

Bringing Death Back into Life: An Exploratory Report for Compassionate Communities in Lincolnshire

Dr Joss Winn & Max Gopal, University of Lincoln



Compassionate Communities are a form of ‘public health palliative care’ that reframes death and dying as primarily a social experience rather than a physical experience. In practice, they are types of community development projects that aim to improve a population’s understanding and experience of death, dying, loss, and caregiving.

‘A realistic utopia’ (Sallnow et al., 2022)	Our recommendations
1. The social determinants of death, dying, and grieving are tackled.	1. Develop a Compassionate Lincolnshire programme that prioritises people who are least likely to receive timely palliative care or community support.
2. Dying is understood to be a relational and spiritual process rather than simply a physiological event.	2. Develop an inclusive pastoral and spiritual care network within Lincoln.
3. Networks of care lead support for people dying, caring, and grieving.	3. Pilot coordinated circles of care and companion pathways, with the recognition of care homes as community assets.
4. Conversations and stories about everyday death, dying, and grief become common.	4. Reframe advance care planning as a relational process and develop a community-based death-literacy programme.
5. Death is recognized as having value.	5. Establish compassionate dying as a long-term civic commitment.

References

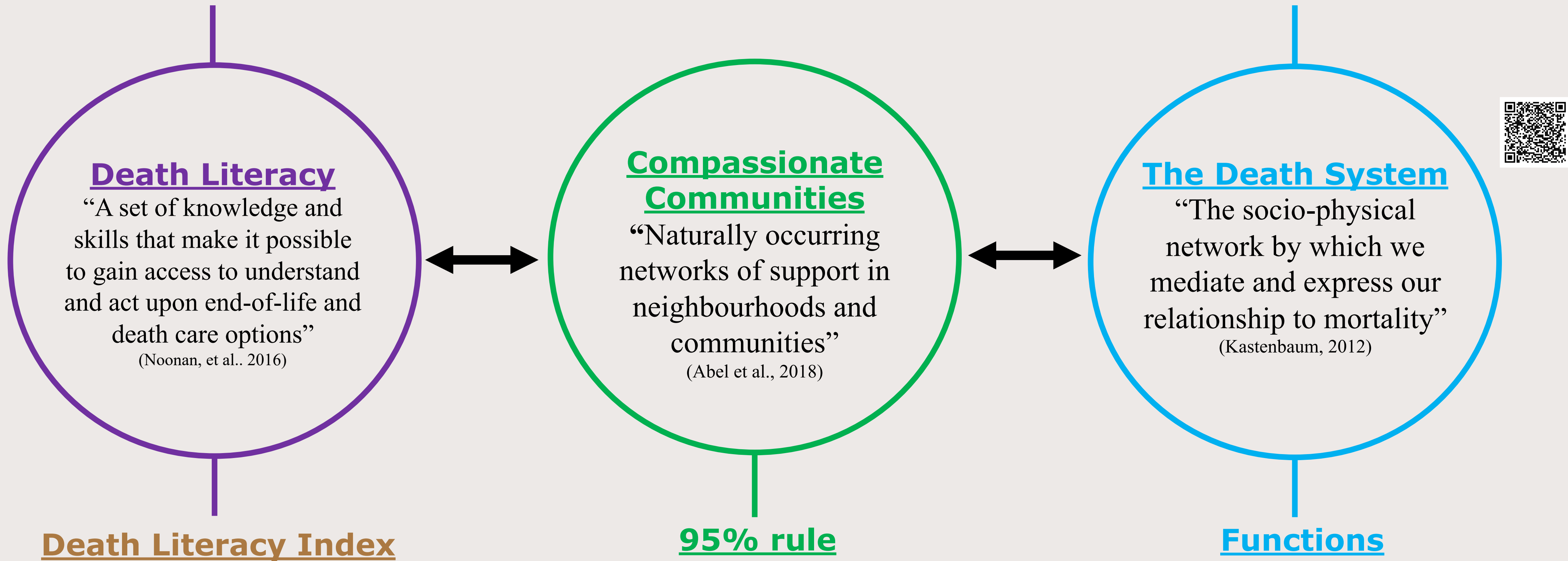
Abel, J., 2018. Compassionate communities and end-of-life care. *Clinical Medicine* 18, 6–8. <https://doi.org/10.7861/clinmedicine.18-1-6>. | Abel, J., Kellehear, A., Karapliagou, A., 2018. Palliative care—the new essentials. *Ann. Palliat. Med.* 7, S3–S14. <https://doi.org/10.21037/apm.2018.03.04>. | Kastenbaum, R., 2012. *Death, society, and human experience*, 11th ed. Pearson, Upper Saddle River, NJ. | Kellehear, A., 2022. The social nature of dying and the social model of health, in: *Oxford Textbook of Public Health Palliative Care*. pp. 22–29. <https://doi.org/10.1093/med/9780198862994.003.0004>. | Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., Rahn, A., 2020. Death Literacy Index: A Report on its Development and Implementation. Western Sydney University. <https://doi.org/10.26183/5EB8D3ADB20B0>. | Noonan, K., Horsfall, D., Leonard, R., Rosenberg, J., 2016. Developing death literacy: Progress in Palliative Care 24, 31–35. <https://doi.org/10.1080/09699260.2015.1103498>. | Sallnow, L., Smith, R., Ahmedzai, S.H., Bhadelia, A., Chamberlain, C., Cong, Y., Doble, B., Dullie, L., Durie, R., Finkelstein, E.A., Guglani, S., Hodson, M., Husebo, B.S., Kellehear, A., Kitzinger, C., Knaut, F.M., Murray, S.A., Neuberger, J., O’Mahony, S., Rajagopal, M.R., Russell, S., Sase, E., Sleeman, K.E., Solomon, S., Taylor, R., Tutu Van Furth, M., Wyatt, K., 2022. Report of the Lancet Commission on the Value of Death: bringing death back into life. *The Lancet* 399, 837–884. [https://doi.org/10.1016/S0140-6736\(21\)002314-X](https://doi.org/10.1016/S0140-6736(21)002314-X).

The four features of death literacy

- Knowledge – understanding of the death system
- Skills – ability to provide hands-on care
- Experiential knowledge – ‘on the job’ learning while providing care
- Social action – development and sharing of knowledge and skills (Noonan, et al.. 2016)

Components

- People – jobs related to death
- Places – graveyards, crematoriums
- Times – memorials, funerals, wakes
- Objects – obituary, death certificate
- Symbols – black arm bands, skull & crossbones (Kastenbaum, 2012)



“A measure of Death Literacy within a population” (Leonard, et al., 2020)

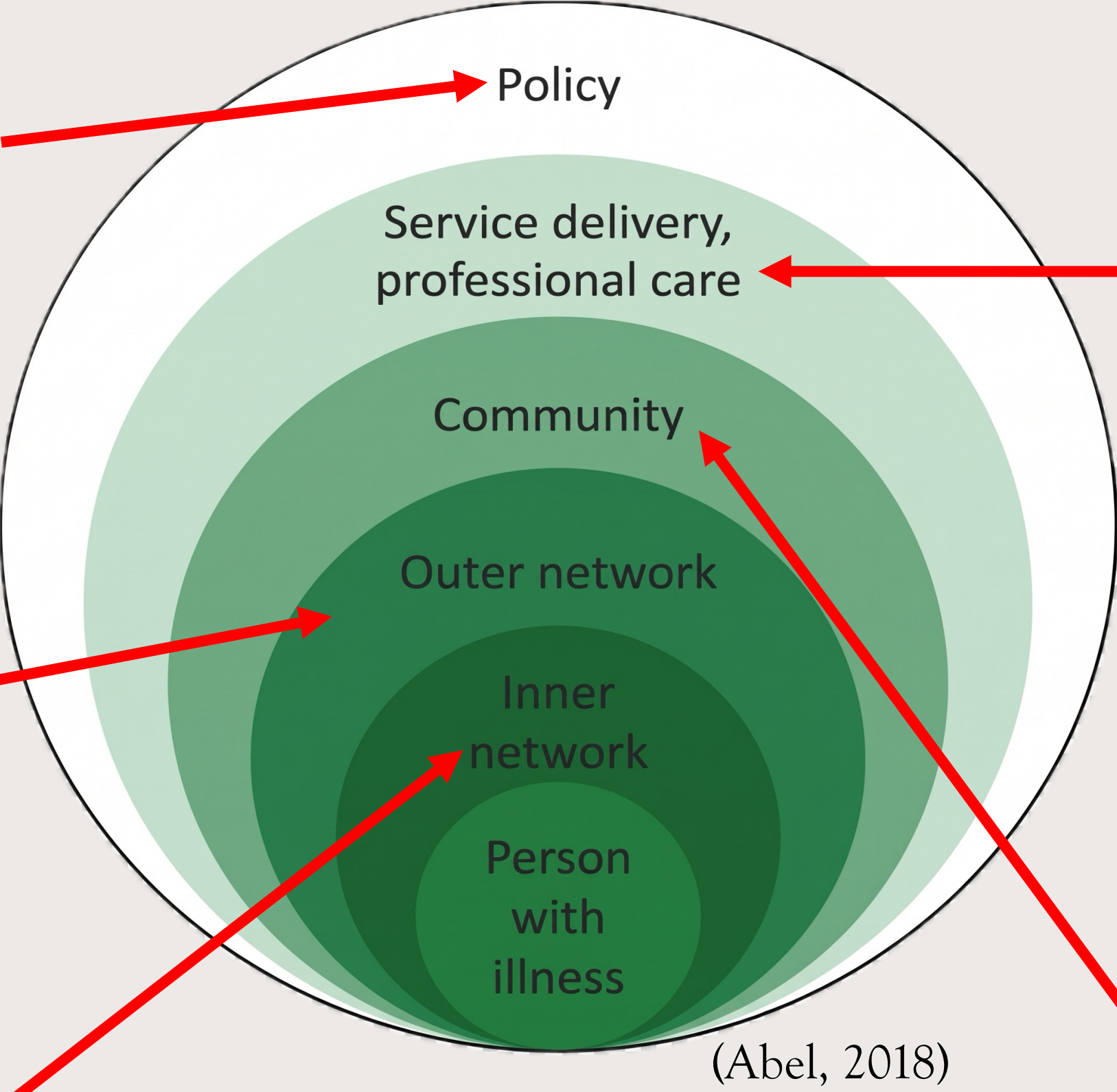
A dying patient spends less than ~5% of their day with professional care, the remaining 95% is usually spent **alone or with their community** (e.g. family, friends, neighbors). (Kellehear, 2022)

- Provide warnings of threats to life
- Prevent death
- Care for the dying
- Dispose of the dead
- Social consolidation after a death
- Make sense of death
- Bring about socially sanctioned killings (Kastenbaum, 2012)

National Palliative and End of Life Care Framework: Ambition 6

“I live in a community where **everybody** recognises that we all have a role to play in **supporting** each other in times of crisis and loss. People are **ready, willing** and **confident** to have **conversations** about **living and dying well** and to support each other in emotional and practical ways” (NHS England, 2021)

People who can help the inner network with everyday tasks (e.g. shopping, washing, cleaning).



The professional care are strengthened by that 95% found in the community, outer network and inner network who interact with the dying person. (Abel, 2018; Abel, et al. 2022)

Examples include:

- Places of faith and religion
- Local groups/clubs
- Health and social care organisations
- Schools
- Workplaces
- Trade unions

Typically, 2-5 people such as immediate family, close friends, or neighbors.