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Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed.
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Report of the Lancet Commission on the value of death: bringing death back into life

Appendices:

The case of Polly Kitzinger, who did not have an advance directive

Jenny and Celia Kitzinger, sisters of Polly Kitzinger and both members of the Commission, write:

In 2009 we celebrated our mother's 80th birthday with a family gathering. Our sister, Polly Kitzinger, talked about her work around "service user involvement" in the health service. The following day she was in a head on car crash and sustained catastrophic brain injuries. Rushed to hospital unconscious after the car crash, Polly was intubated, put on a ventilator and a nasogastric tube was inserted. Treatment over the following weeks included a tracheostomy, suctioning, intravenous antibiotics for serious infections and then surgery to place a percutaneous endoscopic gastrostomy (PEG) tube to provide nutrition and hydration directly into her stomach.¹

We were told from the outset that Polly might never regain full consciousness but that "only time will tell." Every brain injury is different and in the early period there's uncertainty about the prognosis. If she did regain consciousness, medics were clear that she was likely to have severe neurological and physical disabilities. And it was unlikely that she'd ever regain capacity to make her own choices about serious medical treatments.

Our focus was on what Polly would want. Self-expression, adventure, and autonomy were core to how Polly lived her life and the values she expressed in family debates and in her letters, poetry, and drawings (some displayed on the website we created for her:

WeLovePolly.org.uk.²) Soon after her injury we concluded that Polly would have refused all life-sustaining interventions rather than risk the kind of future that now seemed likely.

Polly had not written a legally binding Advance Decision making it clear that she refused life-sustaining treatment in these circumstances. She'd also not appointed anyone as Lasting Power of Attorney for health and welfare, which would have meant that someone she knew and trusted would make decisions for her. Without these legal protections, it was up to her clinical team to determine whether treatments they might provide were in her best interests, or not. Their 'best interests' decisions were not, we believe, what Polly would have decided for herself.

We had to fight to get a Do Not Resuscitate order (DNACPR) on Polly's records and only achieved this several months after her injury. Eventually clinicians also accepted ceilings of treatment such as no antibiotics for life-threatening infections. But they insisted on clinically assisted nutrition and hydration – an intervention that continued for several years, until she graduated to being spoon fed.

A decade on from the car crash, Polly remains trapped in a life we are sure she would not have wanted. Nothing fundamental can be changed for Polly now. Medical interventions have left her with no options. She no longer has a feeding tube, so withdrawing this is no longer an option. Ceilings of treatment in place (such as DNACPR) are unlikely to make any difference. She may live into her eighties.

A decade on from Polly's injury, medicolegal values have shifted somewhat. Patients' own wishes are now given more weight in making best interests decisions about their treatment. This is, in part, Polly's legacy.

1 Kitzinger C, Kitzinger J. Grief, anger and despair in relatives of severely brain injured patients: Responding without pathologising. *Clinical Rehabilitation*. 2014; **28**:627-3.

2 We Love Polly. <http://www.welovepolly.org/> (Accessed 23 September 2021)

The nature of community

“Community” is a concept which is notoriously difficult to define precisely. Community may be taken to refer to a local area or neighbourhood, but there are also communities of interest and communities of practice. The word “community” stems from the Latin *communis*, meaning common, general, shared by many. In Ancient Greek philosophy, Aristotle (384-322 BCE) talks of the distinctive way that humans have of being together as *koinonia*, meaning communion or fellowship. Towards the end of the 19th Century the sociologist Ferdinand Tönnies (1855-1936) differentiated community [*Gemeinschaft*] from civil society [*Gesellschaft*]. Whereas in civil society people are essentially strangers to one another who construct an artificial commonality to enable the fulfilment of their personal needs and ends, communities are more-or-less organic wholes comprising people who already have something in common. However, the visions of community deriving from

Tönnies's initial formulation, and from the political philosophy of communitarianism, run the risk of being exclusionary and homogenising and suffering from a latent nostalgia.

The Commission seeks to avoid investing the notion of community with any ideological freight. We are not so much interested in community as a type of "thing" but rather in the underlying relations that constitute a community, in the basic sense of being together or fellowship. Such fellowship arises from direct personal relations which entail some intimate knowledge of one another. These personal relations may arise from living together, alongside one another, or in a shared space or area, or from sharing social conditions. In contrast to the economic relations or of the professional relations that we find in healthcare, the relations of community are not constructed as means to ends (although communities can function with the purpose of accomplishing collective ends). Rather, in communities, relations may be ends in themselves.