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As a nurse and family carer, I value the wisdom of lived experience. Increasingly, we hear from carers who are actively experiencing caring benefits and challenges, who seek and offer peer support. More so as we have become more digitally focussed. There are support groups, books, blogs and other social media bringing new and current knowledge about caring, including in the era of Covid. This paper now brings an interesting analysis of the experiences of a group of family carers who have moved to a new stage in their caregiving journey. This group have lived through the death of their loved one as part of that experience and are in a unique position to reflect, review and regroup about their long experiences of caring. It could be argued that looking though this lens may distort the memories of a long, diverse and changing care journey, yet all experiences are precious and capturing the whole journey brings a unique value to the knowledge offered here. This whole journey experience has been termed the care trajectory and a scoping review by Carter et al., (2020) found that there is no single way to provide peer support for family carers that will fit everyone.

Subjecting such rich data from these participants to qualitative analysis could offer an evidence that is lacking, despite the plethora of stories and experiences in the grey literature and media. While active peer to peer support can bring such positive emotional support and a deep understanding of the other person (Keyes et al, 2016), this paper could add to this knowledge and support carers and professionals in this important role.

While all experiences bring knowledge, in this case much of the learning comes from a group who are less often heard in research. The research themes generated from those who have completed the experience of living with a person with dementia to the end of the journey might reinforce or challenge what we already know. Yet the findings are familiar and interestingly still relevant, despite active caring coming to an end. Clearly, the support, kindness, self-care and education of family carers are themes for the complete caring journey. This is only the start of building deeper knowledge for practice.


Dementia Action Alliance Resources and Stories (dementiaaction.org.uk)


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Bio

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