

Supporting the dying is a community responsibility

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If death and dying are to be everyone's business and responsibility,¹ we have to change the way we speak about and organise end-of-life (EOL) care. Many people die in a way and a place that is not necessarily reflective of their values or their choices. Often their EOL journey is interrupted with preventable or unnecessary admissions to hospital and they do not feel in control of this part of their life.²⁻⁵ With the number of people dying expected to keep increasing,^{6,7} the question is who is going to provide the care that will be needed and what kind of death will people want to experience?

Although dying is a social process, in many industrialised countries the answer is often an ever-increasing professionalisation and medicalisation of death and dying.^{3,8} This approach, leading to unnecessary or futile treatments that impose a further symptom burden on the dying person, is neither sustainable nor affordable. Voluntary assisted dying (VAD) legislation has further relegated death to a medical event that focuses on the needs of a few and distracts attention from the needs of many.

However, debates about legalisation of VAD in several industrialised countries as an EOL option^{9,10} could provide a useful opportunity to start the 'difficult conversation'. While VAD is an EOL choice for a small minority, it is a non-starter for the vast majority. This is where palliative care is critical for the vast majority of people managing life-limiting conditions or those who are elderly or frail. The common misunderstanding is that palliative care is an EOL option when all else has failed and there is nowhere else left to go.¹¹

If we are to reduce de-medicalisation of death, we need to foster a community-focused approach to palliative and EOL care that supports realistic decision-making about EOL choices available to each individual. Evidence shows it is possible to

improve the experience of dying for families, communities, and ultimately the person with a terminal illness using a public health approach.¹² This approach recognises that death is a social event with a medical component, not a medical event with a social component.⁵ The answer lies in supporting, looking after and caring for those who are unwell, dying, or grieving within their community network.^{1,13}

'Compassionate communities' is a term often applied to public health palliative care interventions that promote social outcomes such as network enhancement,^{13,14} partnerships between formal and informal organisations,¹⁵⁻¹⁷ death literacy,¹⁸ and civic engagement.¹⁹ A 'Compassionate Communities' approach recognises death and dying as everyone's business – where the community is an equal partner in the long and complex task of providing quality care at the EOL.^{1,20}

When family carers and dying people are supported within an active community, workplace, school, or other civic network, research shows that they feel less isolated and powerless.²¹⁻²³ People can and do care for each other in the community particularly when there is a network of caregivers of ordinary people and health professionals working together.²⁴ Researchers in the United Kingdom showed that proactive community involvement with primary care support resulted in significant reductions in unplanned admissions to hospital and reduced healthcare costs.²⁵

By encouraging improved community literacy about death and grief, hallmarked by early conversations around death, dying, and loss, we can foster resilient and engaged communities who can contribute positively to the dying process.^{1,26,27}

This approach is being increasingly adopted around the world by palliative care and other

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health care sectors.^{17,28,29} In Australia, the Healthy End of Life Project (HELP) uses a community development approach to create a collaborative community culture that attends to local EOL care needs. Communities are guided through a practical suite of resources on how to work cooperatively with carers, family, friends, and neighbours, to support those who wish to receive EOL care in their home or community setting.²³ The compassionate connectors model of the South West Compassionate Communities Network provides practical and social support to people dealing with chronic and life-limiting illnesses, in partnership with the health service. This support is delivered by community volunteers (connectors) whose existing assets include EOL experiences and capacities, and their training includes skills in mobilising and developing caring networks.¹⁵

The core idea is to build a system of EOL care that connects health services with community services, and formal care with informal care. The primacy of support from social networks is at the heart of public health approaches to palliative and EOL care which have the potential to enhance integration of services (disability, health, and aged care) and provide a comprehensive approach that engages the assets of local communities.³⁰ And all this must be underscored by civic programmes in compassionate cities that mobilise and nurture compassionate care in local communities. Compassionate cities are defined as

those that publicly recognize people at the end of life and their needs and are aware of the search and involvement of all the main sectors of the city to help through care and accompaniment to reduce the social, psychological and health impact of life's difficult processes and situations, especially those related to disability, ageing, dependence, end of life, burden of caregivers, pain and loss of a loved one.^{16,20}

There are tools and resources to build compassionate communities and cities that have been developed in a variety of jurisdictions. The principal resources are available through Public Health Palliative Care International (<http://phpci.info/tools>).

So much depends on what communities can offer and how their potential is harnessed. But communities necessarily vary, they are different from

place to place and will have to reflect local and cultural preferences.

Shifting the debate from a medical answer to EOL care in favour of harnessing a community's social capital, allows a supported end for all – so that VAD is only part of a whole range of integrated care provisions. The focus should be on individual needs and wishes rather than a one-size-fits-all model which fails to respect autonomy and choice. As a community, we need to shift the debate around dying from medical inadequacies to community potential with better social connectedness.

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Samar M. Aoun: Conceptualisation; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualisation; Writing – original draft; Writing – review & editing.

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