Holland, where a health professional directly administers the means of death, this would usually be described as euthanasia. The British Medical Association's publication, *End-of-life care and physician-assisted dying, Part 1: setting the scene* (Campbell *et al*, 2016) gives a thorough, patient focussed

overview of the debate in the UK and the international evidence on assisted dying.

## What is known about the experience of people bereaved by an assisted death?

There is limited research on the experience or possible effect on the family members or close friends of those who choose to end their lives with assistance in other countries (Gamondi *et al*, 2013) and there has been no research about those bereaved by assisted suicide in the UK. The issues that might be important for these bereaved people in the UK have not been investigated and literature that has been collected in the few studies about the effect of assisted death on bereavement has been limited and reaches divergent conclusions. There is a larger and richer body of research about the effect on families of suicide, much pointing to the many risk issues for those bereaved, finding a higher incidence of distress and prolonged or complicated grief (Jordan, 2001) with specialist therapy groups created to offer bereavement care for the specific needs of this group (Pietila, 2002).

Beder (1998) explored and anticipated the bereavement experience of the bereaved following a PAS using theories of bereavement based on the experience of those bereaved by suicide, and discussed the important part that feelings such as anger and guilt, or ambivalent feelings towards the deceased, contribute to heightened feelings of distress and grief.

However, we cannot assume that the experience of having a relative undertaking an assisted death or suicide will lead to a similar experience of having a relative who takes their own life in the other ways that are possible and which are usually not known about in advance. If the death is planned and is discussed with the family in advance then the impact upon family members might be less negative or even positive, as there appears to be a link between advanced care planning, less aggressive medical treatment at the end of life, and a positive effect for the bereaved (Wright *et al*, 2008).

Using a measure of complicated grief, Wagner, Müller and Maercker (2011) found that there were negative outcomes for those bereaved who witnessed physician assisted suicide in Switzerland and also found some symptoms of post-traumatic stress disorder (PTSD). The study used the Inventory of Complicated Grief (Prigerson *et al*, 1995) and the Impact of Event Scale for PTSD (Maercker & Schutzwohl, 1998) and found that perceived social disapproval of the bereaved by their social groups and society was strongly correlated with an increase in all negative measures. For those bereaved participants who perceived that their social groups and society were more accepting there were no significant PTSD symptoms or complicated grief. The question then arises that if society continues to see this kind of death as stigmatised this might lead to a more problematic bereavement and we might expect disenfranchised grief. Disenfranchised grief is a term used by

Doka (1999) to describe how society's view of aspects of a bereavement, in this case the kind of death, might contribute to the bereaved having difficulty in expressing grief or getting support.

Research with relatives in Switzerland, where there is a legal framework to support this kind of death, found that families had felt unable to talk to some healthcare professionals before their relative had died, as they 'perceived that some had difficulty in dealing with their own personal beliefs sufficiently well, to enable open discussion. This may explain the barriers in communication' (Gamondi, Pott & Payne, 2013, p1643). Healthcare professionals' organisations in the UK have created guidance for members on the legal position and are undertaking to resolve how best to communicate to patients and their families about this possible option at the end of life (Campbell *et al*, 2016; Royal College of Nursing 2016).

A further factor which may be of importance in this experience of grief might be the capacity for the bereaved to have prepared for a death. Anticipatory grief (Stroebe & Schut, 2001) is also seen to predispose for a better grief outcome, and the care offered by hospices for the families of those that are dying enables the exploration of the future, as well as the expression of some of the feelings towards and about the person who will soon die. We might also expect that as a 'planned death' there might be positive outcomes for those involved around the time of death and in the decision making which is found when some form of pre-bereavement preparation can take place (Wimpenny *et al*, 2008).

The expectations of poor grief outcomes suggested in Beder's article (1998) is countered by research by Ganzini *et al* (2009, p807) who found that when comparing family members of those who had requested PAS with a similar group of those bereaved by death occurring due to illness, there were 'no differences in primary mental health outcomes of depression, grief or mental health services use.' In this small study of 95 family members of those choosing PAS in Oregon, grief was measured using the Inventory of Complicated Grief (Prigerson *et al*, 1995). The Inventory uses questions such as 'I have regrets about how he died' and 'I was at peace with the choices s/he made at the end of life' and compared with the control group of families dying of similar illnesses Ganzini concludes that 'families in which aid in dying was requested felt on average more prepared for the death, felt more accepting of the loved one's death' (Ganzini *et al*, 2009 p813). A similar finding comes from a study of the bereavement effects on families experiencing organ donation, where there was not an increased risk in the severity of grief for families whose relatives had chosen to donate organs (Cleiren & Van Zoelen, 2002). This study also noted that there was a need to have good quality information to help process the significant event and to feel that there was a satisfactory standard of support from the medical staff.

The current debate about having a legal framework that allows assisted deaths in the UK continues and raises many issues that can lead to polarised stances which challenge our capacity to research and reflect on the needs of the patients and their families and friends. For many of the bereaved following a PAS there are few obvious ways to find others who have experienced this kind of death except for campaigning groups which tend to have formed their view of what this kind of death means for society and by implication for the individual. Professionals working to support the bereaved are very aware that grief can lead to the need to explore what can be very ambivalent and individual responses towards both the way someone has died and the relationship with the deceased, and that how society views the death can feel supportive or constraining. ■

### How does assisted dying affect the experience of the bereaved in the UK?

- My research project is part of a PhD at Lancaster University exploring the experience of bereaved people living in the UK, having experienced multiple or single deaths of a family member or friend, not less than six months ago, occurring by physician assisted suicide (PAS) taking place in a country that has a legal framework to allow a PAS. Interviews will be taking place throughout 2017.
- Participants must be over 18, male or female.
- It is hoped that the findings will inform professional working to support these bereaved to find the support and services they need.
- If you wish to find out more about the project or know someone who would like to participate see [www.bereavementresearch.wordpress.com](http://www.bereavementresearch.wordpress.com) or email the author.

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