

# **NEW research: Understanding the perspectives of UK-based family members of people who have chosen to end their life by assisted dying**

*by Dr Megan Knights (nee Hitchcock)*

Dr Megan Knights is a Clinical Psychologist who recently completed her Doctorate in Clinical Psychology at the University of Hertfordshire (UH). Here she shares the findings of her doctoral research looking to understand family members' perspectives on assisted dying of people who have had an assisted death.

This research was supported by the supervision of Dr Jen Heath, Principal Lecturer at UH and Dr Marianne Dees, General Practitioner & Senior Researcher at Radboud University Medical Centre, expert-by-experience consultation and DIGNITAS, who facilitated recruitment.

## ***Background***

The option to choose an assisted death, in certain circumstances, is growing in momentum around the world, but at the time of writing, assisted deaths are illegal in the UK. Therefore, those living in the UK wishing for an assisted death, must go abroad to Switzerland, the only country that offers these services to non-citizens, and use an end-of-life organisation such as “DIGNITAS – To live with dignity – To die with dignity”. In these circumstances, family members, aware of their loved ones' plan, are required to choose to travel with them, facing possible investigation and prosecution on their return, or to leave their loved one to go to Switzerland alone. Family members, and others, who may have been excluded from the plans for an assisted death, may need to come to terms with their loved one choosing this way to die.

## ***This study***

Seeking to understand UK-family members' perspectives on assisted deaths, Megan interviewed a small sample of family members about their views on assisted dying, the various contexts informing these views, and the resources that they drew on to support themselves during this time.

Four main themes were identified:

### ***1. A life dictated by illness***

Family members highlighted the significant impacts of a loved one receiving and/or living with a life changing medical diagnosis and how these contributed to them choosing an assisted death. They questioned what a quality-of-life that feels worth living is, and whether a life feels “valid” when experiencing *unbearable suffering*<sup>1</sup>. The toll that living with this suffering can take on others was also discussed. It was felt that, if someone believes that they are lacking quality-of-life, this suffering can be exacerbated by feeling that they are a “burden”/having a negative impact on others, and in these circumstances, they should be able to have the choice for an assisted death.

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<sup>1</sup> \*Unbearable suffering has been defined as “*a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind*” (Dees et al., 2010).

## **2. *Life as autonomous***

Family members described beliefs about the importance of people having autonomy over their lives. This included a strong feeling that people should have the right to choose when to end their life, particularly when experiencing unbearable suffering and when it is felt that all other options for relieving suffering have been explored. Family members also shared views that some might feel 'ready' to die, either to avoid future suffering, and/or because life feels completed; in these situations, assisted dying should be acceptable. It was identified that a loved one choosing an assisted death can be a challenging and emotional time, but that it is important to support them with this decision, if it is what they want.

## **3. *Navigating an "illegal" landscape***

Family members shared experiences about navigating the assisted death journey whilst it is illegal in the UK, reflecting that guidance on this process would have been helpful. Challenges were shared around deciding who the assisted death could be talked about with. This decision was informed by the views of the person having the assisted death, and/or worries about implications of telling others (e.g., their reaction; someone informing the police). Possible implications for medical staff aware of the decision were also considered, alongside the challenges of needing to interact with them regardless (i.e., to access medical notes).

Family members shared different ways of managing the emotional impact of the assisted death. Coping mechanisms included combinations of seeking support from close others (including the person seeking the assisted death before they died), maintaining life as usual or taking up new hobbies.

## **4. *Assisted dying should be legalised***

Family members all felt strongly that the UK should legalise assisted dying. Family members stipulated the importance of individual autonomy and saw assisted dying as part of progression within medicine. However, it was recognised that others, particularly those holding religious beliefs, may disagree. Issues around possible misuse of these services were also identified and it was felt important that protocols and policies should be implemented to safeguard against misuse. It was felt that these concerns should not prevent those seeking an assisted death from accessing one.

It is hoped that these findings will contribute to understandings of the current position of assisted dying in the UK and the debate around legalisation. Should the UK legalise assisted dying, it is hoped that this research will inform relevant policies. Regardless of legalisation, it is hoped that these findings can inform health and care provision in considering the support that is offered to individuals seeking an assisted death, and their families.

Weblink for full report: Hitchcock, M. (2023). *Understanding the perspectives of UK-based family members of people who have chosen to end their life by assisted dying*.

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If you have any thoughts on this research, please contact Megan: [drmeganknights@hotmail.com](mailto:drmeganknights@hotmail.com)