

# Research highlights the need to support family carers when discharging dying patients

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New research funded by Marie Curie has highlighted the importance of identifying the support needs of family carers before dying patients are discharged from hospital so that carers are better prepared for end of life caregiving at home.

Researchers from the Universities of Manchester and Cambridge looked at barriers to supporting carers, which are often responsible for a breakdown of care at home and ultimately, for dying patients being unnecessarily readmitted to hospital.

Interviews with [healthcare professionals](#) and carers revealed an absence of formal procedures for identifying carers' support needs within current hospital practice. The researchers describe an "organisational focus" on patients' needs that tends to not take the separate support needs of carers into account. Carers were involved in discussions around discharge but in relation to patients' needs which overwhelmingly emphasised practical issues, such as equipment requirements, with little consideration of emotional needs.

Healthcare professionals felt that carers often had "unrealistic expectations" in terms of the realities of providing 24-hour care to a dying family member and lacked a clear understanding of the physical and emotional demands involved. They also explained that carers tend to overestimate the level of community support that they will receive once

at home, with expectations around support at night being a particular difficulty.

Another barrier identified by healthcare professionals was that carers often had limited awareness that their loved ones were approaching end of life. In these cases, it was difficult for carers' concerns to be elicited and for healthcare professionals to put appropriate community support services in place.

Professor Gunn Grande, University of Manchester and Lead for End of Life Programme at the National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care ) Greater Manchester (NIHR CLAHRC GM), said:

"Carers will often be very eager to get their loved ones home but they may not have a clear idea of what 24-hour caregiving entails. There is a crucial need for healthcare professionals to discuss carers' support needs before discharge to ensure that they are prepared for the challenges involved in caring for someone who is dying. But they need clear processes and resource in order to do this. Bearing in mind how crucial family carers are to making care at home following discharge work, we believe that systematic assessment of the support needs of carers should be a routine aspect of the discharge process."

Presenting the findings today at the Palliative Care Conference at the University of Salford, Dr Jane Collins, Chief Executive for Marie Curie said:

"Enabling successful discharge of terminally ill patients home and prevention of readmissions are key issues for our health service. Family carers clearly play a central role in this but these findings show that they often feel uninvolved and unsupported - the result being that they find themselves unprepared for the challenges of caring and are forced to go

back to hospital when a crisis occurs. As well as the pain and distress this causes to patients and their families, readmissions place a huge unnecessary pressure on our health service. Recognising the personal burden involved in caring for a dying loved one and providing carers with the support they need and deserve is vital to providing to the compassionate, community model of care that we aspire to."

In response to the highlighted challenges, the study identified the utility of a Carer Support Needs Assessment Tool (CSNAT) for healthcare professionals, to help facilitate conversations with carers and prepare them for the realities of caring for someone at end of life. The study, which has been funded by the terminal illness charity Marie Curie and supported by NIHR CLAHRC for Greater Manchester notes that this approach was viewed positively by both carers and healthcare professionals. Potential benefits of using the approach included; giving carers permission to consider their own needs, assisting communication around support needs, and offering a 'way in' to difficult end of life discussions.

The research is published today in the journal *Palliative Medicine*. This coincides with the launch of Marie Curie's annual fundraiser, The Great Daffodil Appeal. Marie Curie is the UK's largest charitable funder of research in palliative and end of life care thanks to the donations it receives.

**More information:** Gail Ewing et al. Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach, *Palliative Medicine* (2018). [DOI: 10.1177/0269216318756259](https://doi.org/10.1177/0269216318756259)

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