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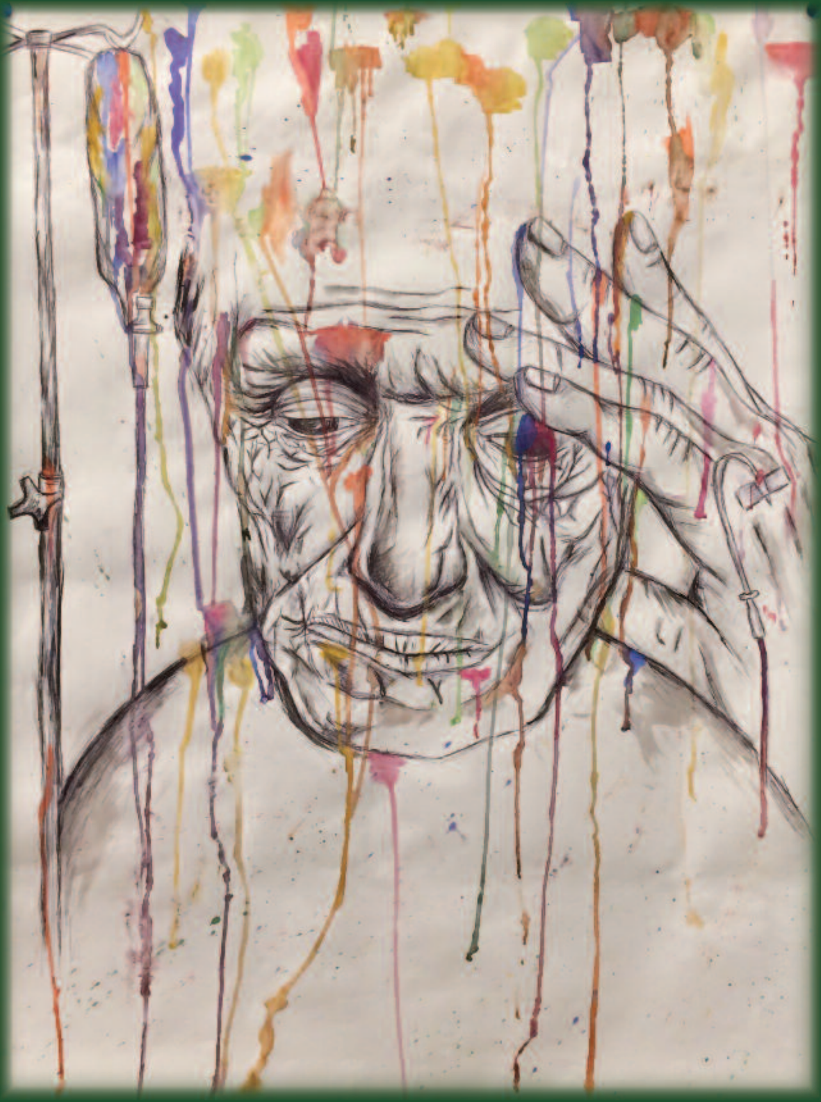

The end of life issue

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Editor-in-chief
David Peter • infoprofpeters@gmail.com

Editorial Board
Professor David Peters
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Production editor
Edwina Rowling • editor@bhma.org

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The Wait, by year one medical students Keya Khan, Rebecka Lichtenecker and Aquiline Lobo, 2018, hosted on Bristol medical arts website www.outofourheads.net

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David Peters
Editor-in-chief

The end of life issue

Do you remember The Future? A hugely popular weekly BBC science programme called *Tomorrow's World* began in the late 1970s. At its peak 10 million people tuned in to be reassured that the latest inventions (often British – hovercrafts, supersonic airliners) were going to make our lives ever more amazing. Its predictions were sometimes wildly inaccurate – flying nuclear cars, humans living on Mars by 2010, tunnels spanning the planet. The show didn't foresee laptop computers, iPads or the internet, but it did tell of acid rain, the ozone layer hole and, in 1989, the prospect of global heating. Still, back then the future was definitely going to happen, and it was going to be brighter, better, easier. In the real world of today we could easily be nostalgic for that optimistic future, mournful about assumptions of progress, fearful that science can't restore that brilliant future.

But many people born this century, who never had the comforting foundations of faith in The Future, say humankind has no future (Hickman *et al*, 2021). For them, future-grief is real and personal. Hence the theme of this JHH is *The End of Life* issue. We live in a decade when the mythic scale of life's potentially terminal decline is prodding us to confront the related fact of our own brief stay on Earth. We humans build our lives and cultures around stories of what we are, why we are here, of how and why life ends. The largest stories – great myths and entire religions that ensure us an afterlife or reincarnation, that sing of heroes journeying into the labyrinth to face the monster – depict the ungraspable fact of personal non-being. Yet in our century a bigger story is unfolding; a story foretelling the end of life itself. Long before the event, saying goodbye to someone we love can trigger a maelstrom of emotions. So might it be that our planetary predicament subliminally stirs up anticipatory grief for our personal predicament but also for all life?

TS Eliot observed, 'Humankind cannot bear very much reality'. Maybe so, yet all around we see evidence that the public and the professionals are more than ever keen to talk about dying and death. We see more end-of-life planning, death cafes, dying matters, end-of-life doulas; whole new social inventions in the mainstream too – the hospice movement itself, and the emergence of palliative care as a respected specialty. Departure Lounge, an initiative from the Academy of Medical Sciences, aims to encourage a national conversation about death and dying. And right now we have the prospect of a law to permit assisted dying.

Whether or not the big picture 'end of life issue' is behind it, a world-changing shift in the 21st century story of dying could be under way. The 2022 *Lancet* Commission on the Value of Death – arguing that death and life are bound together, for without death there would be no life – proposes a new vision for death and dying, with greater community involvement alongside health and social care services, and increased bereavement support. This social re-awakening to community and relationships has a parallel in Gaia theory, in ecological and systems thinking; the knowledge that everything is connected, everything goes somewhere, and there's no such thing as a free lunch – ie holism. Mind and body and culture are entangled, and humankind is part of the natural world not apart from it. By the same token everything has its limits – resource extraction and economic growth, the years of our life and the triumphs of medicine.

The JHH end of life issue takes a look at these overlaps. Palliative care doctor Marina Malthouse tells a story about death and the newly qualified doctor's experience of dying and death, Aly Dickinson, herself a very experienced doula, shares her experiences of helping care for people who chose voluntary fasting to death. Even though social attitudes to grief are fast changing, still it can be difficult for others to acknowledge and validate suffering. Regular contributor David Zigmond reflects on shame, an emotion that can be part of complicated grief. Marianne Rosen explains how in her own loss to suicide, writing a structured journal was transformational. It is healing to truly be heard in one's grieving as Annabel Park and Helen Selka know from their work with deep listening. Annie Blampied-Radojčin developed the quietude course at Emerson College so that people could learn the skills that being with suffering calls for. Paquita de Zulueta was much involved with supporting local people affected and grieving in the wake of the Grenfell Tower disaster. With an eye to developments in public services Paul Thomas proposes ways of facilitating healthy deaths on a local scale. Robert Weaver, now a GP in the south west, shows us reflections he crafted while studying at Bristol. QMUL medical student Maria Najlah draws and writes about 'grieving a place I've never been to – and Cian Patel has given us her poem about pollution and asthma. We loop back to ecological concerns in our article where psychiatrist Prem Jeyapaul and I contemplate the mental health impacts of the climate emergency on patients and doctors. There follows a preliminary report on the BHMA's lively 40th anniversary celebration conference in Bristol. In his endpiece column urban GP Jonathon Tomlinson takes us full circle back into how doctors tackle death.

Our cover picture, made by medical students at QMUL, shows the face of a person near their life's end. It captures a mix of inwardness, loss or resignation, perhaps of feeling abandoned: a lonely face, and behind the face, the drip stand – a tool of biomedical care.

Hickman C, Marks E, Pihkala P, Clayton S, Lewandowski RE, Mayall E… van Susteren L (2021) Climate anxiety in children and young people and their beliefs about government responses to climate change: a global survey. *The Lancet Planetary Health*, 5(12) https://doi.org/10.1016/S2542-5196(21)00278-3.

Death and the newly qualified doctor

Marina Malthouse

Retired palliative care physician; consultant for New School of Psychotherapy and Counselling, Middlesex

Pre-2015, my 20 years in palliative care was concerned primarily with death and dying. Before this, there were inevitable encounters with the dying while working in other specialties but opportunities to learn specifically about care of the dying and how to cope with experiences around death were not part of my medical education. Rudderless, I found my own way, realising that connecting and forming close relationships with people who were dying and their families was a key essence of medicine. My doctoral research explored death and dying experiences of GP trainees and similarly several found their own interests in the end of life. Others found it an ongoing challenge but despite the challenges, we all found it rewarding.

Summary

The story published here is one of four I wrote as part of my doctoral research into junior doctors' personal experiences of death and dying. Each story describes experiences at different stages of their early careers. Junior doctors' encounters with dying patients can be a source of personal and professional growth, but without structured opportunities to discuss these experiences many doctors conform to our clinical culture's narrow view of death and learn to cope in silence. Reflective and narrative practices can help us process complex emotional experiences of dying and recognise the value of personal knowledge and experiential knowing. This shift could foster a change in the culture of medicine.

Introduction

This story was written as part of my doctoral research between 2007 and 2012, titled *Paying attention to death and dying in medical education: A narrative inquiry of junior doctors' personal experiences of death and dying*. I used traditional qualitative interviewing methods to gather data from 12 GP-trainee participants and their unique narratives moved me to write stories-to-think-by. I wrote fictional stories as evidence from my interview data, re-presenting the data to convey a sense of truth, an invitation to 'consider this way of seeing the world' (Gergen & Gergen, 2010, 5). The story published here is one of four that I wrote for my thesis where each story describes junior doctors' experiences at different stages of their early careers.

The research evolved primarily from my role as lead for palliative care education for a GP vocational training scheme. During teaching sessions I had become increasingly curious about how the topic of death and dying always provoked very emotive discussions. The young doctors gave me a sense of having a voracious appetite to learn anything concerning the care of dying patients as if reacting or responding to some kind of vacuum in their medical lives. Also, knowing how my own experiences with death and dying as a doctor had evoked a rollercoaster of emotions since qualifying 30 years previously, I started asking myself some questions, wondering about: their experiences of death and dying; whether these were affecting or influencing their care of terminally ill patients; how medical education prepares doctors to deal with death and dying, and lastly whether the practice and culture of medicine influenced how they experienced death and dying. The doctor participants of my research were regarded as social actors, where the doctor–subject moves away from a fixed identity of medical professional with traditional understandings that tend to lie within the discourse of humanism (as a rational, conscious, stable and unified subject) (St. Pierre & Pillow, 2000). In this moving away, I explored the subjective meanings that doctor participants assigned to events and conditions of death and dying where the past, present and future were remembered within their lives as a whole.

When junior doctors qualify, their first few years of work are predominantly spent in hospitals where they care for dying patients and inevitably experience death in its various forms. 56% of deaths were occurring then in hospitals (this has now fallen to 45%), a third of dying patients are admitted to hospital three or more times in their last year of life, and for those dying there, about 50% of patients are recognised as dying less than a day and a half before death. Death therefore cannot be avoided and as it isn't always managed well; exploring how medical education and how medical work environments prepare and support doctors in the face of their experiences felt like a reasonable endeavour.

Medical training focuses on clinical, scientific and technical skills to train competent young doctors. It concentrates on preserving life so the emphasis of student learning is to diagnose diseases, treat and manage with the aim of cure or improvement, and to deal with emergencies and acute trauma. Students who then qualify as doctors 'learn' that if life cannot be preserved, death is perceived as a professional failure. This can generate feelings of self-blame and guilt, helplessness and vulnerability, and distress and trauma or what has poignantly been described by Poirier (2009, 141) as an 'emotional cauldron'.

By its very nature, death and dying have the ability to be significant, painful and even traumatic. Junior doctors, known to more commonly encounter emotional strain and elevated general psychological distress when compared with other occupational groups, particularly in their early careers, can experience additional distress from their experiences with death and dying. This can negatively impact on their job satisfaction, affect their personal lives (such as leading to professional burnout and other psychological or psychiatric disorders), and affect their care of patients resulting in adverse events, complaints, litigation claims, or lack of adherence to treatment (Firth-Cozens, 2001; Meier *et al*, 2001).

But rather than only consider the negative effects of this work, along with others, my research found that caring for dying patients can be rewarding for doctors, be a source of job satisfaction, represent opportunities for personal growth and to understand themselves as therapeutic agents. Some of the GP-trainee participants found the immediacy of their experience a starting point for interpretation which they then shaped within the contexts of their own lives into something they could gain from. This could then be built on for future experience – to feel more comfortable with the end of life thereby learning how to both care for dying patients and themselves from their dealings with this work. But they had to find this out for themselves, in their own way. The participants described a lack of opportunity at work to dialogue and consider broader meanings of death. Without opportunity, a silent subtext around death can occur where doctors' voices are muffled, learning instead to conform to the accepted cultural behaviour of other work colleagues, and to cope by getting on with the job. This perhaps both contributes to and perpetuates the singular clinical meaning of death in medicine.

When caring for the dying, doctors face existential anxiety, helplessness and sadness in others. To be able to care for these others, Evans (2003) identifies a philosophy of practice that comes from *within* the practitioner, a specific requirement for self-knowledge, moral and spiritual strength. Providing opportunities to discuss, analyse and critique episodes of care can help students and junior doctors to find their voice and develop practitioner skills outlined above. By drawing on narrative methodologies, educational theory and philosophy, my research adhered to Evans' philosophy of practice that comes from within the practitioner. Finding ways of knowing for doctors to understand multiple meanings of death in medicine, make meaning from their significant personal experiences of death and dying, and to use these experiences to bridge connections between their personal and professional lives. The relevance and value of their personal knowledge and experiential knowing could provide opportunities for a change in the culture of medicine and its learning environments at every level in a doctor's career.

* * *

'Hello, is that Dr Evans?'

Jenny Evans was only just getting used to her new title, still finding the attachment of 'Doctor' to her name something of a novelty. In her first week of nights, already her memories of medical school seemed distant. Standing alone in the long hospital corridor she answered her bleep on the grubby, wall-mounted telephone. Empty bed frames lined the scuffed walls, their metal frames stark without mattresses, linen and blankets. Jenny shivered. The hospital felt eerie at night.

'Staff nurse on Stellerby ward here. Could you come and certify a gentleman who's just died please?' 'Oh…er yes okay,' Jenny replied, 'I'll be along in a few minutes'.

She replaced the receiver slowly. A week before, called to certify a dead patient for the first time, a list she had learnt at medical school had come randomly to mind: death certificates, coroners, notifiable diseases, fixed dilated pupils, no heart sounds, rigor mortis. She hadn't certified any deaths before, so her senior house officer had come along to show her what to do. As he'd said, the corpse wouldn't be anyone known to her. He had reassured Jenny that it had been unnerving for him too at first, but now it was just a job to be done quickly. 'Try not to think about it too much'.

Thinking of dead bodies reminded Jenny of her early days at medical school. Memories of the dissection room: the corpses, the smell of formaldehyde, heads sliced open, a bucket of knees, anatomy room technicians sawing off body parts in the corner. At first, the preserved cadavers lying in rows on metal trolleys had shocked her. She found she couldn't connect them with anything that had lived a life. Death had been something new to her then, but with the passage of time dissection helped her get used to the dead. One of the corpses hadn't yet been cut into. It looked like a person sleeping. Neuro-anatomy intrigued her: cutting into a brain was like slicing into someone's thoughts, as if she were tapping into all the neuronal connections their life had made. The jokiness of her fellow students seemed odd to her at the time. She wondered whether it distracted them from the reality of what they were doing. For somehow they were adjusting to a medical school world, where they experienced things most people would never have to deal with. At the time she had shrugged her shoulders.

Jenny wondered why she'd told the staff nurse she would only be a few minutes. If she'd left more time there would be more definite signs that the patient was actually dead. A feeling of loneliness threaded through her body as she imagined herself alone on the ward with a dead body. She sensed her heart's strong and steady rhythm… thump, thump, thump. She wiped clammy palms down the sides of her skirt. Five years of learning and being examined about every cell in the human body, yet she hadn't been taught how to deal with this part of the job. In a pocket she had a piece of paper with her checklist of how to certify a death.

The sign hanging from the ceiling told her she had arrived at Stellerby ward. A deep breath, a firm stride. I can always ask the nurses, she told herself. The nurse standing at the nursing station looked busy. 'Come to certify Mr Hudson?…he's in bed 2, bay 4.'

Jenny wandered across the ward. In the soft night-light glow, she saw curtains drawn around one of the bay's six beds; in the other five, patients breathing rhythmically in their sleep. Torch and stethoscope in hand and hoping to slip quietly through the gap between the curtains, she caught the eye of an old man in the neighbouring bed. The way he smiled at Jenny made her feel understood. Remembering her grandfather she felt like a child again, encouraged by his presence to feel brave and safe. Less timid in her movements now, and acutely aware that a mere piece of fabric separated the dead from the living, she drew the curtains carefully. Turning around, she froze. In front of her a man lay under the bed covers as if asleep. She made herself breath slowly before coming closer to the bed. Gently, she folded back the sheet to expose the man's chest.

'Hello Mr. Hudson,' she whispered, 'My name is Jenny Evans, the doctor. I've just got to check on you. It won't take long.'

She was surprised by her urge to communicate with the dead man. Was it because he had so recently breathed and lived? Jenny recalled the voice of a consultant at medical school who had told the students to maintain respect for a patient even after their death. Somehow this memory guided her through her tasks. She touched his hand. The skin still felt warm. His youthful appearance made her glance at the date of birth on his identity band.

Leaving it until last, she raised his eyelids, one then the other to shine the torch into each pupil. Life had gone from his eyes. Black, expressionless and empty they stared back at her. Drawing the sheet back over his body as if to keep him warm, she wondered who he'd been, where he'd lived and how he'd lived his life. Finding herself back at the nursing station to document the death, she pulled the patient's file from the notes trolley. Footsteps and a squeaking wheel announced the arrival of two porters.

'We've come to collect the body,' one of them said softly. The staff nurse repeated her instructions. 'Bed 2, bay 4'. Jenny looked up. Her heart jumped. Holding her hand across her mouth as if to muffle any sound, she let out an unprompted audible gasp.

* * *

In the cramped hospital flat they shared, Anne-Sophie jumped off the faded sofa to make Jenny a cup of coffee. The two young doctors had a custom of sharing intense new experiences at the end of the working day. Their close friendship felt richer and more familiar than it should have been, given that they had only met a few weeks before. They were laughing because Jenny had thought the body boxes for transporting dead patients to the mortuary were mobile libraries. Then Jenny's expression suddenly changed. 'I felt stupid and petrified when I got that call,' she said. 'It was weird. The nurse sounded so matter of fact, as if she was asking me to take some bloods or put up a drip.'

On the sofa, Anne-Sophie tucked her feet up under her. Shifting her position as she listened to Jenny, she was suddenly back with her parents and five siblings in Germany. In the big house where her family ran a nursing home, death had been part of everyday life. The children had their favourite residents but they were used to the old people passing away. Their coffin would rest awhile in the entrance hall so everyone could say their goodbyes. Her father always held a small service of prayers or read a psalm. Anne-Sophie would peep into the open coffin before the service to see who it was, lying there. She couldn't remember ever being scared or frightened, recalling only an overriding sense of peace and respect.

Certifying deaths on the wards didn't bother Anne-Sophie at all. She felt comfortable with this duty, so there was a pause in the conversation as she wondered how to bridge the gulf between. Should she try telling Jenny about her childhood? Glancing over at her friend it just didn't feel right. 'Oh that must have been so awful for you. But it sounds like you did OK?' she said. 'And I really like your idea of talking to the dead man. I'm sure that was nicer for him even if he was dead.'

Anne-Sophie was on call one evening the following week. Silencing the bleep in her pocket she dialled the number displayed on its small screen and connected to a ward nurse at the other end of the line.

'Could you come and write up some night sedation please? We've got a few other bits and pieces for you to do too.'

On the ward the late shift nurses were handing over to the night staff. Three drug charts lay in a row on the nursing station, each with a yellow note stuck to the front with instructions for the on-call doctor to prescribe new drugs. That's helpful of the nurses Anne-Sophie thought; if only all the wards were this organised. A sudden odd-sounding noise made her jump: someone in the ward moaning like a wounded dog. The sound drew her to one of the bays. On one bed were two entangled bodies she could barely distinguish in the dim light. A staff nurse coming up behind propelled her to the bedside. 'Can you give me a hand please? I can't get hold of the doctor' she whispered. The nurse filled in the background as Anne-Sophie listened: a 32-year-old woman with suspected pneumonia and persistent chest pain had been admitted that afternoon with her 10-day-old baby. Now her blood pressure was plummeting. Sophie's eyes darted to the woman, her new baby asleep in a perspex neonatal cot. The two people on the bed suddenly disentangled and parted as the man got to his feet. His wife lay lifeless on the bed. Panic-stricken, face contorted with dread he staggered towards Anne-Sophie. The nurse dived at the bed to feel for a pulse. The words 'I think she's arrested!' launched the well-rehearsed crash call sequence. In the eye of the storm Anne-Sophie was facing her biggest fear – of being first doctor to arrive at a cardiac arrest. The man backed away mumbling 'I think I'd better leave now'; their eyes met in mutual desperation. Both desired life not death. Would faith or technical expertise defy fate? While Anne-Sophie grabbed the crash trolley the nurse swung the back of the bedhead away. In swooped the crash team, rushing against the clock to bring this young mother back to life. After 20 minutes or more of struggling, her heart and lungs were still unresponsive.

When the crash team left Anne-Sophie found herself alone. Unable to move, with a disabling heaviness in her body, she stared at the scene in front of her. On the bed a dead mother with all the detritus of an unsuccessful cardiac resuss scattered around her. Pulling herself together, she rested the bell of her stethoscope on the young woman's chest but no heart was there beating. Anne-Sophie shone a pen-torch into dead eyes. In the blackness of the fixed dilated pupils she saw a young mother smiling lovingly at her first-born child.

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Living well, dying well

A conversation with

Hermione Elliott *Founder, Living Well, Dying Well*
and
David Peters *JHH editor-in-chief*

I feel fortunate to have discovered complementary and alternative approaches early in my nursing, midwifery and palliative care career, and am grateful to have been able to maintain a foot in both camps. I have been passionate about whole person health, and in particular what it takes to engage in a therapeutic relationship as means to support deep healing. Most recently my focus has been on influencing a change in attitudes to death and dying among professionals and the public, through our training programmes. My dream is to see death and dying integrated into everyday life as natural and normal and a consequence of life rather than thinking of it as a medical event that requires intervention. I would like to see us return to a deep awareness of the extraordinary process and the profound transition that unfolds before us when death takes place, and for ordinary people to be able to care more confidently for their dying. Perhaps asking the question 'how would I like to be "held" in this situation'. *Hermione Elliott*

Summary

This conversation centres on the evolution and impact of the Living Well, Dying Well organisation, which began around 2007–2008 with courses on death education and awareness. The organisation, founded by Hermione Elliott, aims to support individuals and families through end-of-life transitions, providing training for death doulas to offer non-medical, community-based support. Despite initial scepticism and challenges, the programme has grown, becoming a recognised form of citizenship training. This discussion also touches on the integration of doulas into healthcare systems, the need for cultural change, and the importance of recognising personal agency in end-of-life care.

DP The theme of this edition is end of life. There's a double meaning here because the biggest issue ever is the apocalyptic possibility that we could be the first species to choose extinction and take all of life with us is. It's no longer just little me who is on Earth for a short time only! So this under-current is a constant background noise in our time. Interesting, is it not, that just as it is with death, we find ways to pretend it's not going to happen. But of course, being as we are, both three score and ten year (and the rest!) you and I have a growing awareness of our own impermanence.

HE Yes, it was this lack of engagement with the inevitability of death that led me to this work. Living Well, Dying Well (LWDW) was incubating for a few years. I probably started to think about the need to raise awareness around death and dying around 2007. In 2008 I ran a series of one-day workshops for the public and professionals: one was called Death Matters, and one called What Is a Good Death. But I wasn't interested in 'talking at' people, rather more to facilitate people to reflect deeply and ask the questions. And these courses were quite successful though I didn't at the time realise I had been testing the water. Anyway, out of that came a realisation of the huge gap between what was being offered medically in palliative and community care, and what families were having to cope with if somebody chose to die at home. There was really no support in the spaces between. It's interesting that I learned later that Allan Kellehear's research identified only 5% of the time dying people spend is with health or social care professionals; the rest is with family, friends, the TV, pets, the internet and so on. So even though there are community services where people come and go in and out of people's homes there was nobody consistently alongside that person, their family, or friendship group, holding them through the experience and through frightening or unknown territory. I passionately believe we're more able to do difficult things if we're well supported. So the thought of people trying to care for someone at home without this kind of constant, consistent help seemed really shocking to me. It made sense to me that if something like this was in place the revolving door – in and out of hospital – wouldn't need to happen so often. Not only that, people would be able to die in their place of their choosing.

Through these workshops I also discovered that lots of people weren't sure of what was actually 'allowed': that they believe they must hand over responsibility for care of the dying, or after-death care, or for funeral arrangements. It was as if there were a set of unwritten rules we should all abide by. There was no sense of the possibility of ownership or self-determination about the process, at all.

So the idea of end-of-life doulas, or death doulas, took hold about 2008 or so, and I worked with my colleague Ruth Sewell. We had worked together to develop the sister organisation to the BHMA – the British Holistic Nurses Association – in the 1990s and also were also involved with the Bristol Cancer Help Centre (later Penny Brohn Cancer Centre). I told Ruth I wanted to design a course for ordinary people to support them to be with death and dying, and for them to be able to support others. We co-created the structure and content of the training, and although it has evolved, the basic framework is still pretty much the same. Ruth was involved in delivering the pilot course with me and I continued to run it – the foundation and diploma – for the next 12 years.

The foundation training, which I now see as citizenship training ,is life-changing for many participants, because they don't realise how much is possible. We share a lot of information that everybody should know, but it is also experiential in ways that help people begin to confront death in a very held and safe setting. Not only that, people are amazed to be in a room full of others who are willing to talk about death and dying. So for many people the foundation is quite a powerful experience. Not everybody chooses to go on and do more. And I'm really fine with that. Becoming a doula is not for everyone, but I think the more people who are more informed, the better, because I really have come to see that facing death and dying could be the most profound experience of our life. We pay huge attention to preparation for birth but so little to death. Of course this is understandable, but I believe preparation for death is a lifetime's work. Sadly we usually leave it until it's too late, for example to reflect on the life we've had, or say what we need to say to other people, or to make our choices known about how we want it to be; or if people have a spiritual perspective, to be able to engage consciously with their process. I'm sad to see it pushed back and back – in our minds we place it as far as possible into the future, and then, when people receive a terminal diagnosis along with those around them, they find themselves in a critical or emergency situation, it suddenly all becomes very fraught.

The trainings have grown very gently over these years. I didn't start out as a businesswoman: early on I was doing everything, but gradually I was able to employ staff. We've always been a not-for-profit. We were a charity for a short while, but that structure became quite onerous and didn't serve us well. How LWDW works is still unfolding, but we are now in the position 15 or so years on of having a really great certificated training, with wonderful external support from Crossfield's Institute and a fantastic team who run the organisation, a fabulous head of learning, a support team for the learners and a wonderful group of trainers, with new trainers coming on all the time. It has to be said it's not an easy role, there's a lot of content, but it's also very much about modelling what it is to be a doula and being able to facilitate a group.

It's quite humbling when I look back, and I'm in awe really that we've reached this point. Because it's been a struggle in many ways and financially always challenging. Thankfully we are receiving grants now, and we have a huge waiting list of people wanting to do the training. You know, it's pretty extraordinary where we've arrived. I'm able now to step back and just do some training from time to time, and check in with the team, but I have very few day-to-day duties, which is a huge burden off my shoulders. I'm totally confident of them and what they're doing.

DP You may know that for many years I was involved at the interface between complementary medicine and the NHS. I saw some of those emerging clinical professions gradually (not always painlessly) brought in. Others were too hard for mainstream medicine to make sense of. However, even when a profession like osteopathy gained its hard-won statutory registration, doctors weren't sure how to understand or deal appropriately with this unknown new profession. It's still an ongoing slow process, and what I'm suggesting is a parallel with end-of-life doulas. Just as complementary therapies blossomed to fill what the public perceived to be 'effectiveness gaps', so end-of-life doula-hood is emerging to meet the call for something people don't feel they can get from 'the system'. Now this has set me wondering: first off it highlights a failure in 'the system'. So for folk working at the NHS coalface this could trigger resistance – shame or anger even. My second concern is that whereas complementary therapies seldom impacted directly with work in conventional settings, in places where people are dying doulas will necessarily be rubbing shoulders with all sorts of hard-pressed workers in the NHS. These workers might be suspicious of doulas' ideas or attitudes or practices, and sceptical of the value of their services in the system. So the scope for misunderstanding is pretty big, but in my view these challenges are typical whenever we enter interdisciplinary territory. Not to put too fine a point on what I mean, in organisational life there are established pecking orders, turf-wars, habitual defences and clashing of worldviews. So if I'm right about these parallels I bet there will be huge variation in for instance how some palliative care professionals, hospice people, community nursing or care home staff accept the notion and value and the offer of doula-hood altogether.

HE I don't think we can underestimate the enormity of the social change that is required for death to become normalised and for it to become family-led rather than expert-led. This doesn't mean we throw the baby out with the bathwater, we will always need good symptom control and nursing care. I think it will require a shift in the relationship dynamics, between the resources available and those who need them. In any therapeutic relationship it's always good to ask, where does the power lie? Collaboration is key.

I think the reception we have had as doulas is obviously very mixed. There has been some pushback from individuals on the ground, and a bit of resentment at first. It's easier for community teams to recognise the value of doula support when care is happening at home, but also interestingly, where doulas have gone into a hospice with a client, once they are embedded in that environment with their client, everybody gets it – they can see the relationship-based model at work.

It's important to recognise doulas are not trying to be nurses or clinicians. It's very much about developing a relationship to support people to feel as safe as they can be really. And even though hospices very often do such a great job in terms of managing symptoms, people are going into an alien environment and meeting an army of unfamiliar people. So to have a single individual (or possibly even two, because we do sometimes work in pairs) who they know and have grown confident in is a massive comfort really; someone who can be a kind of translator or advocate. So we have seen this interface working well in other situations – nursing homes and hospitals too.

I hope that the value and importance of the role will gradually become clear more widely in end-of-life care and collaborative working will become the norm. After all everyone is working towards the same end.

In terms of integration there is some interesting work going on which I find very hopeful. Emma Clare, the chief exec of End Of Life Doula UK is a doula and a PhD academic and researcher. Her thesis was related to end-of-life doula work. She has recently been working with a pioneering pilot project in Leeds. Funding was made available from the clinical commissioning group to enable GPs to fund a doula and the outcomes were evaluated by the Open University (Howard, 2022). Another pilot study is happening in south west London.

While I celebrate this development my concern with this incorporation into the system is that doulas come to be seen as just another resource within the 'service delivery model', which is culturally very different from what we bring and how we work.

It is no wonder, where capacity is small and the need is so great, that some commissioners in community services will grab any extra resource that's offered! Whereas for us, it's much more about being part of the local community, if you like – becoming embedded (with appropriate boundaries) with that family as an informed companion, or guide, able to be a consistent flexible presence.

There are other potential challenges ahead for what we're doing and how we're doing it, given the levels of desperation and overwhelm in the health service. I was with someone a couple of months ago who was very unwell and then went into the dying phase very rapidly. She was known to the palliative care services months and months before, but hadn't needed (or wanted) them. The community services were doing really well in their care of her, but I needed to get the palliative care team involved urgently. But they weren't able provide any support until five days later! I was amazed and horrified. The nurse I spoke to was fully aware of how unacceptable it was and was as distressed as I was. He said they simply don't have any resource. So yes. there are really, really challenging things going on.

So for us it is important we send a clear message about what a doula can realistically fulfil. And sometimes there is an expectation that doulas will have more skills than they actually do. But despite all these challenges I see a growing acceptance of the need for this role. Some hospices now have their own neighbourhood companion schemes, recruiting and training people as volunteers. Their training is very simple. It doesn't go into the depth that we ours does, but at least there is the recognition that that the companion role has a place, and they're doing what they can to fulfil it.

Another major challenge is 'professionalisation' of the doula role. This is a fine line that we have to navigate within the doula community. To volunteer or to be paid? To see ourselves as experts, or in service of our fellow citizens? To self-regulate and maintain standards as peers, or register with an external monitoring body?

The original intention was to be neighbourly, if you like; for support to be a part of ordinary citizenship and integral to a compassionate community somehow to bring death back into everyday life and for people to be more confident and resourced to be with that. What is being asked of us lies somewhere in between, I believe, and holding space for unfoldment, being open to a way of engaging with death that is not about polarisation, is an exciting prospect.

DP They say it takes a village to raise a child. It's the same for accompanying a person who is dying perhaps. Or for good deaths to become the norm maybe it will need a culture change.

HE Exactly. And I think we're at the very beginning of that culture change, but the prevailing model is so embedded, not only in the minds of clinicians, but also the public, and so the sense of wanting to take ownership of your experience or feel that you have any agency is quite unusual. Right now it takes some determination for someone to say 'I want to have some authority, or I want my wishes to be respected, and I would like to work with people that are going to make my experience of dying as good as it could possibly be'.

DP Yes we need a new story because right now the unexamined assumption in our culture is that when it comes to dying, it's not up to you anymore. This dying business is so unacceptable that it must be taken out of your hands and managed! And yet it will take a paradigm shift to change that story, so that it's taken as read that we can retain some autonomy at our end of life. So much of our worldview of life and death defends us against the reality of our impermanence. Then how are we to realise instead that actually we humans are not individuals separate from one another; nor apart from the natural cycle of birth and death. Not that we can appropriate ancient early indigenous ways – even if we knew what they were – but I do think if we're going to get through this time we have to find a kind of new indigeneity, a new relationship to the cycle.

HE I agree completely and I think the separation from that reality may be what's leading us into the current assisted dying debate. I suspect people say they want this option because they would like to have some control and they possibly fear mainstream medicine may subject them to unwanted interventions.

But as you know most dying is not exciting. It's not dramatic. It can be beautiful. Sadly, young doctors and nurses don't very often see ordinary dying. Like ordinary birth it's becoming more and more complicated because things have to be rushed along, or intervened with in some way, or in medical terms strict protocols are in place. It ceases to respond to the deeper process of dying. So I'm waving the flag for ordinary dying. And it's happening hundreds of thousands of times every year in this country. You know, in England and Wales roughly half a million people will die this year. And mostly they're not dramatic deaths. They're not extreme experiences. But they are happening to real people, living ordinary lives, who mostly are loved and cared for by people who are close to them. Difficult though it is, everyone involved deserves for that experience to be the best it can be. Whatever our discipline, I would like us to put our emphasis on and our effort into improving the quality of those experiences.

DP We hear about agonised dying, and we hear about ecstatic dying but we are rarely given reassurance that ordinary dying is not spectacular. I think that's a fine point to end on. Thank you Hermione.

Howard S (2022) Leeds trials 'end-of-life doulas' to ease pressure on beds and GPs. *BMJ*, 378.

Shame: healthcare's unmeasurable undertows

David Zigmond
Retired GP and physician in psychological medicine; founder member BHMA

Early on in my 50 years as a frontline NHS doctor I sensed that, often, what was *not* evident or explicit in consultations could be a key to our best therapeutic understanding and influence. Here are three vignettes that cross as many decades: they illustrate, I think, how shame – such an unspoken undertow to ageing – is a common and powerful example of how important imaginative non-disclosure can be.

Summary

Medical and mental healthcare have become increasingly transmitted by notions and language of the explicit, the designatory and the measurable. What happens to the rest of our humanity? Three vignettes from different decades illustrate how shame, though a near-universal accompaniment of human compromise, often generates major distress, yet rarely finds direct language. How, then, do doctors – now so often seen as 'fixers''deal with such an elusive problem?

Medical and mental healthcare have become increasingly transmitted by notions and language of the explicit, the designatory and the measurable. What happens to the rest of our humanity? Three vignettes from different decades illustrate.

> *We never forgive those that make us blush*
> Jean François De-La-Harpe (1770), Melanie

Shame, a near-universal accompaniment of human compromise, often generates major distress, yet rarely finds direct language. How, then, do doctors – now so often seen as 'fixers' – deal with such an elusive problem?

1 Cyril

January 1970. A small hospital in the Midlands.

Cyril, aged 71, had never before – apparently – erupted with such aggressive instability. Known instead by his family for his great kindness and calm, none had ever witnessed the kind of shouting, flailing, accusatory invective he hurled at the two young women – Dr Y and an attendant nurse – when they attempted to introduce a penile catheter to relieve his obstructed, now increasingly distended and painful, bladder.

They hoped their professional patience, kindness and reassurance would rapidly calm him: they did not. They assumed his aggressive barrage was due to impersonal physical determinants – pain, exhaustion and a bloodstream now loaded with opiates and renal failure. 'He will settle now', said Dr Y to the nurse soon after Cyril had been tranquilliser-injected and his catheter secured, 'maybe we'll all, at last, get a good night's sleep'. They both sighed with wearied relief.

Cyril did settle and all did sleep well that night. When Cyril awoke many hours later he seemed utterly transformed: docile, submissive and largely wordless and withdrawn though clearly sentient. But three days later Dr Y's relief has turned to a new concern. 'Are you depressed?', she asks Cyril softly, but Cyril turns his head to gaze away from her and does not answer.

Later that day he sees me passing, alone. His wizened right hand emphatically beckons my attention. By his chairside I carefully avoid his catheter bag and then bend to him slowly and receptively. He reciprocates similar movements and gestures: our convergent leanings are already a rapport.

'Can I talk to you?' His tone is confidential and fraternal: I sense this initiative has great risk and importance for him.

My smile is intended to embolden, not just mollify.

'Look, this has all been very difficult for me…' Cyril's voice quakes a little.

I think I know, but fear misattribution. 'What is?' It is important I secure a safe foothold.

'I felt terrible…those young women having to do that … I'm a private person and those are certainly my private parts. I know they're trying to help me, but I can't describe to them just how small and pathetic I feel…'

He holds my gaze. 'You're very young, too…but you're a man. I hope you don't mind me saying such things.' Cyril pats my hand to reassure us both. Without saying more he trusts that I understand far beyond.

*

This brief interchange occurred in the first week of my first job as a doctor. Yet the subtext – of such power, poignancy and meaning – has endured as a sharp and instructive personal memory for decades: yet it was merely one of thousands of similar examples of the centrality of imagination and the implicit in our understanding and exchanges with others. What is such subtext? And are we dealing with it better with the passing decades?

*

2 Home. 2010

Forty years later I am reading a novel. Its central character is a man, A, struggling with ageing – his successive losses, retreats, compromises and griefs. In one passage his previously strong and athletic frame missteps to a clumsy, weakened and fracturing fall. Soon after he is mindful of how another quotidian and basic function is failing him: his micturition. This previously brisk, predictable and controllably efficient activity was now anything but: frequently troubled in starting, stopping, controlling or directing. On one occasion he fumbles urgently in his underclothes to find his penis, then gazes at it sorrowfully: *a dead mouse*, he thinks, an organ of loss, failure, sorrowful reticence and shame. His mind reels back to his youth's very different organ: one of potency and possibility, of charismatic and mysterious pleasures, of mutual desires and the generation of new life. But A's organ of pride and pleasure has involuted to one of humiliation and encumbrance: a dead mouse, a source of avoidance, not attraction.

The pathos of these thoughts and experience now crystallise to a dark epiphany: A's urogenital decline is a symptom and metaphor of his life-course and fate. A knows that such is the ineluctable and near-universal price we pay for age. Yet this commonality does not relieve A's gnawing shame: it constantly tugs, distracts and sullies. It is worse still – he must not and cannot talk about it…

Over my decades in medical practice I have seen the many ways that this powerful and poignant paradox gets acted out – yet so rarely talked about by either patients or practitioners. Indeed, this provides an excellent working definition of shame or humiliation: they are states that defy direct expression or exploration. So the state is rarely stated; instead we must infer it.

From what? Well the displacements and defences are common enough: anger, avoidance, agitation, bravado, 'depression', too-brittle alacrity, blame, withdrawal … all of these may conceal and harbour the disturbingly unspeakable. So, to decipher, we must turn to *context*, and for that we must employ *imagination* – a capricious if seminal enterprise and one easily mistimed: like wet soap, if we attempt to grasp the shame or humiliation of another too strongly or rapidly it will certainly slip away, sometimes irretrievably.

*

3 Sybil and Sam

January 2017. General practice.

I have known Sybil nearly 40 years. She is two decades older than I, so she is now enduring and struggling in the undrainable swampland of age's losses and compromises: I am gazing towards it, grateful for my vantage point at its margins.

In her middle years Sybil was formidable, attractive and successful in her work, her family and her wide social network. Until her 80s biology had been kind to her, too: she had retained a youthful vitality, autonomy, trimness and wit sufficient to retain her central roles of matriarch, hostess and wise older woman.

But in the last few years such biological benevolence seems to have abandoned Sybil. First, she lost her beloved husband and oldest child, then – widowed and alone – her own health: a failing heart, a post-cancer colostomy and a painfully degenerating spine have slowed, weakened and housebound this previously gregarious and independent woman. And her confinement is not even to her own long-cherished home: practicality has necessitated sheltered accommodation.

She is now sitting with me in this new and much-reduced residence.

'I wish I could make you a cup of tea, doctor', she says forlornly, trying to retrieve her erstwhile initiative and hospitality.

'Oh, it doesn't matter…I'm fine' I reply, attempting to be both reassuring and unintrusive.

'But it matters to *me*! I suppose because I know I'm *not* fine…I'm sorry, I shouldn't talk like that…' Her spiked anger fades rapidly into contrition, and then abject candour. 'But then I've known you so many years, doctor, that I think you'll understand. You see, I hate living like this: my body failing, my marriage and home gone, my reasons for being in this world now largely beyond me… I don't now even have the resources or the wherewithal to take control of this…' Sybil's gaze is direct, desolate yet defiantly spirited. *You know what I mean*, she seems to be saying.

Possibly to relieve my own sense of helplessness as much as hers I tell Sybil I would like to refer her to our psychology service. 'They can visit you at home. But don't worry, you won't lose contact with me. I'll come and see you again in a fortnight.'

*

Sam the psychologist seems quickly to understand my description of Sybil and her plight. 'We'll go through our usual procedures to engage her and then decide what to offer her.' Sam is cheerfully matter-of-fact: I imagine I am talking to a travel agent.

The 'usual procedures' consist of a brief telephone call, followed by a long and standardised questionnaire that enquires about the range and severity of Sybil's symptoms and possible risk factors. Sybil returns this by post.

I promptly receive a formatted email from Sam's office. It informs me that Sybil's symptom and risk scores are low. This leads to their procedural care pathway: a short-term low-intensity intervention by an assistant (inexperienced) psychologist. This makes little sense to my understanding and experience of Sybil. What sense does it make to Sybil? I call her.

*

Sybil's voice is welcoming yet weary; she sounds slightly short of breath. I ask her about her preliminary contact with the psychology services: the screening phone conversation and then the questionnaire.

'Oh. I answered their questions', she tells me, as if to excuse herself.

'Well, sort of. But I think there was a lot you *didn't* say…' I venture, hoping I have not, already, said too much.

'What does that mean?' She sounds stronger in her wariness.

'Well, they seem to think you're just a bit down, a bit worried…but we both know that's too simple and a big understatement…' This is tough territory; I hope she hears tenderness, too.

'Yes, but that's between you and me. I'm not going to have that conversation with anyone else. Particularly if their staff keep changing but keep asking difficult and personal questions. You've got to have trust for those kind of conversations, and that takes time…Yes, I'll talk to you because I know you'll understand. But no, I don't want to talk to a series of strangers who don't understand and might have me put away somewhere…'

*

Despite Sybil's stoic circumspection I still think she needs help beyond the time and attention I can provide.

I ask to see Sam again, to describe the interlocking predicaments of Sybil and myself.

Sam listens carefully, looking up towards the ceiling and stroking his chin.

'This is tricky. She definitely has low scores, so our suggested care pathway is correct for these. You'll know that our assessments, treatment programmes and outcome studies are now all based on measurements and then statistical analysis and correlation. That's how we assemble a solid *evidence basis* for our treatment packages and then our tendered services. It's important to understand that we need this schematic approach to satisfy commissioners: we can then assure them of the nature and quality of our service, its costs and its likely outcomes…'

I feel I am being lectured and schematised. 'Maybe that looks impressive on a management spreadsheet, but that's not much help to me trying to help Sybil… do you need to design a shame questionnaire first?' I hear peevishness in my tone now.

'But we *are* offering help', says Sam, tartly.

'But it's not the kind of help she needs.' I feel flushed with impatience.

'Why do you think that?'

'Because of my conversations with Sybil – what she's told me.'

'Well, with respect, that's hearsay. In contrast, we've conducted an extensive questionnaire, directly with the patient. That tells us a lot and we can quantify it, too…'

'But there's a whole stratum of experiences she won't tell you about…not yet, or possibly ever.'

'The problem with that is it's *you* saying that, not her. Our system can only really work with direct speech and evidence…'

Sam is logical but I am frustrated by his apparent incapacity for the unspoken or irrational. 'So everything else is deemed an irrelevance or a contamination', I say.

'In a way, yes.' Sam seems pleased to return to this simplicity.

'But Sam, aren't there times in your life when you want people to perceive and understand something painful and compromising that you don't want to, or cannot, verbalise …to respond to the *implicit*?'

Sam looks away and shifts in his chair. 'Well maybe…I don't know…but this is work, it's different…' Sam's voice fades into equivocation.

He clears his throat to continue. 'Look, we've got lots of patients to see, targets to meet, commissioners to satisfy. Amidst all this I want our service to survive. These procedures we have – to assess and treat people – are the best ways we have to achieve all that.'

As he talks of 'the service' I notice how purposeful and strong Sam's voice becomes.

That is one example of how to deal with shame, I think.

A man is hid under his tongue
Ali Ibn-Ali-Tabib (7th century), Sentences

Interested? Many articles exploring similar themes are available at www.davidzigmond.org.uk/david-zigmond-archive-homepage

Many of his videos are also on YouTube.

Hama: grieving a place I've never been

Maria Najlah

Medical student, Barts and The London School of Medicine and Dentistry, QMUL

Syrian-born final year medical student at Barts and the London.
Interested in creative enquiry based journalling and identity arts creation.

My submission for my second year module on flourishing in medical education was focused on my unconventional relationship with grief as a Syrian medical student, artist and former refugee. My main perception of grief through my own lens revolved around the forced estrangement from my home country, Syria, in 2014 amid the Syrian revolution against the Assad dictatorship. To me, I lost more than a person; I lost a country and everyone in it. To have been stripped away from everything I ever knew and to be forced to adapt to a new environment so young, I felt like I had no opportunity to grieve, which later built up insidiously into resentment. It was important for me to explore aspects of my identity outside of the label 'medical student', to understand what influences have shaped my perception of myself, and thus my perception and relationship of being a medic.

Hama: grieving a place I've never been; Maria Najlah, gouache on canvas

This piece was the result of allowing myself to explore and express homesickness. Despite the ambiguous relationship between 'homesickness', 'grief' and the 'medical identity', to me there could not have been a clearer link: my identity as a Syrian is the reason why I pursued medicine. Having lived through the revolution, witnessing the selflessness of Syrian doctors risking their lives to save their patients when hospitals were being targeted, I was inspired to follow suit. By creating art that reminded me of home I was subsequentially reminding myself of why I chose medicine, and thus it provided me with the fortitude to get through a difficult time in my life. Therefore, by creating a space whereby I could reflect on myself and my emotions holistically in ways that did not directly involve association with healthcare, I was paradoxically able to strengthen my identity as a medical student and even find a resolution and conviction in the relationship I had with pursuing medicine.

The painting itself depicts Hama; a city in Syria I've never been to. I always wanted to visit Hama but during my stay in Syria the political climate did not allow for luxuries such as travel and tourism. Being able to paint Hama like this enabled me to have a deeper appreciation for its historical landmarks and natural beauty, away from the feelings of disappointment and alienation that I never did get to go. This piece felt as though I was reconnecting with parts of myself I had shut off for the sake of being able to 'move on' and progress in life, it almost felt like rekindling a relationship with my land.

The transformational impact of awareness-centred deep-listening training

Annabel Park and Helen Selka

Co-founders of The People Project

The People Project is a boutique consultancy with a specialism in team coaching and awareness centred deep listening training (ACDLT). We came to awareness-centred deep-listening when we were looking for a way to strengthen our consultancy practice seven years ago. It has been a cornerstone of our work ever since and has had a profound impact on our lives both professionally and personally. For Helen, having trained as an actor at the Royal Academy of Dramatic Arts, deep listening has allowed her to give space to others rather than taking the space as she would on the stage. Annabel has found that connecting of mind and body through coming to embodiment allows her to work in a more nuanced way with clients using her own emotions and perceptions.

Summary

Awareness-centered deep-listening training (ACDLT) was developed by Rosamund Oliver in 2003 to enhance listening skills in healthcare staff, especially in hospices. ACDLT fosters a non-judgemental, compassionate, and safe space for individuals to feel heard. The ACDLT model comprises three core skills: coming to embodied awareness to stay grounded and present; holding supportive presence to create a non-judgemental space; generating compassionate connection to foster a heartfelt connection with the speaker.

Approaches that promote healing and flourishing are essential for both patients and healthcare professionals. Awareness centred deep listening training (ACDLT) is one such method, and perhaps an unusual one in that it serves both to upskill our interactions while also providing protection against burnout.

When making meaningful connections with others, being able to listen well is an important skill. By simply listening with awareness and presence we enable the other person to be more in touch with what is happening for them. 'True listeners no longer have an inner need to make their presence known. They are free to receive, to welcome, to accept. Listening is much more than allowing another to talk while waiting for a chance to respond' (Nouwen, 2006). We offer ACDLT for health professionals who want to develop these skills. One GP trainer explained, 'Through this course I learned how to listen, and how to give space to the patient, to my trainees and also to give space to myself'. In The Netherlands, this training is available to doctors and GP trainers at universities in Amsterdam and Utrecht and in France at the Centre Hospitalier Universitaire Bordeaux.

The origins of deep listening

ACDLT was developed in 2003 by Rosamund Oliver after the matron of a local hospice asked her to create a training for her staff, which would build on their listening skills and enhance how they provided care. Oliver drew on her experience and training as a psychotherapist to combine listening skills with contemplative practices from the Buddhist tradition. The method she developed had immediate application in medical settings, but also in a wide variety of professional settings where listening is an essential part of day-to-day work.

Deep listening is not a therapy, though it can be combined with therapeutic approaches and other types of listening. It brings together the person-centred approach of humanistic psychology, with Tibetan Dzogchen awareness meditation, and the Mahayana Buddhist emphasis on compassion. All these approaches are holistic and assume the basic beneficence of human nature (Ricard, 2015). In deep listening, we bring our awareness into the present moment as we listen, and pay compassionate attention to the other person.

Deep listening supports listeners to develop a greater capacity to connect with presence, awareness and compassion that comes from the core of their being; and to hold a safe compassionate listening space, without judgement, so another can truly express themselves and be heard. Chantal Bergers, a doctor and senior ACDLT trainer, describes, her first experience of using this method in *Mindful Communication* (Bergers & Oliver, 2023). 'When, as an experienced GP, I first took this course, I was immediately struck by the simplicity and power of the method. I had just recovered from burnout, which was partly caused by thinking that I always had to solve everything for others. Here I learned something completely different.'

Method

Awareness-centred deep-listening methodology draws on elements of practical understanding from humanistic psychology, particularly Carl Rogers's person-centred approach and neo-Reichian body-centred psychotherapy. These contemporary approaches to embodied relationship are combined with traditional elements of reflection and contemplation deriving from the Buddhist tradition. The practice of these methods aims to bring more attention into present awareness and to develop greater compassion. Mindfulness and awareness meditation exercises are now widely used across the world within health services and in many other organisations.

The deep listening model

Awareness-centred deep listening is a process. There are three connected core listening skills in this process:

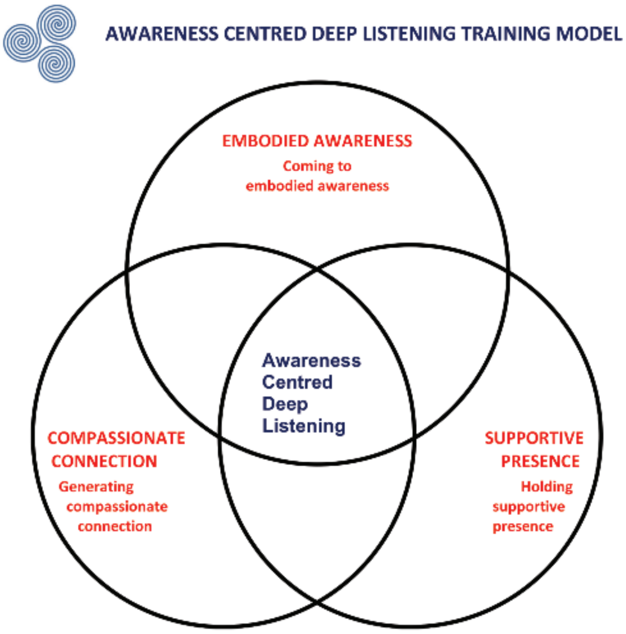
- coming to embodied awareness
- holding supportive presence
- generating compassionate connection.

Coming to embodied awareness

We experience embodied awareness as we come more fully to feel into our body. Jon Kabat Zinn (Kabat-Zinn, 1990) calls this *interiority* the experiencing of our own body and all our senses, including the mind: both our body's postures and movements (*proprioception*) and the responses or emotional reactions we generate within ourselves and the corresponding physical sensations (*interoception*). With practice, our bodies become sensitive listening instruments, sounding boards for the speaker's verbal and non-verbal signals: 'To do this the clinician must access his or her own bodily based intuitive responses to the patient's communications.' (Schore, 2012).

Holding supportive presence

In order to hold supportive presence for another person, as we expand our awareness outwardly, we hold an intention to stay present to *ourselves* and be available to listen.



'I don't have to try so hard to ask good questions, to guide the process, to push people with words or to save someone. So I can listen in a more relaxed way. It doesn't mean that, as a doctor, I put my diagnostic and therapeutic skills aside. It's more that deep listening creates a kind of basis from which I work; and in this way it is much more than just an addition to my profession.' (Bergers & Oliver, 2023)

Generating compassionate connection

> *By listening with calm and understanding,*
> *we can ease the suffering of another person.*
> Hanh (2006)

Alone, the combined core skills of coming into embodied awareness and holding supportive presence are not enough. Alone, they do not naturally make listening beneficial. So deep listening also requires the third core skill of generating compassionate connection. This ensures the compassionate intention of our listening, so that it is kindly and ethically directed for the benefit of the speaker.

Compassion is more than just empathy. It is the wish to relieve suffering and its causes, coupled with the urge to act in order to do something about it. Compassion includes a strong cognitive element of reason. It is very much about respect for the other person, not pity. Compassion requires the capacity to understand the feelings or emotional states of others, which includes two major components. Affective empathy is the ability to emotionally and viscerally share the affective states of others; and cognitive empathy, or the ability to take in the mental perspective of others and make inferences about their mental and emotional states (Cox *et al*, 2012; Shamay-Tsoory, 2010).

> *A good head and a good heart are always a formidable combination.*
> Nelson Mandela

Generating compassion may lead a listener to take a step back to assess what is best needed, and after the listening has finished to let go of the effect of empathic responses and not take these on. Compassion, according to social neuroscientist Tania Singer, can help us not become overwhelmed by emotions or stressed when we listen to someone recounting an experience of pain and suffering. Compassion activates regions of the brain associated with the regulation of emotions, which allows us to maintain a sense of connection with the listener whilst preserving our own emotional stability. (Singer & Klimecki, 2014). By choosing a compassionate response, the deep listener becomes energised rather than exhausted, potentially contributing to protection from burnout. This is important when listening is a major part of our work.

> *'I can experience a very heavy feeling in my body when I talk to someone who is depressed. In this way, the sensations in my body can be an antenna for what may be going on with my conversation partner. It is important to recognise that these physical sensations come from the other person and do not "belong" to us. If we are not aware of this and do not "channel" these feelings, a day of listening can be tiring, and in the long run can even lead to burnout.'*
> Bergers & Oliver, 2023

The three parts of the model all work together to create a protection against burnout while improving their interactions with patients and colleagues. Our experience of using this model with trainees is that even after a one-day training they leave feeling energised, refreshed and inspired, and the experience stays with them.

Awareness-centred deep listening in action

The method can be used not only in longer sessions (therapy, caregiving, coaching) but also in ten-minute sessions, such as in GP consultations and everyday care practice. Our experience has shown that a person can feel totally heard in ten minutes or less.

> *'I wish that this kind of training was more available in medical schools. By discovering this listening method, I experience myself, others and my environment in a very different way. This method is very useful in my work as a GP. The skills are very helpful and bring more joy and quality to my work. I learn to "recharge" myself after work and not to get burned out.'*
> Dutch doctor, on completing a deep-listening training.

After attending a workshop in Berlin, a doctor said: '*My way of listening when I take a medical history becomes more aware and multifaceted when I employ and internalise the many aspects of deep listening and bring them into my meetings with patients and staff.*'

On a recent retreat (May 2024) that The People Project ran, feedback from the group of doctors who attended was overwhelmingly positive:

> *'This has been the best learning experience of my life, and so enjoyable.'* Neil Calderwood, trainee GP

> *'The way you held the sessions with such lightness, humour, joy and sincerity has been astounding. This will come with me through my life.'*
> Jess Zollman, junior doctor

Our own deep-listening journey has been transformational for our practice as consultants, and we strongly believe that anyone working in a healthcare setting could benefit both personally and professionally from the training.

To see a GP share his experience of the training go to https://vimeo.com/770744906/5e1a84a7ae

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Resources
www.thepeopleproject.uk.com; www.deeplisteningtraining.com

Riding the waves of grief – a spiritual perspective

Annie Blampied-Radojčin
Interfaith Minister; founder of Quietude

Ordained as a OneSpirit Interfaith Minister in 2004, I am a funeral and marriage celebrant and spiritual counsellor, with a background of 20 years' experience in Steiner Waldorf education. I created Quietude, a training for those wishing to offer spiritual support in end-of-life care in 2020. Having volunteered or worked, over the years, as a chaplain in a hospital, a nursing home and two hospices, I became convinced that, in the UK, we needed more inclusive opportunities to learn the art of compassionate accompaniment and spiritual care for those on the journey of death and dying, and a deeper understanding of the processes of grief.

Summary

In this article I explore the paradoxical nature of grief, both for someone dying as well as for those left behind. Opening to the idea of continuity of consciousness beyond the gates of death can give us a deeper understanding of death as a journey, and indeed as an adventure into a life more beautiful than we can imagine. We may be very sad our loved one is dying, and at the same time wish them well and assure them that they go on the wings of our love.

> *Spiritual care is an important part of palliative care. Having a terminal illness often leads people to think about their lives in new ways, and their spiritual needs may change. All health and social care professionals can help explore the patient's spiritual needs, and identify when someone might need more support.*
> Marie Curie charity

For those of us in the position of offering spiritual and holistic support for people on the journey of death and dying, to be aware of the immensity of the grief that a dying person may be going through is important.

In my early days working as a chaplain in a hospice, I remember meeting a woman who had arrived on the in-patient unit. She knew she was going to die soon, and that was why she was there. Her son had brought her in. I asked her what it was like to leave her home for the final time. She told me she had looked out of her sitting room window, gazing into her garden, drinking it all in, knowing it was the last time she would see it. It appears a simple thing, but in that poignant moment, I suddenly grasped and felt it viscerally, how huge is the grief someone experiences in their final months and weeks. Unlike those of us who lose the one person we love most, someone with a life-limiting illness is having to say goodbye to every person they know, and let go of the life they have known, and all that they have cherished: the people, their animals, the landscapes and nature, their hobbies, lifestyle, social groups, religious practices. Letting go of grandchildren I am often told is one of the hardest things. In my most recent conversation, with someone in a different hospice just last week, a patient shared with me how grieving for the loss of the life she loved was deeply troubling for her.

The benefits of spiritual belief

I have been offering spiritual support, either voluntarily or through employment, in a hospital, nursing home, or hospices for many years. Through what I have witnessed with those who have died or been bereaved, and my personal experience of bereavement, I have become convinced of the importance of holding the vision for people, of the continuity of consciousness, that there truly is something in us that cannot die, after the body falls away.

It is equally important to sit with someone, just where they are, in their beliefs and what they hold dear without any intention to put across my own point of view. The way to do that, I have found, is to practice a profound open-hearted listening, and to allow my heart, as an organ of love and perception, to radiate a loving presence that can hold someone in their grief and sense of loss, without the need to change or fix anything.

If a person knows they are going to die but trusts that this is not the end, only a transition into a new realm of greater awareness and light, the process of letting go may be easier to bear. A friend of mine was preparing for death, after a successful remission from cancer, but which metastasised three years' later into her bones. I sat with her on a bench in her garden, warmed by the late summer sun, about six weeks before she died. It was time for her to say goodbye to her friends, as her circle dwindled to just her immediate family and carers. She had been on a spiritual path for years and had studied many lectures in which Rudolf Steiner describes the worlds we may experience after death. Although she was sad to leave behind her beloved family, she shared with me that she was excited and looking forward to her life after dying.

I have heard highly paradoxical statements from patients over the years. For example: 'I don't believe in life after death, but I know I'm going to see my mum again' and from another, 'I don't believe in God, but I'm really interested in near death experiences'. It is natural to be contradictory in how we feel about things, that's part of our humanness.

Recently I was sitting quietly in the reflective space in the hospice when someone burst into the room in tears. She was the mother of a young woman who was actively dying on the ward. I invited her to sit with me and she poured out her grief and her panic that her daughter was dying, and how extremely difficult it all was. As she shared with me the complex family situation, I realised that like many people today she did have some kind of spiritual belief, and so did her dying daughter. I helped her see things from her daughter's perspective. 'Actively dying' is a term used to describe the labour of dying, when, like a pregnant woman in the labour of giving birth, surrender to a process that cannot be stopped is our only choice.

We talked then, about how much her daughter needed the support of her family, and especially for them to wish her well at this time. Might she be able to see that the light in her daughter could not die, though it was time for her to leave behind the tired and very diseased body that could no longer carry her; that the light of her daughter's true self was preparing to join a greater light? One could say that spiritually she was giving birth to herself, and that we could trust that her loved ones and spiritual helpers on the other side of the threshold would be there to welcome and support her. This mother could help the family stay calm and allow her daughter to let go and make this transition: to release her and honour her journey. After praying together, she brightened up, thanked me and returned to her daughter's room, prepared now to give her daughter the freedom to go; accepting her own sadness but at the same time filled with the love and blessings her daughter and family would need at this sacred time.

Grief is paradoxical

We may feel deeply relieved that the person we've been supporting has finally died. They are free from their suffering, and we are free from the (at times exhausting) work of looking after them. At the same time, we may feel guilty, that the burden is lifted, and yet in deep shock, being both sad and angry they have gone. I think of grief as being like ocean waves. We never know when a wave is going to come, and when it does it can crash over us. All we can do it let go into the tumbling chaos of the wave, flooded with tears in which we feel we are drowning, and yet emerging somehow cleansed and breathing more deeply. The waves of grief may come thick and fast, but over time, may slow down, but still hit us with unexpected force. At other times, we may find the wave of grief carrying us, in a sweet sorrow that can soothe and comfort.

We may miss the one who has died with what feels like a never-ending emptiness and ache, and yet, at the same time, feel closer to them than when they were alive, and that somehow they are inspiring us and helping us in our present lives.

More than one friend of mine lost a child when they were young adults, either through serious accident or through illness, and I have often been told by their mothers how some people in our village community would hide in the aisles of our local supermarkets because they didn't know how to approach the grieving mother. Yet it's at this time that you need a kindly word, and a natural response, and not to be avoided even if it's only to say 'hello, I don't know what to say, but you're in my thoughts'.

Rituals matter

There is a growing trend in the UK for 'direct cremations'. This is when someone who has died is cremated, without any gathering of friends or family at the time of the cremation. They may choose, however, to hold a memorial or festive gathering at another time, to remember and give thanks for that person's life. It is often the choice of the one who has died, to be cremated this way, not wanting 'a fuss' or to cause additional expense.

Having conducted many funerals and cremation services my own experience has led me to sense a value in gathering together to not only give thanks for the person's life, but also to accompany and bless the soul and spirit of the deceased, at the moment just before committing their body to the earth through the element of fire, or through burial. My understanding is that our continuing love and prayers are a very real support as our loved ones journey through the spiritual world.

Time for joy

In the book called *The Bridge Over the River* a soldier in the first world war is able to communicate with his sister after he dies. He asks her and his other siblings to mourn for him no longer, that it is agonising for him to feel their pain, and that it is holding him back from progressing.

'If you only knew the beauty I have already experienced here' he tells her, that is, in the life after death.

In Nick Cave and the Bad Seeds' new album, Wild God, there is a song called *Joy*. The lyrics tell the story of a visitation of a boy, (I guess one of his sons who died) who tells him, 'we've all had too much sorrow, now is the time has for joy'.

And then I saw a movement around my narrow bed
A ghost in giant sneakers, laughing stars around his head
Who sat down on the narrow bed, this flaming boy
Who sat down on the narrow bed, this flaming boy
Said, we've all had too much sorrow, now is the time for joy

The Quietude course

Through being a chaplain I saw the need for development in the training of those who wish to offer spiritual support in end-of-life care. To this end, in 2020, I founded a course called Quietude. This is a training course open to people of all faiths and doubts but asks that they have an openness to the idea of life after death. I am now working with my fourth cohort of students. The course attracts professionals and volunteers in many areas of health care, allopathic and alternative, and those wishing to offer spiritual and emotional support to family members, as well as those looking for a new life direction, or those who want to know more about life after death, and those wishing to add into their self-employed work as quietude practitioners. Sometimes people just feel an intuitive hunch that this course is for them. In every course there have also been birth doulas and teachers of young children, because of the recognition that at the beginning and end of life, we are going back and forth across the same threshold.

The first three training courses ran as seven weekends, spread over 10 months, with assignments, case studies and projects in between the modules, to deepen and integrate what was being learnt: a total of approximately 90 contact hours. By request from friends in Australia and New Zealand who wanted to do the training, I have created a new format, with a 10-day residential at the same venue where all the work has been held, Emerson College in Sussex, followed by approximately ten three- or four-hour online sessions spread over six months to allow for the necessary integration and continued learning (www.emerson.org.uk/quietude).

The main wisdom that informs the course comes from Rudolf Steiner, an Austrian spiritual philosopher who lived at the beginning of the twentieth century, as well as from the *Tibetan Book of Living and Dying*. Kirsten de Leo, author of *Present Through the End*, is a teacher of Tibetan Buddhism and trainer in Buddhist approaches to support in end-of-life care. She is one of the guest teachers on the Quietude training.

Part of the training course is a deep dive for the participants into their own journey with grief and loss on all levels as well as looking at their unfinished business, and the journey of dying, and considering what happens after death. This approach is based on the idea that you cannot really be alongside someone else suffering bereavement or facing death, unless you have embraced those questions for yourself. I have been moved by the way the students of each course have connected with each other and formed strong bonds of trust and loving acceptance. The people attracted to the course are naturally kind and open hearted, and the subject matter induces intimacy and authentic sharing.

During the quietude training course the students learn the art of deep listening, and develop an understanding of the stages of grief, and the paradoxical and myriad ways grief shows up in our lives, or silently tugs at us. They will practice supporting each other, in their process of becoming equipped in their role as future quietude practitioners.

Painting by Ninetta Sombart © Photo: Raffael-Verlag

Solace

The grief suffered by a family who lose a child (whatever their age and for whatever reason), or the experience of young children who lose a parent cannot be compared with the toppling of a great old oak of a person. For someone fortunate enough to have lived a long and fulfilling life, we could view their death as a blessing. The physical body has loosened and finally dropped away, its mission accomplished. I like to imagine the beauty with which someone is met on the other side, experiencing the universe as one giant organ of love. Despite the sadness and loss, we naturally feel, is this not also an opportunity to celebrate? In no way do I diminish the devastation of bereavement, but at the same time broken hearts, cracked open by grief can in time allow a greater light to pour in and eventually bring comfort and new direction.

I imagine that each person reading this article will have their own story of loss and bereavement. I hope that something you have read will have touched your heart, and given you fresh insights, compassion for yourself or others, and the courage to choose love as your guide in each decision you must make.

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Between loss and life: making space for grief

Marianne Rosen

Author, journal coach

I'm an author, journal coach, and advocate for writing as a means of healing and growth, with a background in entrepreneurship, literature and teaching, I transitioned to a writing career after two decades in design. My own journaling practice began as a child and has been a companion through life's transformations. Today, I empower others to explore the impact of narratives in their life and encourage them to rewrite their own stories. I host *Rewrite Today*, a newsletter that combines storytelling with journal prompts for a regular dose of encouragement.

Summary

Exploring the isolating experience of grief and how journaling can provide a transformative space for processing loss through personal testimony, Marianne Rosen reflects on the complex emotions following the suicide of her partner and the societal disconnect that followed. Drawing on the dual process model of grief and her background as a journal coach, she discusses how journaling offers both a release and a way forward. This practice ultimately inspired her to co-create Transformational Journaling for Wellness Practitioners, a course supporting others through grief and beyond.

Anyone who has experienced grief will tell you how confusing it is, especially in the face of society's mixed messages on how to grieve.

In grief, you are told to ask for support, but suddenly lose friends because you are being unreasonably needy.

You are told to take time to grieve, but also to move on and not keep going on about it.

You are told how lucky you were to know love, but the loved one's name is never mentioned.

The effect is isolating. People want to help, but have no idea how to help, and hate their helplessness being exposed. Grief pushes you into a social bubble, floating between the life you had and the one you must move toward.

To the general strangeness of this place are added the nuances of your personal experience of grief. They are determined by your relationship to the one you lost, and the way in which they died. Was it child, parent, spouse, friend? Was it illness, age, sudden or lingering?

Cariad Lloyd, podcast host of *Griefcast*, calls these the many 'rooms' of grief in her book *You Are Not Alone* (2023). The title is a defiant rebellion against the feeling that you are most definitely alone in your grief. Lloyd prefers the term 'room' to the other one bandied about by those struggling to help you, 'club.' That term conveys a sense of fun that is not to be found in any version of grieving.

My own experiences of grief are varied. I lost my father to lymphoma at 59. I held my great aunt's hand as she passed at 97. I heard three months after the event that a past lover had died of a pulmonary embolism at 41. I watched my father-in-law pass peacefully in his bed, surrounded by his family. These were all painful losses that took me time to accept but I muddled along uncomfortably with them through the ongoing but shifted nature of life. But my most recent loss was traumatic and violent. It disrupted life entirely.

In the aftermath of the Covid lockdowns, as we were navigating separation and co-parenting, my partner left our young daughter in the house putting up the Christmas tree, called his elderly mother in to keep an eye on her, went outside and self-ended his life.

He was determined about it. Prescription drug overdose, three industrial gas tanks, and a loaded shotgun on the passenger seat beside a week's worth of letters.

His mother and our daughter found him.

If this sounds shocking, it was.

If this is a club, we were dragged into it by a revelry of police and paramedics.

The nuances of the suicide club are both complex and taboo. But the first rule of suicide club is that no one talks about suicide. Anyone who isn't already rendered speechless by death is silenced by suicide.

> Journaling…is safe space, it is patient space, it is empty, endless, empathic space

The taboo has a kind of nuclear half-life impact. Half of my contacts blocked me overnight. Those who survived the first six weeks disappeared after the funeral. Three months in and neighbours were crossing the street to avoid me. A year on, as Christmas loomed for everyone again, two of my closest friends turned tail and ran. My initial shock over this settled into sympathy.

Death is abhorrent to life. As you read my story, did your body reject it? Perhaps your tongue thickened with saliva that drowns words and your mouth twisted in distaste? Did your eyes blink repeatedly or squint to reject the images? Our bodies hurry to move past this taint. Our everyday capacity to help those during grief is limited, and professional help and practical tools are essential for recovery and processing.

I resonated deeply with Lloyd's complaint that Elisabeth Kübler-Ross' five stages of grief framework (Kübler-Ross, 1969) which has somehow become so socially popular as to be invasive, is the most useless framework to help the grieving. It was never intended to in the first place. The five stages of grief are meant for the dying. And dying is an entirely different process to grieving. Dying is progressive and has an ending.

A more viable framework to help those grieving is the dual process model of grief, developed by Margaret Stroebe and Henk Schut (1999). This framework recognises that those in grief must both pull apart the death to feel the loss and put aside the dead to feel toward the life ahead. Stroebe and Schut call these two aspects of grief 'loss-oriented' and 'restoration-oriented' processes. Grieving is an 'oscillation' between loss and rebuilding, where there are no clear stages or end results. Grieving is simultaneous and messy.

Whichever framework you find to help process grief, you need to anchor those ideas in the actual space of grief. Those on the inside need to claim it for their own for however long and messy the stay is. Whether this space is a family member or friend who can hold space with them, or a support group in real life or online, or a counsellor or therapist who creates professionally supported space.

For me, that space was, and still is, journaling.

It is safe space, it is patient space, it is empty, endless, empathic space.

Here, in the isolated depths of traumatic loss, I could scream my rage loud enough that it felt heard. Here, I could remind myself daily; this is who I am, this is my story, this is my life. Scratching my truth onto the page as a testimony. And it was the place that could pick me up, that could hold a narrative of what life might look like. As my home, my finances, my parenting, my community, my identity were torn apart and reshaped by the violence of suicide, journaling became a daily lifeline to sanity. It was the deep breath I took every morning that gave me the courage to navigate the world and continue to show up as a parent.

I don't know that if I had begun journaling in that moment that I would have been able to move beyond recycling the scale of loss. But this process was already a deeply embedded habit, begun in childhood and nurtured as a writer. I was lucky to have well-established systems that upheld me while pivoting to the challenge. I was able to finetune it for the nuances of grief. Intuitively my journaling shifted into a two-page process.

On one side, the spillage of loss. Why? Why? Why?

On the other, the demands of reality. What next? Where next? How next?

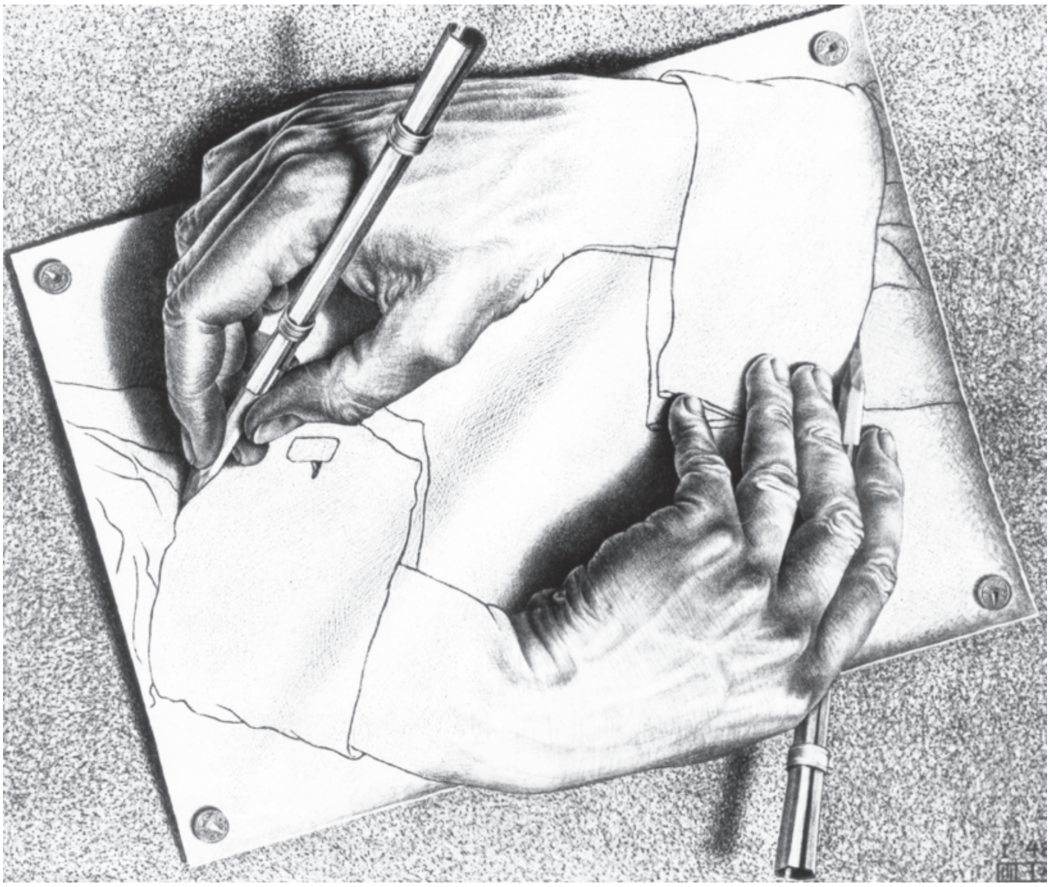
In the first year after our loss, I was incapable of writing creatively. My work ground to a halt, but my words kept flowing. Journal after journal, page after page. I filled the walls of my grief room with ink. I sought structural tools and reshaped them to fit my space.

When I finally received the professional support of a counsellor and was introduced to Cariad Lloyd's work and heard about the dual process, I recognised that I had already accessed it. It had fitted itself right onto the pages and carried me forward. Connecting my rebuilding processes to the wellbeing wheel of life had given me a solid framework. Structurally allowing myself no limit to the space needed for expressing my loss had given me permission.

Grief brought the power of journaling formidably to the surface but connecting it to practical systems and structures made it functional. Journaling isn't the vague, nebulous idea that most people are inspired by, but which leaves many a beautiful notebook unfilled. Journaling is multi-dimensional and multi-applicable. Before I turned it to managing 'big grief', journaling had carried me through the common griefs of divorce, illness, IVF and career change.

This recognition that any tool must be used with solid systems is the belief that brought me to Jo Permaul.

Jo is the dynamic director of Wellness Professionals at Work (WP@W), an accredited online training provider dedicated to empowering wellness practitioners and coaches. Jo's background in education – ranging from mainstream secondary schools to specialist psychiatric units and Gypsy Traveller education – means she brings a compassionate, grounded understanding to every aspect of the curriculum at WP@W. As a leader, she is constantly



Drawing Hands © MC Escher

forging connections and embracing collaborations.

Sharing my story with her led us to create the new course Transformational Journaling for Wellness Practitioners; a course that explores all the ways in which journaling can help those in the wellbeing, health and education industries to connect this superpower to functional strategies.

This autumn we launched our beta test group to finetune the content and delivery for our launch in January 2025. The course is accredited for 42 continuing professional development (CPD) points with the Association for Coaching and the Complementary Medicine Association, and Jo continues to expand the range of professional bodies who are endorsing the certificate.

In seeking to create a unique course experience, Jo and I have focused on the value of practical tools and immersive experience.

> In the first year after our loss, I was incapable of writing creatively

On the practical side, we present journaling in eight different forms. With a thorough explanation of how to use them, who they might benefit and how to introduce them to clients; from the grounding of intentional journaling to the uninhibited release of expressive journaling, exploring differences such as the comfort of gratitude to the trust of abundance. Understanding these clearly defined forms will illuminate how to shift between them as life circumstances evolve. With Jo's experienced direction, the course has clear connection to holistic coaching frameworks.

And on the immersive side I deliver a directed experience of writing and reflection. Having led writing groups and workshops, I've experienced the resistance to move beyond our own protective layers. Often built up through years of life management, these coping strategies keep us safe but inhibit our growth and authenticity. Re-creativity and expansion begin when we dare to step into the unknown. For highly qualified professionals, this can be a particularly daunting process. Each of the eight modules is taught over two weeks, with a weekly online writing session where students gather in a virtual circle of like-minded practitioners. This is a space to share peer knowledge and experience collective learning. With an experienced writing leader to support your journaling, you can rapidly move beyond theory and into confident practice.

As a writer I am proud of this course. As a griever I am grateful. I know that this course will help connect solid frameworks to the tool of journaling, helping those in the painfully isolated depths of loss – offering a multitude of ways to nurture and support themselves, and to grow a garden of memory from the room they never wanted to enter in the first place.

Perhaps you are already familiar with loss yourself. Perhaps you have experienced seeing others navigate loss. Perhaps you dread loss. Though we are inadequate before grief, all of us must face it.

When you do, I hope you will consider entering that room with a pen in your hand.

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Reflection on *Im Abendrot*

Robert Weaver

Somerset GP; music director of the Bristol Symphony Orchestra

As a GP and a medical examiner, I continue to draw from my experiences in music and medicine. My work involves supporting the recently bereaved, and through music, I find a language to express the inexpressible moments.

Summary

I wrote this reflection as a medical student in Bristol in 2014, during my foundation training in whole-person care. At the time, I was also conducting the university chamber orchestra in Strauss's *Four Last Songs*. The final piece, *At Sunset*, seemed to encapsulate the complex, layered emotions around mortality. Music and medicine have always been my two main passions; each has enriched my understanding of the other.

At sunset (Im Abendrot)

Through trouble and joy we have walked hand in hand;
we can now rest from our wanderings
now, above the peaceful countryside.
The valleys fall away around us,
the sky is already darkening,
Only a pair of larks still rise
dreamily into the scented air.
Come here, and let them fly
For soon it will be time to sleep
and we must not lose our way
in this solitude.
O broad, contented peace!
So deep in the sunset glow,
How exhausted are we with our wanderings –
Can this perhaps be death?

Joseph von Eichendorff

So many times on my attachment in care of the elderly I have been struck by the varied ways that elderly people face death. They are much closer to it than many of us caring for them, and some handle it peacefully, trying to stay positive perhaps for those around them, whereas some struggle with it. I was particularly moved by an elderly patient, Mrs R, who had terminal breast cancer. Her husband was at her bedside in the hospital for every possible hour of visiting times, if not more. They didn't always talk, instead they were comforted by each other's company. They said to me that they had experienced a long and happy marriage and had no regrets about life. They had been together through the ups and downs, the challenges. Mrs R felt peaceful about her death, not wanting to fight it: 'If it's time for me to go now, it's time.'

I chose a work by the composer Richard Strauss (1864–1949) who wrote his very last ever song in May 1948 to words by the poet Joseph von Eichendorff (1788–1857). It's called Im Abendrot (At Sunset). It's about an old couple coming to the end of their life, reflecting on it as they come to terms with approaching death. In the music, after a long orchestral introduction we are introduced to the companions, gazing 'hand in hand' upon the setting sun. The old couple 'so weary of wandering', reflect as they come to the end of their life. Through the music, Strauss invites us to imagine what that final moment must be like. The couple pose this question, 'can this perhaps be death?' At this point Strauss quotes a motif from his tone poem, *Tod und Verklärung* (Death and Transfiguration), written some 60 years earlier. This is a poignant moment, where we find Strauss looking back to a point in his life when at 26, at the start of his career, he had reflected on death in an abstract sense. This strikes a chord for me – as so many times when I've seen elderly patients close to death, I've tried to imagine what it feels like to be at the other end of life. This is how Strauss imagined when he wrote the piece in his 20s, but now he is actually there – he has the opportunity to reflect on what it is really like.

The final bars are prolonged with a second inversion chord in the strings – a delayed suspension of the conventional ending, almost as if Strauss is struggling to let go. At this point we hear distant echoes of a lark's song as the harmonies finally resolve to the major. On his deathbed in 1949, Strauss revealed to his daughter-in-law: 'Dying is just the way I composed it in *Tod und Verklärung.*'

Strauss never lived to hear these songs performed. The world premiere was on 22 May 1950 in the Royal Albert Hall, London, conducted by Furtwängler and sung by Kirsten Flagstad.

Possession

A poem about grieving

They say
it's the quiet times
the mornings when
there is mist
the still sea
on the stones
the silence
when
the words are done
the box
in the earth.
These are not
your remains
not your grave
the barely
spoken stone
just a gong
a clanging cymbal.
They cannot know
you did not die
and lie
breathing
on the ground
in summer's wheat
how you fill
the room
with your undressing.
how you hold
the part of me
that loves.

Reverend, Peter Owen Jones
Author and parish priest, Sussex

Facilitating healthy deaths at scale

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Enhancing independence in people with complex neurological presentations: a person-centred approach to occupational therapy

Paul Thomas

Hon GP teaching fellow, Dept Primary Care & Public Health, Imperial College; visiting professor, College of Nursing, Midwifery & Healthcare, University of West London; COIN co-chair (Community-Oriented Integration Network UK)

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Summary

A healthy death honours the individual while empowering the community. But in Western societies dying is overly medicalised. Key principles for improving end-of-life care include addressing social determinants, recognising death as a relational and spiritual process, fostering care networks, encouraging open conversations about death and its value, and helping people manage complex issues. With practical support and proactive planning healthy deaths and the skills for achieving them can become a natural supported part of society. We will submit this paper to inform the 2024 UK government strategy for neighbourhood healthcare.

In her article of April 2021 Clare Fuller (Fuller, 2021) said that despite having been a palliative care practitioner for nearly 30 years, she discovered that there was a lot she did not know about good end-of-life care when she became a carer for Jim, a family member. She reminds us that carers need guidance and support to do their job well. She wrote:

> *'I could never have imagined how difficult the position of caregiver at end-of-life would be and… the stress on us as a family cannot be overstated.*
>
> *Without my professional knowledge, I am unsure if we would have been able to support Jim to have a comfortable death at home.*
>
> *Yet… It is impossible to overstate the privilege and value of being able to deliver care*
>
> *And…stepping into the role of a relative and caregiver in end-of-life care…. led me to question previously held assumptions and identify potential barriers to the provision of end-of-life care that are uncomfortable to consider but important to raise.'*

I have had a similar experience and arrived at similar conclusions.

I stepped into the role of relative and caregiver in December 2015 when my wife, Eunice, developed myeloma, from which she was in remission two years later, in Spring 2018. Six months later, in October 2018, she developed Creutzfeldt-Jakob Disease from which she died in April 2020, a week after the UK national lockdown started. Eunice and I knew that end-of-life needs planning because we were both GPs. This helped us to feel confident to plan together for what I call a 'healthy death' – one that develops a positive story of that time that is shared by those involved. We aimed for open discussions and broad participation. Our plan was written on the fridge door: '*Parties, Music, Fresh Air, Fun*'.

What is a healthy death?

A healthy death, like a healthy life, requires us to respond creatively to whatever happens and from this develop a positive, meaningful story – a story to be proud of. Its theoretical roots can be found in MacIntyre's idea of *narrative unit* (MacIntyre, 1985) (health means being able to tell our life stories as integrated wholes), Antonovski's idea of salutogenesis (Antonovski, 1987) (health means retaining a sense of coherence despite severe stress) and the 1978 Alma Ata Declaration (health is physical, mental and social wellbeing, and not merely the absence of disease) (WHO, 1978).

I interpret these theories to conclude that each of us is the lead actor in the 'feature film' that is my own life and the support actor in the 'films' of many others. Health is being able to make good 'films'. Diseases can affect these films – in both bad and good ways.

Healthy deaths means that our life stories end well, and the life stories of those connected to us also move forward well – my 'family'; my 'friends'; my 'community'. It is a community development initiative. District and palliative care nurses are well placed to help carers with this because they are there at important moments. As I was soon to discover.

Obstacles to a healthy death

The 2022 Lancet Commission, *The value of death: bringing death back into life* (Sallnow *et al*, 2022) argues that since 1950 dying in the UK has become overly medicalised and needs to be rebalanced.

> *'At the core of this rebalancing must be relationships and partnerships between people who are dying, families, communities, health and social care systems, and wider civic society.'*

The Commission describes five principles of its vision for death and dying:

1 The social determinants of death, dying, and grieving are tackled.
2 Dying is understood to be a relational and spiritual process rather than simply a physiological event.
3 Networks of care lead support for people dying, caring, and grieving.
4 Conversations and stories about everyday death, dying, and grief become common.
5 Death is recognised as having value.

The Commission is effectively calling for society to enable *healthy deaths* at scale. But how do you do this? And why is over-medicalisation an obstacle?

The fact that the western medical model is an obstacle to health (and healthy deaths) has long been known. In 1992, Macdonald explained that this is because it is an 'engineering model' (p30). We think of the body as a 'complex machine… understandable through a micro-scope (p31)… 'What is important is to realise the limits of (this way of thinking)…(and use it) 'as part of a health-care approach, not the entire approach' (p37).

Thinking of the body as a machine is valuable. It sees faulty components'‘facts', 'dis-eases' – to be separately defined and instrumentally fixed. But if we want to follow The Lancet Commission call to re-balance dying so that 'at its core are relationships and partnerships…' we need a science of connectivity. Egon Guba described three different kinds of truth (paradigms) termed (post)-positivism, critical theory and constructivism (Guba, 1990) that together can do this. They distinguish singular facts, complicated connections and complex emergence. With Yvonna Lincoln, Guba described 4th generation evaluation (Guba & Lincoln, 1989) that integrates these three paradigms through cycles of collaborative inquiry and coordinated change in which facts are considered to be snapshots of stories-in-evolution.

Others have arrived at the same conclusion as Guba and Lincoln – the world is more dynamic, complex and changing than the 'western medical model' can see. Faith traditions, educationalists, 'holistic' and 'alternative' practitioners, and practitioners of experience use different languages to describe the complexity and 'humanity' they encounter. Even within the 'western medical model' many acceptable languages and models already exist – for example participatory action research and organisational learning. In healthcare, nurses are often ahead of others in using such approaches. District nurses and palliative care nurses could lead the application of such approaches at end-of-life.

To develop healthy deaths at scale, practitioners, researchers and everyday people need to understand theories about connectivity (Thomas, 2006). Without them we lack language to describe 'soft' humanity and default to 'hard' engineering language that gets called 'over-medicalisation'.

Caring for someone who is dying is difficult, but full of potential to do good

My experience as a GP, a service developer (Thomas, 2006a), a researcher (Thomas, 2018), and now as a carer, all lead me to agree with this statement by The Lancet Commission:

> *'Conversations about death and dying can be difficult. Doctors, patients, or family members may find it easier to avoid them altogether… leading to inappropriate treatment.'*

Eunice and I planned an open, positive approach to her dying. About 100 people enthusiastically embraced this. About six didn't – they avoided open conversations and invented accusations that caused unnecessary harm. One person accused me of killing her. Another made safeguarding complaints (because I took her out of bed to join family events). Another took my son aside to say that 'everything I was doing was wrong'. Their accusations were easily refuted, but the fact that they happened illustrates how difficult end-of-life can be. The district nurses were particularly understanding and supportive.

Painful difficulties are common at end-of-life. Carers know this well, as Fuller explains:

> *'One night, lying exhausted in bed…. I tweeted "I could never have imagined how difficult this would be". The response was instant, with people sharing stories….'*
> (Fuller, 2021)

End-of-life is full of potential to do good, especially when difficulties are positively explored. Difficulties are inevitable – the whole range of bio-psycho-social-spiritual difficulties. Many people have never come across anything so deeply affecting before and naturally miss opportunities to do good and minimise harm. Some simply project their anxieties and prejudices, and default to inappropriate treatments and thoughtless use of protocols. Some feel compelled to re-ignite longstanding complaints. Some simply want someone to blame. Some are just exhausted. Whatever the explanation, they need guidance and support to positively explore their concerns. And it could leave them with skills of reflection and relationship-building that could serve them well for the rest of their lives.

Many in a network of friends want to help, but don't know how to, or fear it would be unwelcome. Examples of success (Thomas, 2009) and opportunities to engage can help.

Carers often see all of this. Many also have skills to make good arise out of such difficulties, but lack encouragement and opportunities to use them. Mentorship, support groups, training courses and recognition of how difficult and skilful their job is can greatly help.

Acknowledging these difficulties early in an end-of-life drama and providing guidance and support could help to shape a healthy death. At scale it could develop a network of local people with skills to manage a range of issues as a 'compassionate community'.

This positive approach can also save hospital costs and prevent illness of carers – a common result of the stress they are under. In my instance, input from dozens of individuals, two schools, a general practice and two churches helped to build a caring community around our home, avoiding need for costly hospital care. A memorial for Eunice in September 2021 brought new people into this community, helping us to make a film of her life (Eunice, online).

An opportunity for change

Now might be a good time to plan for healthy deaths, at scale. The Covid pandemic and Ukraine war have made people everywhere aware how important it is to face life-threatening challenges with dignity, and strategically plan to integrate diverse actions.

In the UK, the 2019 NHS Long Term Plan [now being updated] provides a great opportunity. The plan describes a vision to integrate diverse efforts:

> *'We will give people more control over their own health and the care they receive, encourage more collaboration between GPs, their teams and community services, as "primary care networks", to increase the services they can provide jointly, and increase the focus on NHS organisations working with their local partners, as "Integrated Care Systems", to plan and deliver services which meet the needs of their communities.'*

Primary Care Networks (PCNs) are an important part of the plan in England – geographic areas of about 50,000 population where different organisations align their ways of working to enhance their effects on health. PCNs could develop strategies for healthy deaths by promoting community-oriented integrated practice (Thomas *et al*, in press) – a way to practice that develops multidisciplinary teams skilled at whole system operating. NICE Guidance (NICE, 2019) already encourages health and social care practitioners to practice in this way, so many carers already see district nurses as sources of wisdom for healthy deaths. I certainly did.

Routinely-gathered data aligned to PCN areas could help to evaluate integrated practice. This could inform shared care for other complex issues, like diabetes. It could help everyone to enhance health as well as treat diseases, in populations as well as individuals.

Things that can help to shape a healthy death

A healthy death means that I finish my life story well, and the life stories of those I have relationships with also develop well. People warm to this idea but often don't know what to do, or feel they lack permission, or fear being overwhelmed. Simply saying publicly how difficult and skilled caring is, especially as one approaches end-of-life, with guidance to consider a range of options, could help. Ways to help people to collaborate and think through their own plans (rather than simply adopt protocols or defer to others) could also help. The core caring team, the extended community and the dying individual need different kinds of guidance and support because they have different roles and needs.

Fuller describes practical things that help an individual who is dying (Fuller, 2021):

- **Proactive planning** – advance care planning, treatment escalation plans, DNR, CPR decision support…
- **Community care** – involvement of primary care, community care, palliative care, specialist care, voluntary care…
- **Clear explanations** – how the system works, what to do when things happen in the middle of the night, how to detect deterioration…

Other things help to build a community. Here are some of the things we did for my Eunice:

- **involve children** – our two teenage sons and their friends helped with practical tasks
- **social events** – a sequence of parties – dancing, singing…

- **rota of visitors** – sitting, holding her hand, playing music, reading stories
- **plan the funeral/memorial** – we even rehearsed her funeral music with her
- **whatsapp group** – this developed a life of its own – about 100 people participated
- **pm of her life** – many in the extended network contributed to a film of her life (Eunice, online).

Policies within geographic areas (PCNs in the UK) that could encourage healthy deaths

- Provide structured guidance and responsive support for healthy deaths – for those who are dying, their care teams and networks, involving relevant organisations when appropriate, including universities and hospices, schools and faith communities, funeral directors, musicians and voluntary groups.
- Train professionals and others to ask about and respect the beliefs and traditions of ill people and their carers – including the rituals they wish to embody, people they wish to engage and relationships they wish to strengthen.
- Integrate primary, community and social services to support healthy deaths – linked to the same geographic areas. When appropriate, include organisations such as schools, pharmacies and faith communities.
- Train local, multidisciplinary facilitation teams to encourage self-care, shared-care and networks of carers to maintain positive household routines and build compassionate communities, even as care needs shift over time. They can encourage participation of local people such as neighbours (eg put out the rubbish) and volunteers (eg shopping). The teams could provide infrastructure to support local participatory democracy, valuable for many issues other than healthy deaths.
- Routinely teach fourth generation evaluation – so researchers, practitioners, citizens and educationalists know how to use approaches to inquiry that illuminate inter-connected and co-evolving stories as well as singular facts.

District and palliative care nurses could lead this approach, supported by primary care, community care, social care, public health and politicians. In my experience some already are, but without acknowledgement and training. Strategic development of this kind of leadership will make it easier for others – schools, faith groups, businesses, universities and others – to contribute, and make collaboration for health an expected part of end-of-life. This could help develop an expectation that 21st century citizens are skilled at self-care, shared-care and collaborating to develop compassionate communities.

We can think of a healthy death as a positive story, co-created from many contributions. PCNs could expect health-related disciplines – primary, community and palliative care services, public health, social work, medical specialists – to develop this approach, within a society-wide collaboration to enhance health and avoid over-medicalisation.

In time this could embed the skills at every stage of life, to make healthy deaths and compassionate communities happen at scale. My own experience shows how powerful the approach can be, with long-lasting effects. I see the effects two years after Eunice's death as people stop me in the street to give me a hug and tell me how much the experience affected them. Her story (our story) matters to them because they are part of it.

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Grief and bereavement

Reflections from the Grenfell tower fire and the Covid-19 pandemic

Paquita de Zulueta

Retired GP; Human Values in Healthcare Forum chair

From 1984 I was an inner-city, London-based GP (retired 2021) with a special interest in mental health, migrant health, clinical ethics and professional education and development. After the Grenfell fire in 2017 I was GP lead for the Grenfell NHS outreach team for a few months. I am a senior honorary lecturer at Imperial College and have been teaching and writing about clinical ethics since 1993. Since 2008 I have worked as a part-time CBT, compassion focused and EMDR therapist. I am also a qualified coach and mentor. During the Covid-19 pandemic I was working on the 'backline' supporting the clinicians and medical students by facilitating Schwartz Rounds and by offering mentoring and coaching. I am chair of the charity Human Values in Healthcare Forum (HVHF) which aims, in collaboration with others, to rehumanise healthcare and prevent dehumanisation.

Summary

Grief is not an illness and is the normal yet painful process inherent to the human condition. Stage theories do not capture the complexity, diversity and unique qualities of the grieving experience. Disenfranchised grief is a salient feature of the Covid-19 pandemic and the Grenfell fire. Moral repair and restorative justice are important, yet often neglected. Most people can regain strength and meaning by connecting with supportive others and tapping into their inner and outer resources. Grieving is an individual and a collective process that brings us together and reminds us of our common humanity and vulnerability.

The nature of grief

Grief is a universal human response to loss. We form attachments, we love, and when these bonds are broken, we grieve. We all experience grief during our lives. Every day as a GP I bore witness to stories of loss – job loss, loss of physical or cognitive function, of cherished relationships, of hopes and aspirations, as well as more profound losses – deaths of family members, of miscarriages and stillbirths, of suicide, of relatives 'lost' to dementia or calamitous brain injuries. Much of my work has been with the involuntarily displaced who have sought safety and a new life in this country. They have lost their homes, their families, their land, even their sense of identity.

Understanding the manifestations of grief helps us to support the bereaved and make sense of one's own experience when we are bereaved. Bereavement comes from the old English word *bereafian* 'to deprive of, take away by violence, seize, rob, to be torn apart'. The bereaved often describe their loss as an 'amputation', of 'losing half of oneself', of being an 'empty husk'. Although every person has their unique journey through grief and mourning, there are some common threads and experiences.

> *'The pain of grief is just as much a part of life as the joy of love; it is perhaps the price we pay for love, the cost of commitment.'*
> (Parkes & Prigerson, 2010)

Francis Weller (2015), a passionate advocate for 'soul psychology' and an 'apprenticeship with sorrow', believes we live in a grief-phobic and death-denying society. Yet grief enables us to reconnect with our deeper selves, our souls, and with others. It invokes us to live rich and authentic lives.

> *'The lack of courtesy and compassion surrounding grief is astonishing, reflecting an underlying fear and mistrust of this basic human experience. We need to restore the healing ground of grief.'*
> (Weller, 2015)

Grief is embodied, as Nick Cave describes vividly: 'We tend to see grief as an emotional state, but it is also an atrocious assault upon the body. So much so that it can feel terminal' (Cave & O'Hagan, 2022).

Freud (1915) in his seminal essay *Mourning and Melancholia* is careful to differentiate between the two: 'Although grief involves deep departures from the normal attitude to life, it never occurs to one to regard it as a pathological condition and to refer it to medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as being useless or even harmful.'

Kay Redfield Jamison, professor of psychiatry and someone with personal experience of depression, eloquently articulates in her memoir the distinction between grief and depression:

> *'Grief conspires to ensure that in time it will wear out. Unlike depression it acts to preserve the self. Depression is malignant, indiscriminately destructive. Grief may bear resemblance to depression but it is a distant kinship. ..In grief, death occasions the pain. In depression, death is the solution to the pain.'*
> (Jamison, 2011)

For a minority there are situations when the process of mourning can become blocked and cause immense suffering, preventing persons from flourishing and engaging with the outer world (called prolongued grief disorder). This is more likely if the death was sudden, violent or there were unresolved issues in the relationship. This minority can benefit from compassionate and skilled counselling or therapy (Shear, 2012).

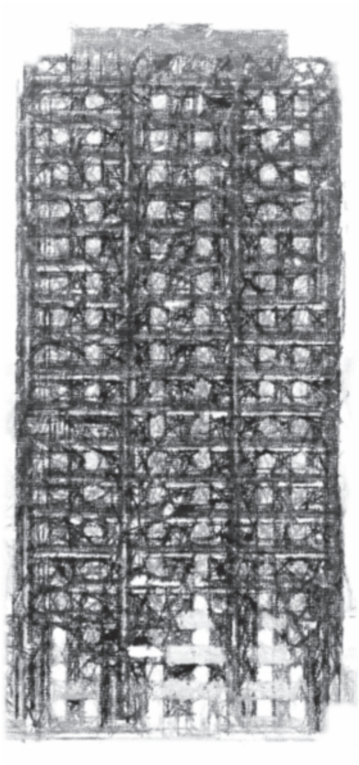
Grief comes in waves as Joan Didion describes in her memoir following the death of her husband: 'Grief comes in waves, paroxysms, sudden apprehension that weaken the knees and blind the eyes and obliterate the dailiness of life. Virtually everyone who has ever experienced grief mentions this phenomenon of "waves".' (Didion, 2005).

CS Lewis (1966) describes this disorientation and difficulty in making sense of what is happening: 'No one told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing. At other times it feels like being mildly drunk, or concussed. There is a sort of invisible blanket between the world and me. I find it hard to take in what anyone says.'

The importance of memorials, rituals and healing practices

Grief is both a private and a public process. Collective grief and social recognition are important for healing from grief even though periods of solitude may also be needed.

Rituals that help us to find meaning are important for grieving and are activities performed with intention and significance (Kleinman, 2012; Schillace, 2015; Weller, 2015). As Schillace says (2015, p8) 'We have not moved towards the acceptance of death, but rather the erasure of it.' This disavowal of death makes it more difficult for us to grieve properly.



Memorialisation ensures the bereaved and others affected believe that their loved ones have been honoured, their pain has been recognised and there is a place for them to mourn. Other forms of solace and healing include being in nature, finding new activities, spiritual practices, dreamwork, writing journals and memoirs as well as creating memorials and legacies.

Disenfranchised grief and moral injury

Disenfranchised grief was first described by Doka (1989) as recognising 'hidden sorrow'. He offered four typologies:

1 The relationship is not recognised
2 The loss is not acknowledged
3 The griever is excluded from the mourning ritual
4 The cause of death is stigmatised.

Later he added:

5 The way that the griever processes their grief, including their religious and cultural mourning – rituals are discouraged, stigmatised or censured (Doka, 2002).

A 6th has been added – non-death losses specifically related to discrimination, marginalisation and oppression (Turner & Stauffer, 2023).

Attig (2004) describes disenfranchised grief as a serious social, empathic and political failure (in the wider sense of power relations), including abuse of power and neglect.

Moral injury refers to a disorienting and disturbing experience that follows violation of deeply held moral commitments and expectations, whether by perpetrating, failing to prevent, or bearing witness to acts (Litz *et al*, 2009; Cahill *et al*, 2023).

There is no 'closure': Forcing a person that it is 'time to move on' can be hurtful and denigrating to the mourner, trivialising the depth of their suffering and the preciousness of their relationship leading to disenfranchisement and moral injury. '*Instead of searching for closure, we search for meaning and hope*.' (Boss, 2022).

Grenfell memorial

Moral repair

Moral repair is deeply needed to help heal the wounds of those who are aggrieved from being disenfranchised and/or unjustly harmed. 'Moral repair is restoring or creating trust and hope in a shared sense of value and responsibility…It is served by acknowledging and addressing wrong, harm, affront, or threat to victims and communities.' (Walker, 2006).

The Covid-19 pandemic – combined moral injury and disenfranchised grief

The pandemic restrictions created many examples of disenfranchised grief (Albuquerque *et al*, 2021). Probably the most painful was not being allowed to be with the dying person, or being allowed but in grossly abnormal circumstances – gloved, masked, and/or behind a plastic curtain. The use of iPads and phones allowed remote connection but this could also cause more distress. Death rites and rituals of mourning were pared down or suppressed. The majority of bereaved felt that the death of their loved one didn't count and was treated 'just as a statistic' (Ryder, 2020). Community engagement, religious rituals and cultural practices were severely curtailed, depriving people of the solace and support they would normally receive. There was little public mourning and frequent public references to 'going back to normal' and 'moving on'. The bereaved were condemned to painful solitude when they acutely needed to be with their family and friends. There was also loss of touch, essential for our wellbeing particularly at times of stress (Field, 2014; de Zulueta, 2020).

Healthcare workers are still suffering from the moral loss and injury they experienced during the pandemic when they were unable to provide the care they felt their patients needed and deserved (Shale, 2020; Delaney & McDougall, 2023; Mahase, 2024).

Shale's 'moral-philosophical version' of moral injury also encompasses citizens' experiences of cruelty and injustice and the inability to fulfil their cherished moral commitments associated with birth, love and death. This was worsened by citizens witnessing their political leaders contemptuously flout the privations and restrictions that they had imposed on the public.

> Collective grief and social recognition are important for healing from grief

Health professionals also suffered and are suffering from disenfranchised grief (Albuquerque *et al*, 2021; Selman, 2021). Labelling them as 'heroes', as well as their own internalised professional norms, prevented them from giving voice to and processing their grief. Moral injury was prevalent before the pandemic but was exacerbated by it. There is a need for a collective response for injured healthcare workers and for ways to be found for changing the conditions which gave rise to moral injury. (Delgado *et al*, 2021; Cahill *et al*, 2022).

The Grenfell fire

The survivors, bereaved and many others involved in the fire also suffered from disenfranchised grief and moral

Grenfell procession

injury. The damning conclusion from the Grenfell Tower Inquiry (2024) – the most lethal fire since the Blitz' was that the 72 deaths from this terrible fire were fully avoidable. It came about from a mixture of greed, dishonesty, loose regulations and an utterly callous disregard for human life. It has been described as institutional violence and even dubbed as 'social murder' (Cooper & Whyte, 2018). The local council's initial response after the fire was woefully deficient. The community response, in contrast, was remarkable for its generosity, energy and strength. More than seven years later no individual or corporation has been held criminally liable. The concerns of residents regarding fire risk before the fire were systematically and contemptuously ignored. They suffered from epistemic injustice (Fricker, 2007). Their testimonies were dismissed and their concerns disputed or ridiculed. As can be imagined the grief and anger arising from this disaster still runs deep and wide.

Following the devastating Grenfell fire, I acted as clinical volunteer at the sports centre close to the tower. Later, in my role as GP lead of the NHS outreach team for Grenfell survivors and the bereaved, I encountered profound grief and outrage, but also astonishing humanity, solidarity and resilience. I witnessed the importance of culture, of individual and collective life stories, and of social factors in shaping how people expressed their grief and what helped and hindered them in their healing. Some stories were almost unbearable – how can you console a mother who was holding her child's hand as they groped their way down the stairs through the black toxic smoke, and suddenly found that he was not with her anymore and she cannot be with him ever again? How can you explain to a five-year-old child that she has lost her mother, father and her two older siblings? There were many other heartbreaking tragedies.

Much has been written about the fire in books (for example Apps, 2022), articles and poems. Several plays have re-enacted the course of events,, giving voice to the survivors. Films, songs, videos and documentaries have been made. I will confine my reflections to a few key aspects regarding grief response arising from the fire and insights I gained from the work I was involved in.

The importance of culture and faith

Culture affects how people perceive health and illness, how they experience loss and death, where they seek help and what treatments they prefer. Recovery for many is interconnected with religious belief and/or notions of justice. This can be challenging for largely secular evidence-based treatments and support frameworks. This was particularly relevant to the residents of Grenfell tower as many were immigrants and refugees, some from war-torn countries. Many were Muslim and faith was of key importance to them. This was insufficiently acknowledged until later.

Imposing Western psychological concepts and remedies can be viewed as a lack of cultural humility and even a form of imperialism (Watters, 2010). Many found focusing on the mind (brain) rather than 'the heart' alienating and unhelpful (Howarth, 2020).

> *'We are people of the heart because the heart is everything. The Quran mentions that the creation of the heart was first. Mind was created later. It is the heart that needs healing.'*

> *'In Africa we talk in stories. It is how it is done in our culture. Stories can be very powerful to educate people, inform them and also engage in their health. It is very different to what happens in the West.'*

At a meeting with a group of survivors I asked them what helped them to keep going, to remain strong. Their prompt reply was first, their bonds with each other, second their faith and third helping others.

The importance of moral repair and justice

Indeed, what was often found to be more helpful than standard therapy was sharing stories, faith-based counselling, helping and supporting each other, and physical therapies such as massage. Also of solace were religious ceremonies, community events, the monthly silent walks and creating memorials. The mental health taskforce, the politicians and much of the public tended to ignore the issues of moral repair and restorative justice, yet it was, and still is, of great importance to the Grenfell survivors and bereaved. Many of them are still seeking justice, accountability as well as systemic change (and removal of inflammable cladding from all buildings) such that this terrible event can never happen again. This quest gives them meaning and purpose, and hence aids them in their healing journey.

Impact on healthcare staff

Imperial College NHS Trust was central to the response and many survivors were admitted to hospital. Several died there. This was deeply distressing for the healthcare staff caring for them and responding to distraught relatives. On the anniversary of the fire, a Schwartz Round was held at St Mary's Hospital Paddington. I was one of the facilitators. 147 members of staff attended. There was standing room only. Grief was palpable. Many said that they had not talked about it for the whole year. Everyone expressed gratitude for the opportunity to share their experiences, their reflections and deep emotions.

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Voluntarily stopping eating and drinking

An end of life doula's personal perspective

Alizoun Dickinson
End-of-life doula
I am an end-of-life doula and write from a first-hand perspective, having accompanied five people who chose to stop eating and drinking as a way to control where, how and when they would die. This is known as voluntarily stopping eating and drinking (VSED) and is a legal choice. I am not an authority or an expert on VSED but I am sharing what I have learnt and my own experiences with others who may be interested. I can be contacted by email alizoun@alid.co.uk.

Summary

Where a mentally capable adult chooses to hasten their death, stopping eating and drinking (VSED) is a legal choice. It requires a detailed advance decision to refuse treatment, skilful support and ideally good multidisciplinary support. Ethical uncertainties continue to surround VSED, national guidance on VSED would ensure appropriate support from health-care teams. A typically successful VSED leads to a peaceful death within 7 to 17 days. Despite its emotional challenges families say they have found the experience rewarding.

Introduction

During my early 40s into my 50s both my parents and two brothers died after long illnesses. I was able to be alongside them either at home, in a hospital or hospice. I played a part in ensuring that their wishes and preferences were respected and that their dying was as comfortable and as dignified as possible. Having witnessed both the very best as well as the not so good faces of our health and social care systems, I came to understand how I might care for dying people and advocate to mitigate some of the pain and the suffering, fear and loneliness.

A few years later I discovered end-of-life doulas, enrolled on a reputable training course and worked as a volunteer in a hospice. It took me 18 months to qualify and since then – for 10 years – I have been an end-of-life doula.

An end-of-life doula provides practical and emotional (plus spiritual if important) support to a person and to those important to them. Our role is not medical; rather from the moment we are called upon we focus on preserving wellbeing, a sense of identity and self-worth. The person, and those important to them, are at the very centre of all we do. Our consistent and compassionate presence, our knowledge, experience and understanding serves to support those we are alongside in exercising choice about where and how they are cared for. We aim to facilitate an end-of-life that it is as peaceful and dignified as it can be.

In 2018, seeing the need for a community of practice and a public facing body for end-of-life doulas, I co-founded End of Life Doula UK https://eol-doula.uk/ and was a director until 2023. I also facilitate workshops to empower people in their communities to support each other with death and dying. I run information sessions on planning for end-of-life and I facilitate death cafes (https://deathcafe.com) and grief support groups.

Early experiences

The first time I was asked to accompany a person to VSED I was anxious I had so little experience. The person had sought support unsuccessfully, both from professionals and others involved in end-of-life care. For me this was unchartered territory, so I set about reading everything I could on the subject, mainly from the USA, written by health professionals and those with lived experience of accompanying a person to VSED. I identified a mentor who was an end-of-life doula and had been a palliative care nurse. I spoke in confidence to two GPs and to contacts in palliative care who wanted the conversations to be 'off the record'. In the absence of clear guidance in the UK I sought to be as informed as possible. I was transparent with the person I was supporting that this was my first time. Together we spent hours and days discussing why they wanted to die by VSED; we went through scenario and contingency plans; we were fortunate in that we had the support of their GP from the outset. The individual was determined that they wanted to die this way and never wavered from their choice. I was with them until the end and then, as they had asked me to, I sat with them for 24 hours before their body was taken by their undertaker. I communicated with their adult children who were entirely supportive of the decision and the process we had agreed. Afterwards I had mixed emotions – relief that there had been no dramas, satisfaction that their choice had been honoured, grief too as we had developed a deep and mutually trusting relationship. I was physically and emotionally drained and needed three days of solitude plus a debrief with my mentor. At the funeral many of the people knew how the person had died We came together to acknowledge all that they had been, and to witness the end of a completed life.

My role as an end-of-life doula

People need enough information and choice to feel in control. It's how we conduct our lives, exhibit our personhood, and maintain our self-esteem and wellbeing.

In all cases the people I have supported had decided that their life was completed. With full mental capacity, they believed they had done everything they wanted to do and were ready to prepare for the end of their life. For my part, I spend many hours exploring with them their reasons for this choice, their understanding of what VSED entails, and what this will mean for the people close to them. I help shape their written plan for end of life – their advance decision to refuse treatment, advance statement, funeral wishes, and putting their affairs in order.

What VSED is and is not

Voluntarily stopping eating and drinking (VSED) is when an adult with mental capacity, in the absence of control or coercion, chooses to hasten their death by stopping eating and drinking completely. VSED is different from the natural loss of appetite that occurs at the end of life, because the individual has made an active choice to do without food and drink with the intention of controlling the manner and timing of their death. Dying by VSED typically takes between 10 to 14 days but the process will be unique to each person, depending on their physical condition. For anyone not living with an advanced or progressive condition, or who decides to temporarily eat or drink at any point, dying by VSED can take longer. Death is normally caused by dehydration. A successful VSED outcome is a peaceful death with minimum discomfort within a predictable period of days or weeks of fasting. Such successful VSED outcomes take considerable planning and co-ordination.

Ethical considerations and debates

Although VSED is a legal option there are those who, because they view VSED as an act of suicide, consider healthcare professionals who provide medical support as having actively assisted in the act. This is not legally the case, so it seems incongruous that those legislators and medical professionals who see VSED as a legitimate end-of-life choice nonetheless continue to oppose legalising actively assisted dying. Others argue that VSED is a passive form of hastening death more akin to stopping life-sustaining treatment, and therefore that it is quite unlike assisted dying. Surely this perspective makes VSED ethically and humanly acceptable, which is crucially important because a person dying by VSED will need professional palliative care at some point to ensure that their dying is comfortable. But regardless of the ethical debate surrounding the issue VSED, although 'an imperfect but useful last resort' is practised in the UK when suffering persists despite the best efforts of palliative care. However, there has been no research into the prevalence of VSED in the UK nor, unlike other end-of-life practices, are there any official UK guidelines for how healthcare professionals should support people who decide to hasten their death in this way.

Some experiences of VSED

In my limited experience a successful outcome is a peaceful death (at home) with the minimum amount of discomfort and distress. In the situations where I have been involved the length of time between stopping eating and drinking until death varied from 7 to 17 days.

Typically the people I have supported fall into two categories: those who feel they are suffering unacceptably, and those who want to pre-empt the last phase of the dying process and avoid potential suffering or unacceptable further deterioration.

I have been part of different scenarios. Sometimes working in a team of two doulas; other times caring for the person alongside a family member, or supporting a person who has one or more paid carers. I have deliberately avoided supporting anyone with chronic eating disorders or with underlying psychiatric problems that could distort how they perceive their situation.

The people I have supported include:

- a person who had a diagnosis of early dementia who still had sufficient decision-making capacity and had a fear of prolonged death from advanced dementia
- a person with a progressive, terminal illness who still had decision-making capacity
- a person with severely reduced independence because of frailty and chronic health problems who still had decision-making capacity.

As an end-of-life doula certain foundation stones need to be in place. No one involved should under-estimate the amount of emotional and logistical preparation VSED demands.

1. The **place** where the person dies (in my experience always in their own home) has to be suitable in terms of space and layout.
2. **There has to be medical support** which is usually from the person's GP and the healthcare community team.
3. There must be rigorous and comprehensive **mental capacity assessment**.
4. The person should have an **advance decision to refuse treatment**, which includes reference to VSED.

We have always had GP support. In one instance the person's existing GP refused to be involved but fortunately the individual found an alternative GP who understood and supported their choice. Another person with terminal diagnosis experienced opposition from their hospice at home providers. Though the issues were resolved, the hospice decided not to be involved in the person's VSED.

Compassion in Dying's report *Voluntarily Stopping Eating and Drinking: A Call for Guidance* (Compassion in Dying, online) says: 'We know from the people we support that some clinicians find it ethically difficult to support people who wish to stop eating and drinking as a way to hasten their death. We also know that some people have experienced their healthcare team being unwilling to provide adequate symptom management. Conversely, we also know some clinicians provide helpful and appropriate support to people who wish to exercise this decision.'

Witnessing the process

In my experience dying from VSED has unfolded in unique ways for each person, depending on their physical, mental and emotional circumstances as well as their medical condition/illness; perhaps also on their willingness to let go. Once VSED is initiated the drive to eat diminishes relatively quickly – usually within 24 to 48 hours. As VSED progresses the person is dehydrating and can become very thirsty.

In the first few days of the fast, some people may remain as active as before but many soon will become weak, fatigued and increasingly sleepy.

- They begin to feel light-headed and weak; movement requires assistance to prevent falls or accidents.
- Mental alertness is replaced by longer periods of sleeping. In many cases individuals eventually cannot be roused and remain in an unconscious or coma state.
- Some individuals have periods of alertness throughout the process up until death.

- The dehydration from VSED affects the kidneys and the heart, and the other organ systems in the body begin to shut down.
- Death from VSED is a natural process. As death nears:
  - breathing becomes shallower and irregular
  - moaning, restlessness or 'rattling' breathing may occur but is not believed to be an indication of pain or distress
  - the body may change temperature and there can be discoloration in the face (flushed red, or pale with bluish or yellowish tones), as well as purple or bluish mottling in the hands or feet.

Important considerations

I learn something new each time I am involved. What follows can only be a summary of a more comprehensive and descriptive journey of discovery.

- As an end-of-life doula I will have a very important relationship with the person I am supporting. I spend a lot of time getting to know them, the life they have lived, who and what is important to them as part of truly understanding and empathising with their choice to VSED – why and how they have reached their decision and their commitment to their end goal. Absolute trust is fundamental to the relationship.
- Supporting the person to understand what the VSED process will entail. That at any time the person can change their mind but at some point, towards the end, this may not be an option.
- Medical support is key as is a watertight mental capacity assessment.
- A plan for end-of-life including an advance decision to refuse treatment is necessary.
- All those involved in the persons' care must understand the VSED process and be committed to supporting the individual to achieve their goal.

Families and relatives

Those close say that supporting the person they love to die by VSED has been fulfilling.

> *'She didn't want to live the life she was living anymore. She hated the fact that her health and dependency was only going to get worse. I had to accept that. I was frightened about how her dying may be but when it came to it – it all seemed natural and undramatic.'*

> *'At one point my father was saying how thirsty he was and I was desperate to encourage him to drink but he was refusing fluid. I spooned ice slivers into his mouth– his smile of total pleasure when I was doing this made me feel that I was honouring his wishes and was loved and appreciated for that.'*

> *'It was exhausting and an emotional rollercoaster but I have zero regrets. I did it because I loved her. I wish more people knew about it and how a dignified and gentle death can be achieved.'*

Bringing VSED into the light

To quote Compassion in Dying from their website (https://compassionindying.org.uk)

> *'The lack of guidance on VSED leads to significant inconsistencies in how it is managed by clinicians. It also gives people the impression that VSED is a legal and ethical grey area. In reality, the law is clear but a lack of guidance undermines good clinical practice. We believe that high-quality guidance and information would contribute to a culture where people can have honest conversations with their healthcare team about what is right for them. It would help to ensure that, for the people who do make a decision to stop eating and drinking as a means to hasten their death, the decision is an informed one. Furthermore, guidance would help to ensure people consistently receive appropriate support and symptom management from a healthcare team that feels confident to provide this.'*

As an end-of-life doula I wholeheartedly support this call to bring VSED out of the closet, and for there to be national guidance. Until that time I will continue to support people who wish to find out more about VSED and who choose it. I will always operate within the existing legal framework, safeguarding those I am supporting and acting responsibly and with compassion. At all times their choices, wishes and preferences will be at the centre of all I do as an end-of-life doula. Personally, I take comfort from the fact that this choice will one day be available to me. I thank, from the bottom of my heart, the people I have had the privilege of accompanying on their VSED journey .

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Climate grief, doctors, ecological distress and our disconnect from nature

Prem Jeyapaul

Consultant psychiatrist; University Hospitals Dorset NHS Foundation Trust green network chair

I am a consultant psychiatrist with 14 years experience working in the NHS. I have extensive experience in assessing and treating both functional and organic conditions. I am also a psychotherapy supervisor. Over the years I have been involved in academic pursuits and teaching, recently with an emphasis on sustainability and research in health and nutrition. I have been engaged in pursuing functional and integrative medicine within psychiatry including looking at ways in which we can facilitate autonomy in patients and engage them in sustainable health and environmental issues, and how services and practitioners can be aligned to achieve this. This is reflected in my interest in the green agenda, digital health and more progressive ways of practising including my affiliation and membership to the BHMA.

David Peters

Editor-in-chief, JHH

Since retiring from clinics I can put more energy into training and coaching. My main concerns are with nature connectedness and practitioners' wellbeing. The two come together in the BHMA woodland and moorland retreats we have been hosting for NHS staff. I feel medicine's troubles are inseparable from our culture's dwindling bond with all that is 'natural'.

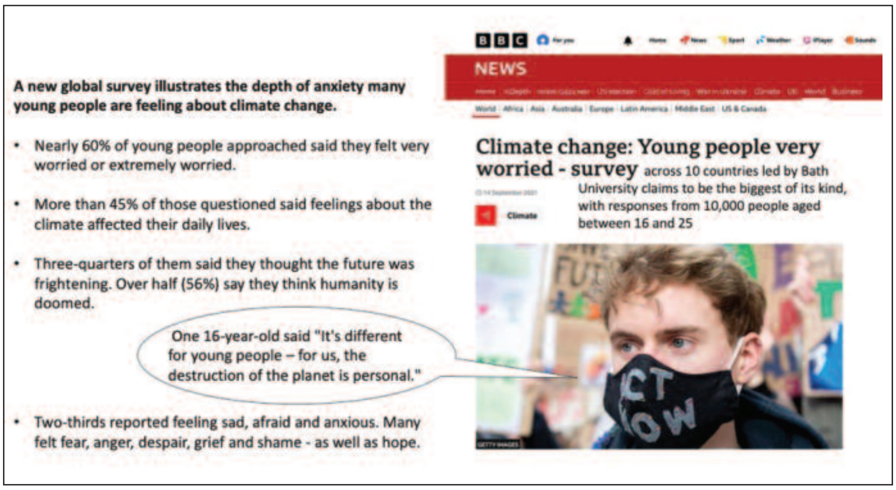
Summary

Climate anxiety may be a healthy response to the climate crisis. However, the pressures on overstretched health services make progressive assessments harder to achieve, and nature-based interventions difficult to incorporate. The persistence of medicine's mind-body split, its focus on biological causes and reluctance to engage with emotional aspects of illness, inadvertently undermine individual agency and hinder the social/political action the climate crisis demands.

Introduction

Humankind co-evolved in and alongside the other-than-human world, and so we are neurobiologically hardwired for nature connection. This subliminal sense of belonging has been called biophilia. But in the extractive economies of industrial consumer societies this connection's unravelling can lead to low mood and worry. While it may also motivate activism, more serious climate distress can manifest as depression and anxiety. Humans are a part of nature not apart from it, and climate grief seems a reasonable response to the sixth mass extinction. As such, these feelings of bereavement ought not to be pathologised; in fact climate grief seems a healthy reaction to the enormity of the Anthropocean. Modern medicine, for its part, still separates mind from body, and the medical gaze prepares clinicians to remain detached in order to focus and survive working amid suffering and stress on demanding frontlines. The unintended consequence of this detachment and objectivity may be an emotional distancing and potentially emotional numbing. However detachment and the imperative to diagnose and treat are potential obstacles when inquiring about a person's climate-related grief, anxiety or depression. In some circumstances rather than seeing their distress as a sign of mental illnesses, we must sometimes be prepared to validate climate concerns and aim to co-create appropriate forms of allegiance to support environment citizenship.

> *For children and young people, the latest evidence suggests that rates of mental illness may be growing at a faster rate than amongst adults. Between 2017 and 2022, rates of probable mental disorder increased from around 1 in 8 young people aged 7–16 to more than 1 in 6. For those aged 17–19, rates increased from 1 in 10 to 1 in 4.*
>
> BMA, 2024



A new global survey illustrates the depth of anxiety many young people are feeling about climate change.

- Nearly 60% of young people approached said they felt very worried or extremely worried.
- More than 45% of those questioned said feelings about the climate affected their daily lives.
- Three-quarters of them said they thought the future was frightening. Over half (56%) say they think humanity is doomed.

One 16-year-old said "It's different for young people – for us, the destruction of the planet is personal."

- Two-thirds reported feeling sad, afraid and anxious. Many felt fear, anger, despair, grief and shame - as well as hope.

Climate change: Young people very worried - survey across 10 countries led by Bath University claims to be the biggest of its kind, with responses from 10,000 people aged between 16 and 25

- Climate change will have a significant impact on global mental health, malnutrition, and displacement.
- The 10 warmest years on record have occurred since 2005.
- Between 2010 and 2020, people were 15 times more likely to die from extreme weather such as flooding, droughts, and storms
- With a temperature rise of another nine-tenths of a degree centigrade from now, the amount of land burned by wildfires will increase by 35% globally.
- Researchers found that climate change was a likely factor in the devastating 2019 Australian bushfires, destroying almost 10,000 homes.
- Greenpeace reports the United Kingdom will see more severe weather due to climate change, including extreme heatwaves, flooding, storms, and wildfires.

U.N. Intergovernmental Panel on Climate Change (IPCC)

To avert catastrophic health impacts and prevent millions of climate change-related deaths, the world must limit temperature rise to 1.5°C. Past emissions have already made a certain level of global temperature rise and other changes to the climate inevitable. Global heating of even 1.5°C is not considered safe, however; every additional tenth of a degree of warming will take a serious toll on people's lives and health. www.who.int/news-room/fact-sheets/detail/climate-change-and-health

In the last decade we have seen climate change escalate and a parallel upsurge of mental illness. Are the two related?

People caught up in climate-related disasters get physically and psychologically hurt (Hayes *et al*, 2018). Whether this is given a medical label or not, all of them will have suffered, and the rest of us can witness their anguish via the media. It's normal now to see images of storm, flood and fire, of human pain, of animals and trees burning. The impact is somatic: just as we wince when we see someone fall over or catch another person's yawn, we mirror the hurt of scorched koalas and bewildered Australians thousands of miles away. It's as if suffering were contagious. Indeed it is, as neurobiologists tell us, evolution hard-wired empathic mirroring into the mammalian premotor cortex, an embodied empathy that acts as an emotional early warning system. Another's non-verbal signals – especially fear or anger – literally stir up feelings in our own body. Mirroring can alert us to threat but it also facilitates pro-social 'tend and befriend' responses, but if a threat stimulus is persistent, the brain eventually turns the mirroring off. Then we go numb to some emotions or we may even dissociate. This numbing may play a part in depression. Emotions can spread like an infectious disease across social networks because of 'emotional contagion' – a tendency to acquire affective states from our social contacts).

- Contagious depression is a real phenomenon possibly due to emotional contagion.
- Contagious depression is related to environmental and intrinsic factors combined.
- Automatic mimicry is a preserved behaviour that allows emotional synchrony.
- The mirror neuron system is a key component for empathy processing.
- Depressed patients have a flawed pattern of brain activation in mirror neuron areas.

(Paz *et al*, 2022)

The climate emergency's impact on air, temperature and water quality add to the adaptive burden in physical conditions such as COPD, asthma and cardiovascular disease. The catastrophic effects of extreme weather changes – fire, drought and flooding – are already displacing entire communities and families. The complex consequences – war, famine and mass migration – will accelerate as global heating proceeds unchecked. These threat signals are not about to erase themselves. According to *The Lancet*, climate anxiety is 'associated with perceptions of inadequate action by adults and governments, [and] feelings of betrayal, abandonment and moral injury' related to climate change. These feelings too are not predicted to disappear any time soon. In short, since industrial societies are becoming a cauldron of strong and contagious emotions, what should be our role as doctors at a time when their resolution seems impossible?

Demand for mental health services is rising

With ever-worsening signs of an oncoming catastrophe for all life, grief and terror don't seem inappropriate. Comfortable numbness looks like a reasonable (albeit unconscious) way to deal with such feelings. But by treating the common forms of depression and anxiety as if they were purely medical disorders our profession may be contributes to a widespread detachment from the reality of the climate emergency.

It has been observed that many doctors learn to survive by desensitising themselves to some extent. If so it would be second nature to collude with our patients' understandable need to numb themselves (Abadilla, 2018). Though the myth of medical infallibility is long dead, doctors are still the nearest most people get to meeting a scientist/expert, someone assumed to have special insights into life and death. When seeking help from a doctor, and feeling vulnerable and dependent, a person is likely to be highly suggestable, and to have their antennae fully extended to pick up clues about their predicament. In such clinical transactions the door will be wide open for social contagion. Unavoidably doctors and the system they work in represent a prevailing worldview that is broadcast through their words but more powerfully through mirrored stress signals. Other non-verbal signs tell their story too —an impersonal austere clinical office bare of art or plants, the crowded waiting area, the industrial scale hospital building and outside, smoky air, urban blight, unsafe streets. All send out subliminal messages about the state of humankind and the technologising of medicine. This then is our 'normal'.

Are doctors part of the problem

Could it be that clinicians' own poor atunement to nature favours medicine's ever-increasing fixation on biological causes and cures? Doctors are schooled to be objective, clinically (=emotionally) detached, steeped in materialist science, hard-wired to diagnose disorders and fix them. How could we not be part of the problem? Yet doctors are far from alone in being set apart from nature, for we are all caught up in 21st century industrial-consumer culture's alienation and detachment from the other-than-human world. Too many of us have become more or less numb to the polycrisis, for few of us can tolerate entering into the mythic dimensions of apocalyptic climate catastrophe, nor cope with our species' responsibility for the sixth mass extinction event.

Doctors' clinical detachment is a learned skill, but one that should come with a health warning. Knowing this, and that clinical detachment can spill over into emotional distancing, doesn't show us how to be more open-hearted when we need to be; particularly when we are ourselves in a stressed state. There are parallels in society's retreat into detachment as a way of coping with the climate emergency. The academic jury is still out on whether psychological distance explains why climate change is difficult to act on because it feels far removed, with remote impacts on distant people or in an uncertain future (Keller *et al*, 2022). We however have no such qualms in proposing that detachment in all its guises – medical, therapeutic, emotional, political – desensitises us to forms of suffering in the clinic, in the community or in nature.

How we think

Modern medicine and psychiatry have done a lot of good but they also perpetuate the assumption that science will ultimately explain and fix everything. In this worldview health breakdowns happen randomly or because of factors intrinsic to the individual. Within psychiatry our current understandings of depression is that the net effects – whether social, psychological, genetic or environmental – cause faulty thinking and imbalanced brain chemistry.

> Over the past decade, antidepressant prescriptions have almost doubled in England, rising from 47.3 million in 2011 to 85.6 million in 2022–23. More than 8.6 million adults in England are now prescribed them annually (nearly 20% of adults) with prescriptions set to rise over the next decade.
>
> The average duration of time for which a person takes an antidepressant has doubled between the mid-2000s and 2017, with around half of patients now classed as long-term users. Scotland, Wales, and Northern Ireland have similar rates of antidepressant prescribing (Davies et al, 2023).

If this diagnostic boom were genuinely due to a disease rooted in genetics, neurotransmitter deficits, intrinsic brain dysfunction or epigenetic factors, surely this surge in prescribing would have delivered far more relief and remissions. But that has not been the case. The bio-chemical theory for the effectiveness of antidepressants has been challenged: a recent review concludes that 'the main areas of serotonin research provide no consistent evidence of there being an association between serotonin and depression, and no support for the hypothesis that depression is caused by lowered serotonin activity or concentrations (Moncrieff *et al*, 2023). This review also raised the possibility that long-term antidepressant use can actually reduce serotonin concentration. In turn these conclusion have been challenged too (Fountoulakis & Tsapakis, 2024).

However, our thinking and practice within psychiatry serve effectively to maintain the dominant biological paradigm. We believe this is having cultural side effects through the erosion of individual agency and a stymying of the social/political actions needed to address deeper, wider roots of individual, communal and planetary distress.

As clinicians, we tick off a checklist of symptoms and signs that correlate with classificatory systems such as patient health questionnaire (PHQ) 9, or international classification of diseases (ICD)-11 or diagnostic and statistics manual (DSM) 5. Once we have a diagnostic pigeon-hole we follow the guidelines. If we do no more than this we might feel intellectually satisfied and professionally safe. However, someone with mild to moderate depression' ie the majority of cases – help with making sense of their upset would probably be of benefit. Furthermore, to restrict our attention to the person's biology risks dismissing their feelings as irrelevant and meaningless and added to their sense of helplessness. The selective serotonin reuptake inhibitors (SSRI) box is ticked but the NICE guideline advises that we should not have left the patient's life predicament unaddressed. Ought we not – even if we do prescribe an SSRI and tell ourselves they need cognitive behavioural therapy to shift the ways they think – to be doing more to help make narrative sense of their life, acknowledge their thoughts and experiences, do all we can enhance agency, self-care and their potential to take action for change? In short, rather than focusing on 'whats wrong with you' can we make room to ask 'what happened to you?'

Perhaps if the next DSM were to give 'climate distress' diagnostic legitimacy, practitioners would feel more prepared to delve into the connection. But beware the implication that distress about the climate crisis is a sign of mental illness.

Many scholars have stressed that climate anxiety is a normal and healthy response to climate change and should not be medicalised eg Bhullar *et al* (2022).

> *'If we label eco-anxiety as a [mental] illness, climate denialists have won.'* Lawton (2019)

Where we work

Our infrastructure and design for seeing patients limits our ability to be more progressive in our assessments. We often work in buildings that could hardly be better designed for maintaining inactivity and inertia. In community mental health settings most patients with depression are seen in the community mental health team (CMHT) offices or occasionally in their own home. How will psychiatry respond to the growing interest in the health-giving and healing power of being in nature, 'forest bathing' and the emerging field of ecopsychology and ecotherapy? Seldom do we see patients in more natural settings – taking a walk and hearing the sounds of nature, or meeting in an organic cafe to talk about nourishment. Should we share ideas about the things that soothe or inspire us – the beauty of music, art or landscape, the joy of exercise or dance. Mindfulness has its place, but place itself can be therapeutic, green spaces especially so.

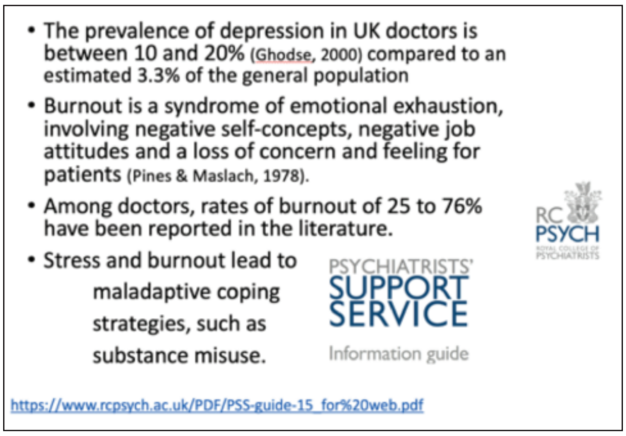
Nature connection

We would be strange creatures, somehow less than human, if emotions – try as we might to keep the lid on – did not leech into our personal and professional collective assumptions about what it is to be alive now. The Anthropocene is surely the most dramatic and consequential of all times to be on Earth. Why would we not grieve the loss of humankind's ancient familiarity with the other than human world? Joana Macy's 'despair and empowerment' work has shown how facing this grief is empowering and can renew our passion for change and reconnect us to the natural world (Macy, online).

This connection is ancient and essential to being human. EO Wilson names this sense of belonging in nature biophilia (Wilson, 1990), literally 'love of life'. Wilson sees our need to connect and commune with other forms of life as an innate, biologically driven need. Our species evolved alongside the animal vegetable and mineral worlds, and this history is encoded in the human genome. The connection is in our DNA, which is largely the same as other animals' (Robbins, online). If this embodied connection is the physical bedrock of Jung's collective unconscious then there is something quite literally unnatural but also uncanny for our culture to cut itself off from the other than human world. Indigenous cultures, unless colonised, have not done this. We suggest there is grief around this lost felt sense of losing this connection, or shame and guilt for the harm humans are doing to Earth systems. Though we may not be conscious of these emotions, they are in the Zeitgeist. In the human biocomputer the programmes are running as in the background. It would not be surprising if sensitive souls were to fall into despair, fear or rage. If you need studies to support this possibility they can be found (Gaekwad *et al*, 2022). But perhaps that compulsive need for objective evidence is a symptom of the disconnect from embodied and intuitive knowing at the problematic core of our medicine's and society's pitiful response to climate grief.

Doctors' own wellbeing

Medical students are not taught how to take care of themselves. They do learn about the many factors that can mediate burnout and depression, including physical inactivity, long hours spent online, loneliness, unemployment poverty, obsession with social media, computer games, social media, doom-scrolling, ultraprocessed foods, recreational drugs and alcohol, preoccupation with wealth, addictions to shopping, gambling, sex, violence. Yet levels of student and doctor burnout and mental unwellness continue to rise (Prendergast *et al*, 2024). Are our education and working lives depriving us of the emotionally intelligence we need to explore the balance between health creation and its depletion. Do we value enough the things that help humans flourish: meaningful work and purpose, love, altruism, intimate friendships, art, beauty, being in nature, connection to community, for our profession as a whole has not been flourishing.



- The prevalence of depression in UK doctors is between 10 and 20% (Ghodse, 2000) compared to an estimated 3.3% of the general population
- Burnout is a syndrome of emotional exhaustion, involving negative self-concepts, negative job attitudes and a loss of concern and feeling for patients (Pines & Maslach, 1978).
- Among doctors, rates of burnout of 25 to 76% have been reported in the literature.
- Stress and burnout lead to maladaptive coping strategies, such as substance misuse.

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In addressing the mental health of our patients doctors need to take their own wellbeing into account. With such high rates of burnout and depression, addiction and women doctor suicide, are we best placed to be healing others? It may be that these levels of upset and dysfunction point to traits, learned behaviours or organisational disorders that leave us reluctant to engage with emotional aspects of illness, or to encourage natural healing processes. The framework we work within shapes our norms and influences what we expect of ourselves. As a profession we tend to perfectionism, to valuing performance and overwork (Martin *et al*, 2022). We too often measure our patient outcomes by numbers rather than in qualitative terms. Would the NHS value an outcome such as 'I helped that patient lead a better life by planting a tree...or recycling …or reducing their carbon footprint?' Not yet.

Ivan Illyich, in his 1975 book *Medical Nemesis*, famously opened with the words, 'The medical establishment has become a major threat to health (O'Mahony, 2016).' Illyich, who named this social iatrogenesis, observed that in its current form medicine is no more sustainable than is our industrial-consumer society, predicated on limitless growth. Both must comprehend their limits. With the two entangled systems heading into crisis as the biosphere teeters at tipping points, medicine must re-imagine the part it can play as an agent of change toward a sustainable future.

Conclusion

We have proposed that the current inexorable rise in anxiety and depression and antidepressants prescribing could, at least in part be consequences of eco-distress, vicarious traumatisation, thwarted biophilia and social contagion. In addition, we speculate that clinicians, in order to adapt to working in regular contact with distress, and having become relatively desensitised, tend to collude with society's apparent detachment from the climate crisis and a widespread inability to respond effectively to it. We argue that the choices made by practitioners who have little time and limited treatment options, particularly if they feel burned out and emotionally numb, may negate feelings that could motivate change and by further exacerbating the public's disconnect from nature may be contributing to the global burden of climate denial and inaction.

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Climate justice in primary care

A poem and reflection on the theme of greenhouse gases leading to respiratory disease

Cian Patel

Former medical student, Barts and the London School of Medicine and Dentistry, QMUL

I am a Barts and The London medicine alumni, and I am currently in the process of pivoting towards a career outside of clinical medicine. Despite this, I remain deeply passionate about healthcare, including its connection to climate change and injustice. I have found that climate change disproportionately affects those from poorer socioeconomic backgrounds, and my poem tries to encapsulate this. I believe those working in the realm of healthcare can and should advocate for the environment, due to the impact it has on health and beyond.

Breathless in a polluted world

As the cars roar loudly near my abode,
The thousands of them, on the motorway road,
I cough, splutter, panic, I scream out a wheeze,
I thought, 'not again', and suddenly, I could not breathe,
My mother ran towards me, screaming for assistance,
Next thing I know, I am fighting for my existence,
It lasted for minutes, but it felt like forever,
Why me, why can't it be never,
But I knew it was where we lived, near the poisonous air,
We could not afford to move, it is simply unfair,
I wonder why we focus more, on the plastic straw,
Rather than the companies, who seem to be above the law,
The world leaders, as they slumber in their palaces,
Whilst my family works all day, for pennies, and calluses,
All those promises they make, they seem so empty,
Words with no meaning, they say so plenty,
I am enraged and exhausted, anxious and upset,
When those in power are flying again, with their private jet,
I worry for myself, I worry for my generation,
They deserve to know, all of our condemnation,
The floods, the hurricanes, the droughts, and cyclones,
They take so much away from us, leaving us with bones,
We call them natural disasters, but what is so natural about them,
Like the smog that surrounds me, as I battle my stubborn phlegm,
I could have been bones, but I am still here today,
It was that time again to go to the doctors, I had a lot to say,
I went to the GP, with tears in my eyes,
They must have saw my notes, they looked at me without surprise,
They let me rant and cry, they let me wail and shout,
I was aggrieved with the world, I had to let it all out,
I asked the doctor, will it happen once more,
As they were sorting my prescription, asking my closest store,
They tried to reassure me, but they could not guarantee,
Even they had no power, over our warmer land and sea,
Over the skies infested with dirty, dangerous gas,
We both want a cleaner world, but alas,
What will it take, for those in power to take action,
How many of us must perish, for their reaction,
No appointment or medication, can fully prevent another attack,
It is up to the richest, to put us on the right track,
We cannot do it all, our recycling bins have no meaning,
Unless corporations do the same, we need to convince them, for their intervening.

Reflection

The poem I created was to give the reader a first-person perspective of an asthma patient who lives close to a motorway and developed a severe asthma attack because of it. It recounts their thoughts and experiences of being exposed to excessive greenhouse gas and climate change as a whole, as well as highlighting the reality of the limitations of clinical medicine in primary care. My piece was primarily brought about by my recollections of the story of Ella Adoo-Kissi-Debrah, who lived in an area close to a major busy road in south London. She tragically died aged 9, and there was a ruling that stipulated air pollution as 'a major causal factor' in her death (Marshall, 2020). Ella's death and the area she lived in I feel illuminates the wider socio-economic inequalities those who live near busy roads in inner city regions may face, with many of those in inner cities being working class. I attempted to encapsulate this in my poem, as it refers to a young person whose family cannot afford to move from their home near the motorway. Additionally, although my poem depicts an extreme case, pollution is well-documented as a risk for asthma attacks (NHS, 2019).

Although I had some prior knowledge of this, it was shocking to hear the level of carbon dioxide emissions related to major corporations. Shockingly, just 57 companies involved in making fossil fuels 'are directly linked to 80%' of these emissions between 2016 and April 2024 (Watts, 2024). I incorporated this in my poem, writing about the frustrations of the personification I concocted, where they relate the contributions of large businesses to their misfortune of having an asthma attack. This also angers me, since I feel that climate change has such a huge impact on us all, whether that is via our health and wellbeing, or the overall ramifications it has on the planet. Although I believe we all have a role in the betterment of the Earth, there are many factors, including leadership and big businesses, that have a greater impact than just individual actions.

Despite the barriers we as individuals face in driving change, I do believe that primary care does have a role in climate justice. Climate change does affect patients' health and wellbeing, sometimes on extreme levels. Patients, especially those who have worse outcomes due to social and economic circumstances, are becoming increasingly affected by manmade actions on the planet. Apart from pollution, I also mentioned extreme weather events in the poem, which themselves can be catastrophic for the healthcare of patients. This can extend to those delivering healthcare, on an individual level the wellness of an individual healthcare professional, including GPs, and to the wider system, in the worst of cases the destruction of hospitals, general practices and other centres from natural disasters that damage both access to, and delivery of healthcare.

The purpose of the first-person point of view was to convey the struggles individual patients may face due to pollution. In the GP setting, it is necessary to be able to empathise with patients. I feel that even though patients may have specific needs, in all cases patients want someone to listen to them and to take them seriously, even if the GP is unable to help them directly at that moment in time. In the poem, I made sure to include this element as well, with the doctor not being able to provide full reassurance that the patient would never face another asthma attack.

A GP appointment usually lasts just a mere 10 minutes, but a patient's life is mostly outside the GP room, where they will be facing various challenges, including climate change. These are changes that GPs cannot address in the appointment setting, but I feel should be able to advocate for outside. Unfortunately, I heard of a recent story of a former GP, Dr Benn, having 'had her medical licence suspended for five months'. She was part of a Just Stop Oil protest and conveyed that she wanted to 'take action to protect life and health' (Lawson, 2024). With vast evidence of climate change and worsening health, I personally found this decision concerning, as public health forms a large basis of current policy and decision-making. At a conference I attended as part of my medical educator elective, known as the GP educator day, I remember one of the speakers emphasising how presenting evidence to the government can help drive change. This may be a direction that could be done in a collaborative way by many GPs and other healthcare professionals in relation to climate change and pollution. Raising the concerns for environmental issues and linking them to patient outcomes, I feel, will become more vital than ever if we are to both treat and prevent poor health outcomes for patients.

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A celebration of change-making

BHMA conference 2024

David Peters
Editor in chief, JHH

> *This conference, organised by a body focused on holistic medicine, lived up to that ideal. It featured discussions on an impressive range of topics but always with the focus on human beings, humanising healthcare, understanding the multiple contributions to our health and searching for new and innovative ways to create health, ease suffering and tackle disease. The participants were mostly doctors from different backgrounds and generations who shared their ideas and experiences generously. It was a healthy antidote to the increasing segmentation and industrialisation of healthcare in the formal health systems of the world and pointed to several very important approaches to health that need to be at the heart of future developments. Several participants were innovative leaders in professional education.*
> Lord Crisp

Our conference was a celebration of the BHMA's 40th anniversary and its central theme was *Health Creation*. BHMA founders, current innovators and an incoming generation of change agents on the NHS frontline met in a spirit of co-creative collaboration to re-imagine what healthcare might look like if it were good not just for people, but also for practitioners and the planet.

Our one-day community of mind–body–spirit creatives set out to:

- appreciate 40 years of holistic developments in healthcare
- share concerns about current problems and the challenges ahead
- see the opportunities for creative change in our turbulent times
- consider how – personally and with others – we may act for 'deep adaptation'.

40 years of the BHMA!

In the heady days of 1983–4, while the Greenham Common Women's Camp was being born, a group of idealistic doctors founded the British Holistic Medical Association. They wanted to halt mainstream healthcare's slide into industrialised monoculture. They wanted to explore all that supports health creation and healing of body, mind and spirit. They wanted to free medicine from the grip of old institutions, from over-reliance on drugs and to be open to the potential of other therapies. They wanted practitioners to nurture their own wellbeing, to flourish in the arduous work of caring for others.

In 1984 we laid out five key principles for developing holistic healthcare and setting out on that journey in practice:

- concern for the patient as a being of body, mind and spirit seen in historical, social and political contexts
- the patient as a potential self-healing agent
- encouraging appropriate power sharing between doctor and patient
- being able to offer a wide range of interventions
- 'self-gardening' – doctors' responsibility for their own self-care and inner development.

It is no longer customary (in the UK at least) for newly qualifying doctors to routinely take the Hippocratic oath. If the oath needed a 21st century update, the five core commitments would be a firm foundation. The five seem less radical now than they were in 1984, yet on over-stretched NHS frontlines in hospitals and GP centres can they be put into practice? If not what would have to change? The BHMA exists to ask the question, promote these values, and support those who are finding ways forward.

The future

Knowing that health, social justice and climate justice are intertwined, a more sustainable and compassionate health and social care is possible. But first we need to tell new stories. Because everywhere industrial medical systems face the same entwining crises of cash, care, cure and commitment; that 'business as usual' isn't working. Medicine is a child of its time and it reflects the culture it grew up in. It will change direction as we all begin to understand Big Health – that the health of humankind, the health of the plant and animal worlds and the health of Gaia's planetary systems are forever interwoven.

Next steps for the BHMA:

- curate and grow our network
- create spaces for active participation, connection and practice – events, webinars, communities of enquiry.
- tell the story, identifying influencers to help us amplify it#
- build our networks and develop the field, through linking, sharing, learning, researching.

Key areas to explore together:

- promoting the causes of health + patient-partnered care
- creating healthy and humane doctors through their medical education
- building intimacy with the self and other and relational rigour, to build back trust in each other and the healthcare system
- healthcare as a practice not a profession, and how we move away from doctors alone driving it
- the role of community in the future of healthcare, responding to the Darzi report
- how we influence system design – education, service provision, community health creation.

The conference programme

Opening the conference, journeys towards holism and insights behind BHMA's origins were reflected on by Professor David Peters, Professor Patrick Pietroni and psychotherapist/social worker Marilyn Miller. However, at the eleventh hour due to illness, Patrick and Marilyn were not able to join us and their contribution was read out.

Crossbench peer Lord Nigel Crisp then addressed the question, can we foresee a time when health is made in the community and hospitals are only for repairs? While Hamaad Khan, currently working as Development Officer for the Global Social Prescribing Alliance, asked, does the upcoming generation of new doctors see a future of medicine beyond pills?

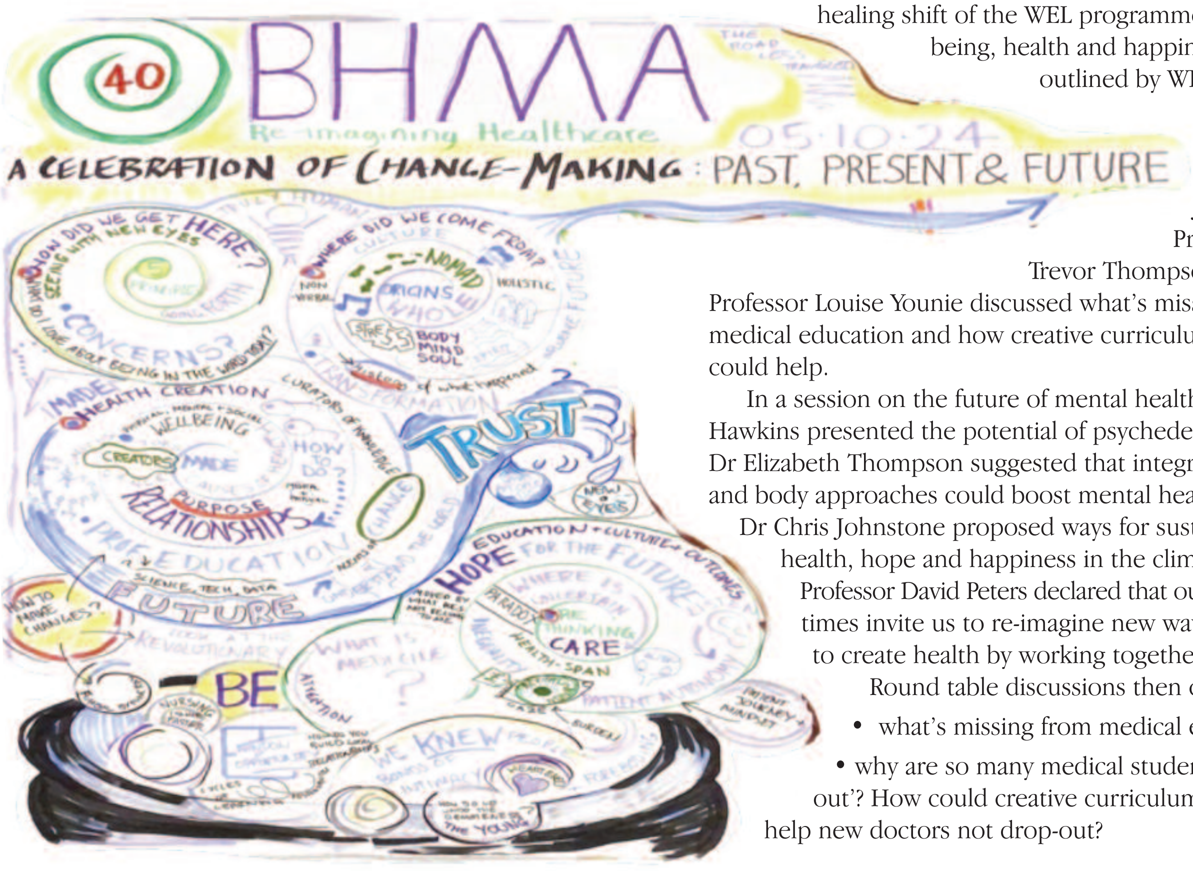
Dr Helen Kingston and Dr Tim Rigg discussed social prescribing describing how a family practice in Somerset has revolutionised primary care and grown a whole co-creative community. The transformative power and healing shift of the WEL programme for well-being, health and happiness was outlined by WEL founder Dr David Reilly. Dr Hugo Jobst, Professor Trevor Thompson and Professor Louise Younie discussed what's missing from medical education and how creative curriculum change could help.

In a session on the future of mental health Dr James Hawkins presented the potential of psychedelics and Dr Elizabeth Thompson suggested that integrating mind and body approaches could boost mental health.

Dr Chris Johnstone proposed ways for sustaining health, hope and happiness in the climate crisis. Professor David Peters declared that our turbulent times invite us to re-imagine new ways forward to create health by working together.

Round table discussions then considered:

- what's missing from medical education?
- why are so many medical students 'burned out'? How could creative curriculum change help new doctors not drop-out?



- the future of mental health and the place of psychedelics – would more integrated approaches boost mental health?
- can we sustain health, hope and happiness in the climate crisis?
- how to create health by working together?
- community-oriented integrated practice (COIP) which weaves a network of ‘safe spaces’ where participants can share different insights into life’s complexities and take meaningful, coordinated next steps.

Two wise elders steeped in organisational development, **Keith Humphrey** and **Lord Nigel Crisp**, offered feedback and suggestions for BHMA’s next 40 years.

> *There has been a breakdown of trust because what’s being delivered is not great…we have to build intimacy with the self and the other.*
> Keith Humphrey, founder of Core Context Consultancy

> *A healthy community of younger and older generations. The theme of the day was people and relationships. I came away reinforced in my view that future health professionals need to be exposed to this wide range of ideas and approaches as part of their education so they can be true professionals and understand these wider aspects of health, healthcare, disease prevention and health creation even if they will ultimately practice only in some of these areas. We need to build our networks and develop the field, through linking, sharing, learning, researching and telling stories.*
> Lord Crisp, All-Party Parliamentary Group on Global Health co-chair

The BHMA Fellowship Awards were made to:

- **William House** much-loved Somerset GP and playwright who breathed enthusiasm into the BHMA as chairman from 2013 to 2020.
- **Elizabeth Thompson** integrative physician who founded the National Centre for Integrative Medicine in Bristol and a longtime supporter of BHMA’s vision.
- **Trevor Thompson** one of medical education’s leading creatives whose inspirational whole person care courses run at Bristol University.
- **David Zigmond** urban GP and founding member of the BHMA who writes powerfully about healing relationships at the heart of holistic primary care.
- **Chris Johnstone** one of the BHMA’s first student group, co-author of the *Active Hope* with Joanna Macy. His College of Wellbeing is online https://collegeofwellbeing.com.
- **David Reilly** an originator of integrative medicine and a celebrated researcher who established Glasgow’s Centre for Integrated Care — one of the field’s finest teachers.
- **Catherine Zollman** one of the BHMA’s first medical student group who was a long-serving trustee alongside her partner Jerome Ungoed-Thomas. Their commitment helped BHMA through challenging times.
- **Sarah Eagger** psychiatrist and founding member of BHMA. As chair in the 1990s her steadiness and depth kept BHMA’s leadership afloat in times when the association’s survival was in doubt.

Conference feedback and appreciation

> *BHMA is like the Kew Gardens of the medical world. Collecting and caring for seeds that are in danger of becoming extinct so at some point they will flourish. The current soil is eroded, dried out, but we at the BHMA are keeping the seeds.*
> David Zigmond

> *Inspiring conference, fabulous speakers and a wonderful merge of likeminded attendees, change-makers and innovators. A real privilege to attend.*
> Karla Hamlet Founder of NURSE Collective UK©+ Innovation Hub

> *I loved this year’s BHMA conference. It reminded me of the pivotal role the BHMA has played in shaping my development as a doctor and a person over the last 40 years. I saw again trusted mentors, colleagues in shared purpose and dear friends, reconnecting with an inspiring community I’m so pleased to be part of. I take away renewal in fellowship and my flow.*
> Chris Johnstone
> Author/trainer/coach for Thrutopian Wellbeing

> *Great talks and presentations, interesting and important topics, brilliant people doing amazing things…and so lovely to reconnect and catch up with old friends too. All very special and inspirational – a wonderful gathering of the tribe and a huge honouring of everything BHMA has created and contributed over the last 40 years…a message ever-more needed in these troubled times.*
> Tania Dolley, Counselling psychologist

Special thank yous to

- Antonia Wrigley
- Gail Davidson
- The BHMA trustees

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Our 2024 student poster competition winners

- Vayika Gupta
- Inaya Sultana

whose posters will be published in the spring 2025 issue of JHH.

Doctors and death

Jonathan Tomlinson
GP, Hackney, London

Jonathon Tomlinson is an NHS GP working in Hackney, London. Read his blog at https://abetternhs.net/about/

'I wish she were dead'

Joy had spent most of her life trying to avoid thinking about death or dying, or anything to do with it, so wishing her own mother was dead was even more unwelcome and intrusive a line of thought than it ought to be. Repelled by anything to do with death, she had tried for the last 40 years to focus her efforts and attention on the living.

Her mother, like her grandmother, her aunt and, she increasingly suspected, her sister, had Alzheimer's dementia. A few years ago her mother had been found hanging happily upside down from her seat-belt in her upturned mini in the middle of Peterborough. She had written off several cars and smashed the front of Top Shop. It was a wonder no-one, including her, had been killed, but at 4.30am on a Wednesday morning there fortunately weren't many people about. Her family knew she was getting forgetful, but she seemed cheerful enough and was fiercely and doggedly determined to hang on to her independence. In the months before 'the crash' her car had become progressively dented as her driving became more and more erratic. A few family arguments had been simmering in that time. Joy had defended her mother's right to independence and quality of life, while her sister pleaded for the safety of other road users, street furniture and pavement dwellers. Joy fought for her mother's right to drive to the end, on the grounds that no-one had actually been hurt, while her sister pointed out that it was absurd to wait for a calamity. After 'the crash', their mother was taken to hospital where she was judged to be suffering from dementia and her car, to the family's relief, was judged to be a write-off. Their mother never fully understood why she shouldn't be allowed to drive again and became isolated and depressed in spite of, or perhaps because of, her family rallying around. The car had been her means of escape.

CORONER'S CERTIFICATE OF THE FACT OF DEATH
ant to Regulation 9 of the Coroners (Investigations) Regulations 2013
DEATH
Ref
Sex
Maiden
Name and Surname
Date and Place of Birth
ccupation and Usual Address

This afternoon, four years after 'the crash', Joy had been to visit her mother for lunch. It wasn't one of the better days for either of them. Usually, at this time of day, Joy is less stressed, and her mother less agitated than in the mornings. In the evenings Joy is frequently as exhausted as her mother is psychotically paranoid; a little, but more than enough.

Her mother was sitting in her rocking chair looking out of the window into the garden. The sandwiches left by her carer had been pushed around on the table in front of her but not eaten. 'Come on mother, you've got to eat something', Joy pleaded. 'Don't tell me what to do!'her mother hissed back at her. 'Don't fucking start'. The words came out of Joy's mouth before she had time to hold the thought back and compose herself. Her mother grabbed the sandwiches and clenched them in her fists, she was still easily strong enough to squeeze the cheese and cucumber and white bread through her fingers. She scowled at Joy when she finished.

'What on earth is wrong with you?!' Joy protested.

'Oh go away!'

After 'the crash' Joy thought it best for her mother to move in with her; she was working part-time and selling her mother's house raised enough money to pay for extra care when she wasn't around. She was increasingly regretting the decision. It wasn't that her mother actually needed all that much care, it was worse than that. The bouts of confusion, paranoia and rage – the rage that always seemed to be directed at her – were increasingly difficult to cope with. Physically, at least, her mother had the constitution of an ox, and while her dementia was slowly and steadily progressing, her fearsome determination was beating Joy down. Joy spent her evenings alone tearfully with a bottle of wine, increasingly hopeless for her future. Her mother was 80 and looked like she could keep this up for another 20 years or more, far longer than Joy could cope with.

Forty years ago in the same room in which they argued, Joy's son Tom had died. Barely seven months old, he had been born with severe congenital heart disease and had spent his life in hospital. When he was finally discharged, painfully thin, breathless and wheezy, all he could do was lie back and pant. His arms and legs were scarred from all the needles, his lips were tinged blue from lack of oxygen and his eyes, when they were open, looked anxious and distant. Joy and Roger, her husband, had brought Tom home in the morning. Neither of them felt prepared to be alone with him without the support of the hospital medical staff. They knew they could call for advice at any time, but were ashamed to admit they were scared and couldn't cope. Neither of them had slept properly since Tom's birth and on the night after his discharge they took turns to sit with him while the other lay fitfully in bed. It was a sweltering hot night; Joy remembered clearly lying on top of her bed, holding her breath so that she could hear the little squeaks and wheezes from Tom's room.

Eventually she fell asleep. She awoke with a start, it was a shock to find herself asleep after such a long time. She sat up and held her breath … silence. She walked into Tom's room hardly daring to breathe, and saw Roger sitting by the window, staring outside, lit by moonlight, holding Tom in his lap. For the first time in his life, Tom looked relaxed, head tilted back against his father's shoulder, arms and legs flopped over him. For a few moments she stood in the doorway, at peace for the first time since his birth. What happened next she cannot clearly recollect. They fought, she knows that, even though the memories are of pain and fury, grief and loss, and not physical violence. The doctor who examined Tom's body – the doctor who had never met them, never spoken to them and knew nothing of what they had been through – insisted on a post-mortem because somehow, in their – her – distress, his body, for God's sake, he wasn't even alive, had been bruised, and they, Tom's parents, were under suspicion.

She had a breakdown of sorts after that. She had always considered a 'breakdown' to be hopelessly vague as a term, but much like 'being beside herself' it was an apposite term for what she went through. To the present day she bitterly resented the hospital for sending Tom home; why didn't they tell her he was going to die? Obviously he was sick, but if they expected him to die, why did they send him home? Why? Because they didn't want another death on their unit? Because they couldn't cope with it? What about us, or me? Roger left soon after, we couldn't bear to be together after that. Is it like that for hospital doctors too? Is it too much to bear to face death and bereavement? Is that driving the pressure for patients to die at home today? She couldn't see the point of it herself.

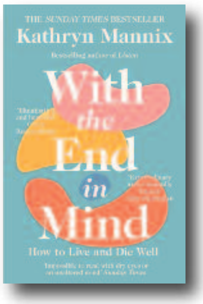
From that day on her left breast had ached terribly. She put it down to grief for the first few weeks, but when it refused to settle, she visited her GP who arranged some tests to check her heart and a mammogram to check her breast for cancer. The tests came back fine and she accepted it from then on as a stigmata, the physical manifestation of her mental grief. Joy sat in her car outside her office after visiting her mother, wiping tears from her cheeks and checking her make-up in the rear-view mirror. Her breast ached more than ever, punishment she believed, for wishing her mother dead.

She slipped her hand inside her bra to rub the pain away…oh Christ, no! She cursed her mother, the witch, it was her fault. It wasn't the first time she had felt the lump, it was there last week, and the week before and she was sure it would go, but if it didn't she would deal with it, make an appointment to see her GP, but not now, not today, not this week. She had too much to deal with already this week.

Joy got out of her car and let herself through the back door into her office, switched on her computer, straightened her jacket and checked her appearance one last time in the office mirror. Taking a deep breath, she walked into the waiting room and called in her first patient.

With the end in mind: how to live and die well

Kathryn Mannix (William Collins, 2022)



This book was published in 2017 and soon became a *Sunday Times* bestseller. Many readers of this journal may therefore already be familiar with its contents, or at least its eye-catching title. For anyone who hasn't read this book, it both informs and enlightens. Made up of short stories with reflective introductory paragraphs, and several single-paged themed insights entitled 'pause for thought', Mannix brings her readers to the pages of her text. It's impossible not to engage with every word, for these are stories about people who are dying (from young to old) where the author aims to give 'a particular insight into the way people live when they know that they are dying'. Real events of care, experienced by Mannix in her 40-year career from junior doctor to consultant in palliative medicine, are crafted into stories about dying that many in Western societies no longer experience for themselves. Where most deaths used to take place in people's homes – a place of familiarity that included families and community – most now occur in hospitals and nursing homes. This makes dying and death in our contemporary society an unknown entity, where the unfamiliar creates a feeling of inadequacy, worry and fear in the very people who used to ably manage and support death.

In the introductory pages, Mannix writes that she seeks to convey 'how the dying, like the rest of us, are mainly getting on with living'. She demonstrates this convincingly. Having worked as a palliative care physician myself for 20 years, I found huge resonance with these words. Reading each story, I recognised not only her characters – the patients, their families and the staff she worked with – but also the essence of each story that captured how the dying were living. In so doing, each dying person is presented as an individual and Mannix pays great attention to detail including how difficult conversations about difficult situations are communicated. Scenarios are about place (home, hospital, hospice), relationships, symptoms, desires, emotions, and ways of thinking, being and doing. Dignity and kindness always prevail, of paramount importance when death is not always approached with peace. As she says, these stories are real events and those of us working or who have worked in palliative care can attest to this. In being real, many of these stories might shock but this is not her intention. Mannix writes that we should be talking about dying and that writing this book is her way of promoting the conversation.

This is a book for any reader seeking to get an understanding of dying and death as it approaches and occurs. Whether it's about people being cared for or people doing the caring, the outcome is death but within these stories, well-managed comforting and compassionate care for the dying helps not only the person who is dying, but also those around them, and those who survive them. Any reader should get a sense of how this level of care requires resources, which currently, are sorely lacking. At a time when this government plans for a parliamentary vote on physician-assisted dying, what might the outcome be if government resources included better care for the dying?

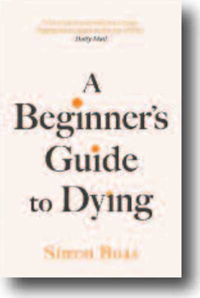
When we live *with the end in mind*, this book grounds us to reflect and consider how we might live.

Marina Malthouse, Retired palliative care physician

A beginner's guide to dying

Simon Boas (Swift Press, 2024)

The name Simon Boas might be familiar to some from his articles written for the *Jersey Evening Post* and interviews he gave for BBC Radio 4. Despite being diagnosed with advanced cancer in 2023 at the age of 46, he continued to live positively and wrote that he was happier than he'd ever been. This and his calm acceptance of approaching death led to an overwhelming response from the public. This book expands on some of the themes he touched on in the newspaper and was completed just before he died in July 2024.



This guide is as much about living life to the full as it is about dying. Some of the ideas Boas discusses were developed in his earlier life, partly shaped by the extensive time he spent in overseas aid work in which he witnessed extremes of life and death. As he approached death, Boas experienced a period of clarity where other realisations came to him, some of which he wished he had understood earlier. So he has written not only a guide for the dying, but also one for those he hopes will have a long and happy life ahead.

Boas believes that the key to his acceptance of non-existence is his positive view of existence. He reflects on the astonishing set of circumstances and chances that allow a human being to exist, and all that has allowed him to have a full life with all the advantages of living in the western world. During his working life he concluded that even in the most challenging circumstances people are fundamentally good, and that we share more in common with each other than we realise. These beliefs underpin much of the content of the largest section of the book, 'Death and Equanimity' which he refers to as a 'little scrapbook' compiled of his personal experiences and views of life. In 12 short chapters he writes with clarity, humour and honesty about fundamental aspects of human behaviour and explores ways of thinking differently. For instance, writing about gaining perspective he muses on why human beings compare themselves socially upwards, rather than consider how fortunate they are. On God and religion, he sets out his personal reasons for shifting from atheism to acceptance of the possibility of an existence after life. He was surprised how helpful it was to talk to a counsellor, and to learn how to meditate. The most challenging aspect was coping with the thought of those grieving after his death.

In the section on interacting with the dying, Boas provides some pointers for people wanting to spend time with someone who is dying but do not know how to. He has compiled a list of don'ts and dos after consulting with others in his position to provide some simple but practical advice about planning visits, listening, offering help, and most of all making it about the dying person and being guided by them.

There is a reading list he found helpful, a brief chronology of his remarkably full and challenging life, and some random facts, like his love of cheese fondue.

An epilogue includes an extract from the eulogy written by a close friend and read at Simon's funeral. Reading this confirms that he was all that you imagined from reading his words. This short book includes so much to admire and reflect on and despite being written from a personal perspective will be helpful to so many.

Caroline Groom, Retired nurse specialist in palliative care

Research

Report of the *Lancet* Commission on the Value of Death: bringing death back into life

Key messages

- Dying in the 21st century is a story of paradox. Although many people are overtreated in hospitals, still more remain undertreated.
- Death, dying, and grieving today have become unbalanced. Healthcare is now the context in which many encounter death and as families and communities have been pushed to the margins.
- Climate change, the Covid-19 pandemic, and our wish to defeat death all have their origins in the delusion that we are in control of, not part of, nature.
- Rebalancing death and dying will depend on changes across death systems.
- The disadvantaged and powerless suffer most from the imbalance in care for those dying and grieving.
- Communities are reclaiming death, dying and grief as social concerns, restrictive policies on opioid availability are being transformed and healthcare professionals are working in partnership with people and families, but more is needed.
- To achieve our ambition to rebalance death, dying and grieving, radical changes across all death systems are needed. The Commission sets out five principles for a new vision of death and dying.

www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02314-X/fulltext

The legalisation of assisted dying

63% of people in England and Wales support legalising assisted dying for terminally ill adults, while concerns about potential risks remain. Two-thirds of the public want assisted dying to be available on the NHS. A notable proportion would rather their MP followed their conscience in a free vote within this Parliament. Despite being relatively split on the financial impact, 63% back this change, compared with 20% who oppose it. Support is lower among younger people and ethnic minority groups.

The public are most likely to say patients should not have to pay for assisted dying themselves although a majority also see a role for the private sector (55% support private healthcare companies also providing assisted deaths – almost double the share who oppose them doing so). People with mental health conditions are perceived to be most at risk from legal assisted dying. 55% of the public support private healthcare companies also providing assisted deaths – almost double the share (24%) who oppose them doing so. Among assisted dying supporters pain relief and dignity are key motivators, while opponents worry most about risks to the vulnerable. Nearly half of supporters also say the poor quality of palliative care is a very important factor informing their position Online data collection took place between 18 and 19 September 2024, with a total of 2,063 respondents from a nationally representative group of those aged 18+ in England and Wales completing the survey. Data was weighted by age, gender, region, ethnicity and education status.

Assisted dying: Principles, practice and politics. Complex Life and Death Decisions Group. The Policy Institute. Kings College. London https://www.kcl.ac.uk/policy-institute/assets/14587oct-assisted-dying-survey-friday-4-oct.pdf

Prolonged grief disorder (PGD)

Is PGD a mental illness?

The distinction between PGD and normal grief is unclear. The holistic practitioner, wary of the downsides of medicalising prolonged grief, will use evidence based pharmacotherapies with caution. But as many as 10% of bereaved people experience similar prolonged suffering.

Prolonged grief disorder (PGD), also known as complicated grief, describes an intense, enduring, distressing and disabling bereavement reaction experienced by a small minority of mourners, that make it difficult to move on with life. To be diagnosed with PGD the loss must have occurred at least 12 months ago for adults and at least 6 months ago for children and adolescents. PGD was only lately recognised as a distinct diagnosis. It is already included in the International Classification of Diseases 11th Revision (ICD-11) and will soon appear in the DSM-5-T. There are minor differences in the criteria stated. According to DSM 5, since the death, at least three of the key symptoms must have been present most days to a clinically significant degree. In addition, the symptoms have occurred nearly every day for at least the last month.

Some symptoms of complex grief include:

- identity disruption (eg feeling that a part of oneself has died) since the death
- marked sense of disbelief about the death
- avoidance of reminders that the person is dead (in children and adolescents, may be characterised by efforts to avoid reminders)
- intense emotional pain (eg anger, bitterness, sorrow) related to the death
- difficulty reintegrating into one's relationships and activities after the death (eg problems engaging with friends, pursuing interests or planning for the future)
- emotional numbness (absence or marked reduction of emotional experience) as a result of the death
- feeling that life is meaningless as a result of the death
- intense loneliness as a result of the death.

How best to treat PGD

A 2024 review focuses on the most commonly used interventions – cognitive behavioural (CB)-based therapies, bereavement and support groups, and brief contact interventions (BCIs), aiming to summarise currently 'clinical takeaways' based on the available research. The review also discusses the use of these therapies in particular clinical populations including the traumatically bereaved, paediatric populations, communities of colour, and underserved communities. Most psychological interventions are effective, but only cognitive behavioural therapy has the highest acceptability. One type of treatment, complicated grief treatment, incorporates components of CBT and other approaches to help adapt to the loss. It focuses on both accepting the reality of the loss and restoration – working toward goals and a sense of satisfaction in a world without the loved one.

Hao F, Qi Fu, Liang Z, Li P (2024) Psychotherapies for prolonged grief disorder in adults: A systematic review and network meta-analysis. https://doi.org/10.1016/j.ajp.2024.104133

JOURNAL OF
holistic
healthcare
AND INTEGRATIVE MEDICINE

About the BHMA

In the heady days of 1983 while the Greenham Common Women's Camp was being born, a group of doctors formed the British Holistic Medical Association (BHMA). They too were full of idealism. They wanted to halt the relentless slide of mainstream healthcare towards industrialised monoculture. They wanted medicine to understand the world in all its fuzzy complexity, and to embrace health and healing; healing that involves body, mind and spirit. They wanted to free medicine from the grip of old institutions, from over-reliance on drugs and to explore the potential of other therapies. They wanted practitioners to care for themselves, understanding that practitioners who cannot care for their own bodies and feelings will be so much less able to care for others.

The motto, 'Physician heal thyself' is a rallying call for the healing of individuals and communities; a reminder to all humankind that we cannot rely on those in power to solve all our problems. And this motto is even more relevant now than it was in 1983. Since then, the BHMA has worked to promote holism in medicine, evolving to embrace new challenges, particularly the over-arching issue of sustainability of vital NHS human and social capital, as well as ecological and economic systems, and to understand how they are intertwined.

The BHMA now stands for five linked and overlapping dimensions of holistic healthcare:

Whole person medicine

Whole person healthcare seeks to understand the complex influences – from the genome to the ozone layer – that build up or break down the body–mind: what promotes vitality adaptation and repair, what undermines them? Practitioners are interested not just in the biochemistry and pathology of disease but in the lived body, emotions and beliefs, experiences and relationships, the impact of the family, community and the physical environment. As well as treating illness and disease, whole person medicine aims to create resilience and wellbeing. Its practitioners strive to work compassionately while recognising that they too have limitations and vulnerabilities of their own.

Self-care

All practitioners need to be aware that the medical and nursing professions are at higher risk of poor mental health and burnout. Difficult and demanding work, sometimes in toxic organisations, can foster defensive cynicism, 'presenteeism' or burnout. Healthcare workers have to understand the origins of health, and must learn to attend to their wellbeing. Certain core skills can help us, yet our resilience will often depend greatly on support from family and colleagues, and on the culture of the organisations in which we work.

Humane care

Compassion must become a core value for healthcare and be affirmed and fully supported as an essential marker of good practice through policy, training and good management. We have a historical duty to pay special attention to deprived and excluded groups, especially those who are poor, mentally ill, disabled and elderly. Planning compassionate healthcare organisations calls for social and economic creativity. More literally, the wider use of the arts and artistic therapies can help create more humane healing spaces and may elevate the clinical encounter so that the art of healthcare can take its place alongside appropriately applied medical science.

Integrating complementary therapies

Because holistic healthcare is patient-centred and concerned about patient choice, it must be open to the possibility that forms of treatment other than conventional medicine might benefit a patient. It is not unscientific to consider that certain complementary therapies might be integrated into mainstream practice. There is already some evidence to support its use in the care and management of relapsing long-term illness and chronic disease where pharmaceutics have relatively little to offer. A collaborative approach based on mutual respect informed by critical openness and honest evaluation of outcomes should encourage more widespread co-operation between 'orthodox' and complementary clinicians.

Sustainability

Climate change is the biggest threat to the health of human and the other-than-human species on planet Earth. The science is clear enough: what builds health and wellbeing is better diet, more exercise, less loneliness, more access to green spaces, breathing clean air and drinking uncontaminated water. If the seeds of mental ill-health are often planted in an over-stressed childhood, this is less likely in supportive communities where life feels meaningful. Wars are bad for people, and disastrous for the biosphere. In so many ways what is good for the planet is good for people too.

Medical science now has very effective ways of rescuing people from end-stage disease. But if healthcare is to become sustainable it must begin to do more than just repair bodies and minds damaged by an unsustainable culture. Holistic healthcare practitioners can help people lead healthier lives, and take the lead in developing more sustainable communities, creating more appropriate models of healthcare, and living more sustainable ways of life. If the earth is to sustain us, inaction is not a choice.

> "The Journal of Holistic Healthcare…
> a great resource for the integration-minded, and what a bargain!"
> Dr Michael Dixon

Want to contribute to the journal? Find our guidelines at: http://bhma.org/wp-content/uploads/2016/07/JHH-Essential-author-information.pdf

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Finished with your journal? Please donate it to your local GP surgery, community centre, library etc so others can read about holistic healthcare and the importance of looking after the whole person, not just their immediate symptoms.

Re-imagining healthcare