

# Step-change needed in support for carers of terminally ill, argue academics

24 April 2018

A new report by leading academics has today urged healthcare providers to radically improve the way they support carers of people approaching the end of their life.

The document, by Dr. Gail Ewing from The University of Cambridge and Professor Gunn Grande from The University of Manchester, argues a major cultural shift among staff is desperately needed to help carers.

Improvements in structures and internal processes are also among the 10 recommendations in the National Institute for Health Research and Hospice UK funded report to improve the way healthcare organisations—such as hospices, hospitals, community nursing and General Practice – to [support](#) carers' needs.

Other recommendations include:

- Training staff in carer assessment and support
- Making more time available for staff to support carers
- Setting up a system to record carer information
- Consistent identification of carers
- Routine identification of carers' needs.

The report, which was written following work with carers and clinical staff, highlights how family members often play a pivotal role in supporting their loved ones at the end of their life.

And that, say the academics, provides more care at home and easing pressure on hospitals.

One of the carers in the report told how it never occurred for him to ask the doctor about his own problems.

Another carer said: "I needed some sort of human support, one-to-one support, somebody to come

round and say, 'I've come to see you, how are you getting on?' and just to make you feel that you are needed and that somebody is looking out for you."

And a clinician described how sections in medical notes for carers' details were not being completed.

The report's publication is to be followed by a national survey of hospice providers to establish what is currently in place to assess and support carers, compared against these recommendations.

Dr. Sarah Russell, Head of Research at Hospice UK and a member of the expert advisory group for the report, said:

"The needs of carers of people approaching the end of life, which are distinct from other types of carers, have long been overlooked. While there have been positive developments in policy in recent years, these have not translated into service delivery. This report aims to tackle that gap and provide healthcare organisations with practical guidance on what needs to change.

"With an ageing population and rising pressures on health and social care services, more people will be called upon to care at home for older relatives with complex, multiple conditions. It is vital they get the person-centred support they need so they can fulfil their caring role effectively and also maintain their own physical and mental health and wellbeing."

Professor Gunn Grande said: "As we say in our [report](#), if we don't support carers, carers aren't going to support the patients, and then we're all going to be struggling. Indeed, professionals who work in palliative care will subscribe to the ethos of being there for the family, not just the patient. But it's very sad that this strong philosophy is not being consistently put into practice."

Dr. Gail Ewing said: "Perhaps the more difficult challenge is resolving where carers 'fit' within end

of life care: whose responsibility are they? "That means we really must answer the question of whether or not carers are to be viewed as true clients of [palliative care services](#), so that we can legitimise their assessment and support. Ultimately this needs to be reflected in commissioning, specific funding for carer assessment and support in end of life care."

Provided by University of Manchester

APA citation: Step-change needed in support for carers of terminally ill, argue academics (2018, April 24) retrieved 3 December 2022 from <https://medicalxpress.com/news/2018-04-step-change-carers-terminally-ill-academics.html>

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