

Little has changed in four decades of dementia care, study finds

October 4 2022



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A new study has found ineffective co-ordination of services and

fragmented care plans in England has resulted in very little improving for dementia caregivers in forty years.

The review also shows the persistent emphasis on "cure over care" in [dementia](#) strategy has rendered [policy recommendations](#) limited when it comes to improvements at a local community level.

Published in *Dementia*, the research from Dr. Martina Zimmermann, Fellow and Lecturer in Health Humanities and Health Sciences and UKRI Future Leaders and Tony Britton, Founder Trustee of the Pam Britton Trust for Dementia (Queen's Award for Voluntary Service), shows that the experience for dementia caregivers remains hampered by [policy](#) and frustrating in practice.

What is lacking and why?

The findings, based on analysis of literary writing, policy documentation and social research, indicate that ineffective co-ordination of services and disjointed care plans are to blame for little improvement to the lives of dementia caregivers. Support for informal dementia care at a local community level is not working for most caregivers today; namely due to an absence of an empowered named [support](#) for the caregiver and an effectively actioned care plan, backed up by sufficient resources.

As a result, the research indicates that the lived experience of dementia care continues to be dominated by feelings of isolation, exhaustion, and perceived lack of support—symptoms which have remained consistent across four decades of analysis of the experience of dementia caregivers.

Cure over care

The study has also found that 40 years of policy-driven efforts to find a

cure have eclipsed attention to care. The Prime Minister's Challenge on Dementia calls for "high-quality relationship-based care and support for people with dementia," but only a small fraction of funding was allocated to improving care. Despite many policy documents recognizing the need for more concrete [caregiver](#) support, change remains incremental at best.

"At a macro-level, a deep culture shift is needed, one that sees the need for care as much as cure. Consequently, this would create a commitment to share finances more evenly between transformation of care and research into cure," says Zimmermann.

Policy is unspecific and therefore unhelpful

Despite efforts made to reduce fragmentation of care, as formulated in policy papers across over a dozen years of papers analyzed in the study, local implementation has not occurred.

Whilst UK Government papers pledge a greater focus on care, it remains with local authorities to allocate resources. These [local authorities](#) may invest in easy to subcontract-out ways, for example to charities. The study notes an increase in demand on local support charities, who are asked to act like a named contact for caregivers, albeit without the necessary resources and healthcare training.

Policy documents often lack specific information to make recommended improvements successful. For example, they consistently fail to identify who should be the named contact for caregivers: those responsible for developing a care plan can be the memory assessment service, the local council or the GP. Ambiguity about this responsibility leads to problems for dementia caregivers, not least since GPs report uncertainty regarding a dementia diagnosis.

What could be changed?

The study recommends that a joined-up approach between health and social care and adequate information on available care support services should be made accessible through an empowered named contact. To enhance the lived experience of dementia care, consistent provision of individual named support and professional care support, as and when required, should become essential to local implementation of the care policy.

Britton says that "the measures proposed would send a signal that people with dementia and their caregivers are fully appreciated by, and integrated in the local community. As long as care is fragmented and caregivers cannot swiftly access specific specialist services, the lived experience of dementia care will continue to be exhausting, frustrating and lonely."

More information: Anthony Britton et al, Informal dementia care: The carer's lived experience at the divides between policy and practice, *Dementia* (2022). DOI: [10.1177/14713012221112234](https://doi.org/10.1177/14713012221112234)

Provided by King's College London

Citation: Little has changed in four decades of dementia care, study finds (2022, October 4) retrieved 27 June 2024 from <https://medicalxpress.com/news/2022-10-decades-dementia.html>

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