

Palliative care matters, now more than ever

This special issue now seems uncannily prescient in view of the devastating impact of COVID-19 on people with advanced dementia or severe frailty, particularly in care homes. The pandemic has heightened awareness of the possibility of a sudden and rapid transition from relative health to a palliative or end of life stage. This has opened up conversations about the potential burden from intensive treatments that are likely to be futile and the benefits of advance care planning. The collection of papers will be of interest to readers involved in planning, commissioning or delivering palliative and end of life care services for our most vulnerable citizens at this time, whether at home or in a hospital, care home or hospice.

A global priority

Palliative care should be available for everyone with progressive chronic disease (World Health Assembly, 2014) and is a priority in the global response to ageing (WHO, 2015). The percentage of European citizens aged over 65 years is predicted to rise to 28% by 2060, and those aged over 80 years will more than double (European Commission, 2015). The prevalence of dementia will become more than double in this period (Prince *et al.*, 2013), and there will be a dramatic increase in disability and dependency (Murray and Lopez, 2013) resulting from frailty, an age-related syndrome of reduced reserve in multiple organs that affects around 11% of people aged over 65 years in the community (O’Caoimh *et al.*, 2018). The mid to late stages of both dementia and frailty are characterised by reduced physical and cognitive function and mark the start of an extended palliative phase of progressive disability at the end of life (Gill *et al.*, 2010).

Despite guidance on effective palliative interventions in advanced dementia (Murphy *et al.*, 2016; Tolson *et al.*, 2016) and in end of life care for frailty (BGS, 2020), there is currently no consensus on the optimal model to deliver these interventions. Community models often involve specialists in palliative care supporting primary care physicians and teams (Gomes *et al.*, 2013). This approach affirms existing expertise and offers additional palliative specialist advice and education as required to support clinicians working with patients, family caregivers and community and voluntary services. A wider population or public health approach considers everyone has a role to play in supporting people at times of crisis or loss and mobilises the collective strengths and “assets” of compassionate communities (Kellehear, 2013; Abel, 2018).

A population based study of physician led palliative care in advanced non-malignant disease reported reduced healthcare use and increased likelihood of dying at home for people with chronic organ failure, but not for those with dementia, most of whom were in nursing homes (Quinn *et al.*, 2020). This study strengthens the case for a specific model of palliative care for care homes residents who have concurrent physical, cognitive and sensory impairments and may benefit from a palliative approach combined with expertise in dementia and frailty (Gordon *et al.*, 2018).

Perspectives from practice

Reflecting on lived experience is a powerful way to bring meaning and purpose to our vision and ambitions to transform practice. *Professor Carroll* describes her experience of caring for



her father during the last six months of his life in Northern Ireland. The deeply personal narrative reminds us of the gap that may exist between policy rhetoric and the reality of practice. Insights from a study in South India highlight a lack of support for family carers of people with advanced dementia. *Ritchie and colleagues* call for culturally sensitive palliative care and dementia-specific education for practitioners and for the local community. Both papers will resonate with those interested in the impact of services that are in some way incomplete or perceived to lack compassion.

Fox and colleagues sought to understand the important components of a community model of dementia palliative care by conducting a survey of health and social care professionals, policy-makers and academics in the Republic of Ireland and in each of the four UK nations. The key components identified by respondents blend the philosophies of palliative care and of rights based dementia practice. These fully resonate with the vision for people centred integrated care that applies in these jurisdictions.

The paper by *Oldam and colleagues* describes genuine co-production with island communities in the development of a Hospice strategy and integrated model for palliative and end of life care. Listening to what matters to local people provided a mandate for a rapid shift towards “hospice influenced care” at home, supported by technology enabled education and specialist outreach to increase the skills and confidence of the community and care home workforce in caring for people with advanced dementia or severe frailty at the end of life.

A key principle in each of these models is support to maximise shared decision-making and to enable people and families to express choices about current and future care and treatments. *Professor Stavert* considers the legal and human rights principles which govern decision-making and which apply to persons with and without capacity. Respecting the autonomy of people with advanced dementia or severe frailty requires skilled assessment and support, particularly in the presence of delirium or communication and sensory impairments. COVID-19 has brought this issue into sharp focus, highlighting an urgent need for proactive anticipatory or advance care planning conversations with people who have dementia or frailty to understand their wishes and preferences before they face an acute crisis.

The transition between curative, palliative and end of life stages of disease is often blurred, particularly for conditions such as frailty or dementia with less predictable disease trajectories (*Murray et al., 2005*). *Sezgin and colleagues* identified only six studies of specific transitional palliative care interventions for older adults with advanced non-malignant chronic disease. The studies report positive outcomes including reduced readmissions to hospital, improved quality of life for patients and better decision-making around hospice care among families. As similar positive outcomes are reported in studies of generic intermediate care services for older adults, perhaps a palliative approach, where appropriate, should be a core element of transitional and intermediate care.

The final two papers report the impact of specific interventions on well-being outcomes. *Gradinger and colleagues* consider the outcomes achieved from introducing well-being coordination by a voluntary sector link worker within an interdisciplinary intermediate care service for adults with complex needs. The link worker caseload included people with mild mental health problems, those with deteriorating physical health, approaching the end of life or experiencing bereavement. Goal setting, self-efficacy and well-being outcomes improved across subgroups, but the intervention had little impact on healthcare utilisation and costs in those with rapidly declining physical health or nearing the end of life. Measures to track the benefits of social prescribing interventions must include quality of life and well-being outcomes as well as system indicators.

Well-being is explored in *Mitchell's* paper on the role of complementary therapy for advanced dementia palliation in nursing homes. Relatives and staff considered the intervention provided companionship for selected residents and reduced their sense of loneliness. Staff reported a reduction in observed neuropsychiatric symptoms associated

with dementia-related stress and distress. The findings underline the importance of touch in communicating care, comfort and compassion and may further encourage non-pharmacological interventions and reduced use of antipsychotic drugs for difficult neuropsychiatric symptoms.

Build on what's strong

A key tenet of integrated care is that it should be well coordinated, designed around people, families and communities and not defined by health conditions or services (WHO, 2016). Implementation of palliative care requires coherent integration with established care services in a range of care settings (Sawatzky *et al.*, 2016). Therefore it is important to understand the synergy and critical differences between existing services in order to avoid duplication and address any specific gaps, particularly for dementia related challenges in managing uncertain prognosis, overcoming stigma, maintaining therapeutic relationships and supporting carers (Van der Steen *et al.*, 2014).

The range of palliative care approaches described in this special issue involve interdisciplinary education and practice, comprehensive assessment, person centred care and support planning, care coordination and shared decision-making about what is important for the individual and their loved ones. These components are central to both palliative care and to geriatric practice (Evans *et al.*, 2019) and feature in both the Dementia Palliative inter-professional learning framework (Tolson *et al.*, 2017) and in the integrated model of care for frailty (Hendry *et al.*, 2018). In advancing palliative care, local systems may achieve considerable traction through education that builds on the knowledge and skills of the existing dementia and frailty workforce.

Time for action

Adopting a collaborative approach that builds palliative care capability within existing local networks of primary care, community, care home and hospital services will be a more pragmatic and sustainable response to the increasing demand. This will enable rapid scale up of integrated palliative care that is attuned to the specific needs of people with advanced dementia or severe frailty, and their family carers, across the care continuum.

As Ghandi said “The true measure of any society can be found in how it treats its most vulnerable members”. Let us not be found wanting. It's time for urgent action to ensure integrated palliative care is available for all who may benefit.

Anne Hendry

*Research, NHS Lanarkshire, Airdrie, UK and
Health and Life Sciences, University of the West of Scotland, Paisley, UK*

Debbie Tolson

*Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland,
Paisley, UK*

Áine Carroll

School of Medicine, University College Dublin, Dublin, Ireland, and

Anne Mills

Scholl Academic Centre, Hospice Isle of Man, Douglas, UK

References

- Abel, J. (2018), “Compassionate communities and end of life care”, *Clinical Medicine*, Vol. 18 No. 1, pp. 6-8.

- British Geriatrics Society (2020), "End of life care in frailty", available at: <https://www.bgs.org.uk/resources/resource-series/end-of-life-care-in-frailty>.
- European Commission (2015), *The 2015 Ageing Report: Economic and Budgetary Projections for the 28 EU Member States (2013–2060)*, Brussels, available at: https://ec.europa.eu/eip/ageing/library/2015-ageing-report-economic-and-budgetary-projections-28-eu-member-states-2013-2060_en.
- Evans, C.J., Ison, L., Ellis-smith, C., Nicholson, C., Costa, A., Oluyase, A.O., Namisango, E., Bone, A.E., Brighton, L.J., Yi, D., Combes, S., Bajwah, S., Gao, W., Harding, R., Ong, P., Higginson, I.J. and Maddocks, M. (2019), "Service delivery models to maximize quality of life for older people at the end of life: a rapid review", *The Milbank Quarterly*, Vol. 97 No. 1, pp. 113-175.
- Gill, T.M., Gahbauer, E.A., Han, L. and Allore, H.G. (2010), "Trajectories of disability in the last year of life", *New England Journal of Medicine*, Vol. 362, pp. 1173-80, doi: [10.1056/NEJMoa0909087](https://doi.org/10.1056/NEJMoa0909087).
- Gomes, B., Calanzani, N., Curiale, V., McCrone, P. and Higginson, I.J. (2013), "Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers", *Cochrane Database of Systematic Reviews*, No. 6, doi: [10.1002/14651858.CD007760.pub2pmid:23744578](https://doi.org/10.1002/14651858.CD007760.pub2pmid:23744578).
- Hendry, A., Cariazo, A.M., Vanhecke, E. and Rodríguez-Laso, A. (2018), "Integrated care: a collaborative advantage for frailty", *IJIC*, Vol. 18 No. 2, pp. 1-4.
- Kellehear, A. (2013), "Compassionate communities: end of life care as everyone's responsibility", *Quarterly Journal of Medicine*, Vol. 106 No. 12, pp. 1071-1076.
- Murphy, E., Froggatt, K., Connolly, S., O'Shea, E., Sampson, E.L., Casey, D. and Devane, D. (2016), "Palliative care interventions in advanced dementia", *Cochrane Database of Systematic Reviews*, Vol. 12, pp. 1-44.
- Murray, C.J.L. and Lopez, A.D. (2013), "Measuring the global burden of disease", *New England Journal of Medicine*, Vol. 369, pp. 448-57.
- Murray, S.A., Kendall, M., Boyd, K. and Sheikh, A. (2005), "Illness trajectories and palliative care", *BMJ*, Vol. 330 No. 7498, pp. 007-011.
- O'Caomh, R., Galluzzo, L., Rodríguez-Laso, Á., Van der Heyden, J., Ranhoff, A.H., Lamprini-Koula, M., Ciutan, M., López Samaniego, L., Carcaillon-Bentata, L., Kennelly, S. and Liew (2018), "A on behalf of work package 5 of the joint action advantage prevalence of frailty at population level in European advantage joint action member states: a systematic review and meta-analysis", *Annali dell'Istituto Superiore di Sanità*, Vol. 54 No. 3, pp. 226-238.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. and Ferri, C.P. (2013), "The global prevalence of dementia: a systematic review and metaanalysis", *Alzheimer's and Dementia*, Vol. 9 No. 1, pp. 63-75, doi: [10.1016/j.jalz.2012.1.9.007](https://doi.org/10.1016/j.jalz.2012.1.9.007).
- Quinn, K., Stukel, T., Stall, N., Huang, A., Isenberg, S., Tanuseputro, P., Goldman, R., Cram, P., Kavalieratos, D., Detsky, A.S. and Bell, C.M. (2020), "Association between palliative care and healthcare outcomes among adults dying from non-cancer illness: population based matched cohort study", *BMJ*, Vol. 370, p. m2257.
- Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J. and Stajduhar, K. (2016), "Conceptual foundations of a palliative approach: a knowledge synthesis", *BMC Palliative Care*, Vol. 15 No. 1, p. 5.
- Tolson, D., Fleming, A., Hanson, E., Abreu, W., Lillo Crespo, M., Macrae, R., Jackson, G., Hvalič-Touzery, Routasola, P. and Holmerova, I. (2016), "Achieving prudent dementia care (palliare): an international policy and practice imperative", *International Journal of Integrated Care*, Vol. 16 No. 4, pp. 181-11, doi: [10.5334/ijic.2497](https://doi.org/10.5334/ijic.2497).
- Tolson, D., Holmerova, I., Macrae, R., Waugh, A., Hvalič-Touzery, S., De Abreu, W., Crespo, M.L., Merta, A. and Hanson, E. (2017), "Improving advanced dementia care: an inter-professional palliare learning framework", *Journal of the American Medical Directors Association*, Vol. 18 No. 7, pp. 561-563.

Van der Steen, J.T., Radbruch, L., Hertogh, C.M., De Boer, M.E., Hughes, J.C., Larkin, P., Francke, A.L., Jünger, S., Gove, D., Firth, P. and Koopmans, R.T. (2014), "White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care", *Palliative Medicine*, Vol. 28 No. 3, pp. 197-209.

World Health Organisation (2015), "World report on ageing and health", available at: <https://www.who.int/ageing/events/world-report-2015-launch/en/>.

World Health Organisation (2016), "Framework on integrated people-centred health services", *Report by the Secretariat (document A69/39)*, Geneva, 23-28, May 2016, available at: https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1.

Further Reading

World Health Organisation (2014), "Strengthening of palliative care as a component of integrated treatment within the continuum of care", *Eighth meeting* 23 January 2014, EB134.R7, available at: http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf.