



▶▶ A Death Cafe, such as this one in Kansas City, Missouri, USA, should take place in a comfortable environment in which people can feel free to converse.

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Reflections on hosting a series of Death Cafes in an NHS context

▶▶ From small beginnings, the Death Cafe movement has gradually spread to more than 50 countries and become a global phenomenon. **Kitty Clark-McGhee, Polly Fitch, Susan Hennessey, Emma Cassidy, David Little** and **Harriet Conniff** adapted the concept for healthcare professionals in the UK. Here, they consider what their series of death cafes achieved.

The Death Cafe movement is a social franchise set up in the UK in 2011 by Jon Underwood and Sue Barsky Reid. It is a space where people, often strangers, come together to share food, drink tea, and talk about death. The movement was inspired by the work of Swiss sociologist Bernard Crettaz, who set up the first ‘café mortel’ in 2004, with the aim of addressing the social taboo of talking about death and dying.¹ Since the Death Cafe movement was established, 5,300 cafes have been held in more than 50 countries across Europe, North America and Australasia.²

The intention of a Death Cafe is to help people make the most of their finite lives, which is facilitated by group-directed discussion with no agenda. They are not therapy or support groups, though those taking part may experience the conversations that occur as therapeutic. Cafes are often aimed at the general public although, as

their popularity has risen, events have been set up with specific groups and communities in mind.³ Likewise, our cafes were specifically aimed at people working in healthcare and NHS settings. In this way, our initiative was to make available these powerful and important spaces within professional health contexts to enable difficult conversations about death and dying, in recognition of the fact that they are central to both our personal and professional lives.

Thus in 2015, to coincide with Dying Matters Awareness Week, we ran a series of Death Cafes across multiple hospital settings within a large, busy NHS Trust. We did the same again for the 2016 Dying Matters Awareness Week, building on our experiences from the previous year. A wide variety of professionals attended, ranging from medics and nurses to technical medical staff and students from a whole range of health professions. The events were completely voluntary and took place within busy working hours.

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Evaluations and reflection

To evaluate the programme and to help guide us in planning future forums, we collected feedback from cafe attendees using a simple, anonymous three-item Likert scale and a short qualitative statement. In general, the cafes we ran were received positively, with an encouraging turnout and a general recognition that such conversations are often absent from hospital settings. Ninety per cent of those who completed the feedback form indicated that their experience of the event was very positive. From the qualitative feedback, respondents seemed to particularly value the ‘openness’ of the space, the chance to hear multiple perspectives and views, and the opportunity to talk about a difficult topic in a comfortable and safe forum.

As the cafe hosts, we also came together during the programme to reflect on our experiences of setting up and hosting these spaces, as well as thinking together about the conversations that had occurred. Each cafe we hosted was unique in some way and stimulated ‘talking about death’ differently; some spaces were quiet, others loud, some joyful, others sad. We also noticed that across the cafes, a number of themes arose repeatedly, suggesting to us the presence of powerful and shared questions and dilemmas in the context of death and dying, for those working in public health settings. Here, we offer up our reflections based on these themes.

The personal and the professional

To begin with, attendees seemed to find it easier to speak from positions of ‘professional identity’. Medical doctors, for example, shared their experiences of talking about and witnessing death with patients and their families. Out of their stories came a recognition of the particularly challenging role nurses face in managing families’ distress, anger and grief. In other cafes, student nurses described a lack of training time allocated to thinking about the emotional impact of death in their work. They were left with unanswered questions about how this might feel for them, what they should say and do and how they might look after themselves.

Some attendees voiced a conflict between cultural and religious and medical beliefs, which posed an unresolved tension for many; this dilemma was explored with thoughtfulness and care.

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Jon Underwood, who founded the Death Cafe movement in 2011, died suddenly in June this year of acute promyelocytic leukaemia.
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A significant moment in one group occurred when a person described how they used to feel averse to Do Not Resuscitate (DNR) orders, in part due to their religious beliefs, but changed their mind after witnessing a family member being resuscitated. Recounting this to the group was emotional and powerful and served as an opening to others to share their personal belief systems in the context of death and dying.

Avoidance and presence

Avoidance was a theme that ran throughout our conversations. Attendees often described issues of death and dying as something unspoken in daily working life. Some had noticed that euphemisms are used in place of the word ‘died’ (such as ‘passed away’ or ‘gone to a better place’). One person shared how they had noticed bouquets tied to benches in the hospital grounds and had begun to remove them once they started to decay, as they did not want to be continually reminded of death. Some attendees disclosed that they have felt embarrassed and uncomfortable around dying patients, and that this has had an impact on how they behave, such as making them feel unable to speak to the dying person’s family, wondering what to say or avoiding the person as much as possible. It felt significant that these attendees then went on to describe the conversations held in the cafes as both scary and helpful.

We had many conversations about the vast array of death rituals and traditions. Most striking, perhaps, was talk about preparations made to a person’s body after they have died and the many variations of this process according to faith, culture and gender. Likewise, attendees from different faith denominations spoke about the smells of incense and food, or the sounds of singing and chanting, as being bound up with their personal memories of death. These rituals were seen in very different ways by different people – as helpful, unhelpful, important, containing or overwhelming. They were understood as both a means to be present in the face of death and a way in which to manage or avoid suffering and distress.

A powerful word

Many people find the word ‘death’ challenging to hear and see; when flyers circulated about the cafes, some felt strongly that it was unethical and disrespectful to have a forum in which cake and refreshments mixed with talk about death. One person reflected

that their personal experience of bereavement made this word feel particularly troubling. As hosts, we were also aware of our own concerns about placing flyers in places where patients and their families might see them and possibly misunderstand our intention. Cafe attendees seemed to have a shared feeling that the juxtaposition of the words ‘Death’ and ‘Cafe’ was shocking, although they acknowledged that a space in which they could directly talk about death was both absent and needed.

Our final thoughts

The topic of death and dying is very much a part of working in public health contexts, even, at times, for staff working in non-clinical roles. At the same time, we are aware of how little support can be available to staff to manage these issues in their professional lives. Our healthcare system aims to keep people living and well for as long as possible, meaning that at various levels the services we provide are intimately bound up with preventing death and dying. We recognise this as an essential aim for services but are also thoughtful about a potential corollary: death can come to be seen as a ‘failure’ rather than a reasonable possibility. This conflict means that death can become an avoided topic, even at times when it is palpably present for staff and patients. For several of the team who hosted these cafes, it is a reality of our working lives.

We were struck by the strength of feeling these conversations aroused, which prompted some of us to reflect further on our own experiences of death as something that can be dreadful and silencing. We recognise that, for a range of personal and professional reasons, coming together to talk about death may not always feel possible. For those for whom it does feel possible, these spaces have offered a unique and open environment in which to explore and articulate some of the anxieties, dilemmas, hopes and fears inherent in working with death and with people who are dying. Indeed, since this project, some of us have noticed staff beginning

to talk about the feelings that death brings up, which suggests to us the emergence of a powerful alternative to the prevailing silence around death and dying. It seems that death is a topic that we need to talk about, even when our various working contexts can make this feel difficult. We have each wondered whether cultivating an environment in which death and dying are open for discussion might help us to feel more personally and professionally prepared to look after ourselves and our patients when these facts of life inevitably become apparent.

Practical issues

For others interested in setting up death cafes in NHS and health settings, the Death Cafe website⁴ offers helpful general guidance. Based on our experiences, we suggest giving some thought to the space itself. We found that a large table around which everyone sat, with cakes and tea in the middle, made for a more open, less formal atmosphere. We have a sense that this set-up fostered an open and warm atmosphere and made thoughtful, personally informed conversations feel more possible. We also recommend that prospective cafe hosts are thoughtful about how they advertise the sessions; based on feedback we have received over the past two years, we have decided to advertise future cafes as ‘a space to talk openly about death and dying’, with a reference to the Death Cafe franchise. We are hopeful that this will make the space as inviting as possible, both to people who feel comfortable talking about death and dying, and to those who are ambivalent or unsure about this opportunity ■

Declaration of interest

The authors declare that there is no conflict of interest.

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Key points

- ▶▶ A series of Death Cafes were hosted across multiple NHS hospital settings with the aim of creating opportunities for people working in healthcare to talk about death and dying.
- ▶▶ Participants were thoughtful and reflective, with recurrent and significant themes emerging out of the conversations; these intersected across personal and professional concerns, beliefs and ideas.
- ▶▶ Feedback from participants was very positive, with a general feeling that these spaces are a valuable opportunity to talk about a difficult subject with openness and without a specific objective.
- ▶▶ Prospective Death Cafe hosts could consider how they might set up future cafes, including constructing a space that invites reflection, and using sensitive, considerate advertising.