



@JDementiaCare

@JournalofDementiaCare
www.facebook.com/
JournalOfDementiaCare**Editor Mark Ivory**

mark@dementiapublishing.community

Managing Editor Sue Benson

sue@dementiapublishing.community

Production Andrew Chapman**Designer Rob Wheele****Editor-in-chief Dr Richard Hawkins****Website editor/social media Beth Lang**

beth@dementiapublishing.community

General Manager Melanie Blake

melanie@dementiapublishing.community

Tel: 0300 030 1028 (10am-1pm Mon-Fri)**Subscriptions**

subs@dementiapublishing.community

www.journalofdementiacare.co.uk

The Journal of Dementia Care is published six times a year by Dementia Publishing Community Benefit Society

Registered address; 16 Broad Street, Eye, IP23 7AF

© Dementia Publishing

ISSN 1351-8372

Dementia Publishing Advisory Board**Caroline Baker**, dementia care expert**Paola Barbarino**, Alzheimer's Disease International**Kate Lee**, Alzheimer's Society**Professor Dawn Brooker**, University of Worcester**Theresa Ellmers**, University of Southampton**Dr Nori Graham**, Alzheimer's Society and Alzheimer's Disease International**Tessa Gutteridge**, Young Onset Dementia, Dementia UK**Karen Harrison-Dening**, Dementia UK**Hazel Heath**, independent nurse consultant: older people**Jo James**, Imperial College Healthcare NHS Trust**Professor Jill Manthorpe**, Professor of Social Work, King's College London**Rachel Niblock**, Dementia Engagement and Empowerment Project – people living with dementia**Sahdia Parveen**, University of Bradford**Maria Pasiecznik Parsons**, Creative Dementia Arts Network**Lynne Phair**, independent consultant nurse & expert witness**Jackie Pool**, Dementia Pal Ltd**Professor Graham Stokes**, HC-One**Professor Claire Surr**, Leeds Beckett University**Jude Sweeting**, Dementia Pathfinders**Dr Amanda Thompson**, South London and the Maudsley NHS Foundation Trust**Toby Williamson**, independent consultant**Lucy Whitman**, former carer, writer, editor and trainer**Hilary Woodhead**, NAPA

Palliative care: time for a change of focus

**Professor Nathan Davies,
University College London**



As people live longer, more are being diagnosed with dementia, leading to what is referred to by Paola Barbarino in this issue of *JDC* as a “tsunami of demand”. We know that it is now the leading cause of death in the UK and that palliative care needs are expected to increase 25% by 2040, with the biggest increase expected among those living with dementia.

More often than not, the condition is not recognised as terminal or seen as requiring palliative care, which is perceived as care provided only at the end of life. The unpredictable trajectory and nature of dementia means it can be hard to identify when someone is at the end of life and palliative care may be appropriate.

But there is also a debate about when palliative care should begin for someone living with dementia. Should it begin immediately following diagnosis, which some consider too soon, or in the severe stages of dementia which many people may not actually reach? In our view, palliative care can be adopted earlier in the disease trajectory and should not be limited to the end of life.

Our recent work at UCL suggests there should be a shift of focus from prognosis and time-based approaches to palliative care for dementia, towards a more needs-based approach that considers the holistic needs of the individual and those close to them. It should attend not just to their physical needs, but also their emotional, psychological, and spiritual needs.

As dementia is the main underlying condition for deaths from Covid-19, the pandemic has made palliative care more visible through 2020 and 2021. It brought about a different approach to care and new ways of working, especially given the loss of face-to-face support services. Many family carers felt alone when providing end of life care at home and were having to make difficult and emotive decisions with little support.

Consequently, we developed a decision aid to help carers make these tough decisions on things like hospital admissions, care home support and continuing to live at home. As the pandemic continues into 2022, it is important we consider how best to support families and people living with dementia at home, as adopting a palliative care approach early on can provide notable benefits.

It's good to see that Marie Curie, a charity dedicated to care and support through terminal illness, is leading calls for the commissioning of end of life care services in England. This is vital in light of the increase in numbers of people dying at home during the pandemic. But we need to do more. Our Empowering Better End of Life Dementia Care (EMBED-Care) programme aims to spark public conversation about about death and dying, develop new approaches to delivering palliative care and share with everyone the value of palliative dementia care. ■

Dr Nathan Davies is associate professor of ageing and applied research, and deputy director of the Centre for Ageing Population Studies at UCL.

The Journal of Dementia Care is a multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and residential care homes, day units and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The *Journal of Dementia Care* is grounded firmly in practice and provides a lively forum for ideas and opinions.

Writing for JDC:

Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? Do you have a strong opinion you would like to express? We welcome letters and contributions that promote discussion and debate about dementia care.

Contact the editor, Mark Ivory:
mark@dementiapublishing.community