The art of medicine: caring for memories

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On the fifth anniversary of my wife Joan’s death from early onset Alzheimer’s disease, after I placed flowers on her gravestone, I immediately felt a rush of chaotic emotional memories—key events in our lives as well as the trivia that had accumulated over almost a half century together, yet said something special to me. Each memory came as an image surrounded by a particular type of feeling. As soon as I focused on one memory, a story spoke: some well rehearsed, others incipient. I saw myself as a curator, stewarding a poorly arranged, shifting, and highly charged picture gallery. That inner exhibition represented our lives. It also said something about the times we lived through and the people and events that had mattered to us and matter still.

As I gave myself over to reverie and requiem, I seemed to shape-shift to a more youthful past, then back to the present. My image of Joan went through the same form-adjusting lifecycle. From dead and buried, she came alive in my memories, an image fused with feelings and narrations that ranged across the five decades of our lives together. Only after that irruption did those images and tales return silently to their imagined grave in my memories. And with that the heat of passionate presence and affirming reciprocity gave way to more distant, bitter-sweet, and less clear remembrances. Nor was this sequence new; it had been repeating itself regularly, bidden and unbidden, over the years since her passing: sadness and yearning being replaced by subtler, more mixed and less unsettling feelings.

Why do memories matter so much? Why do we invest so much time working them through and repeating them to ourselves and others? Why do we attend to them with such alertness and anguish? What do memories do for us? And what do they do for others with whom we are intimately connected?

For those of us who have experienced the loss of a loved one, it is not just that we remember in order to conjure back that partner, parent, or child—though it surely is this too. We seem to need to remember so as to project or reaffirm key meanings in our lives. We remember to recreate meanings that sustain us, that help us to endure.

Those memories are central to the way we talk to ourselves and to others. They humanise our worlds. They distil wisdom from experience. They come right into our lives and illuminate them from within. They enable us to go through pain and hardship. They make it feasible to live surrounded by the precarious and the uncertain which, if we otherwise
contemplated it, would unnerve even the sturdiest of us. They also help us change and understand how those changes in our self-formation work. Without memories of those whom we have loved and lost, our worlds would be bleak and barren and uninhabitable. Indeed, without memories there would be no inner or social world.

Traumatic memories too can be thought of in this way. In the form of post-traumatic stress injury, they damage individuals. They erode relationships. Some cases can be treated, others threaten institutional expectations about what is treatable. And still such memories serve a moral purpose. By reminding us of the centrality of human suffering and the existential limits to what we are actually able to control and heal, they contribute to a tragic view of life that runs like a golden thread of sober wisdom through serious family and professional experiences of caregiving. Life is lived within limits, and so is care.

The work of remembering and the time spent ordering, reordering, and living through memories, when it relates to those who have died, is a continuation of the caregiving we provided when they lived. Caregiving, viewed this way, doesn’t end with the death of the care-receiver. It goes on during bereavement; in fact bereavement is caregiving. And it lasts long after the psychophysiological symptoms of grieving have stopped bothering us. Some of us will care for memories until we ourselves pass on. And even afterward, those who succeed us will keep at least some of those memories alive for the very same reason. Clinicians also participate in this process that shapes their memories of practice into practical wisdom about the art of living and the art of medicine.

Viewed this way, the caring for memories is how societies, generation by generation, remember. How the social—families, networks, communities, institutions—lives on and is reconstituted out of the transmission of images, feelings, and narratives. It is how what is meaningful, what really matters, survives and mutates. Myths, symbols, and rituals help us remember. Yet most of remembering is the work of the self.

Caregiving, when understood as caring for memories as much as caring for the bodies and souls of children, the sick, and the elderly, occupies an enormous amount of time. It is the very glue of life. It holds relations together, and it can make each of us, through the care of ourselves, whole. The care of memories shapes imagination and personhood. It animates presence. The care of memories creates a different and new time: neither bureaucratic time nor biological time, but rather a time of lived experience that unites the imagined with the real, the lost with the found.
Today psychologists and other neuroscientists insist that memory is about cognitive processes that reinterpret stored images, feelings, and ideas in light of what is currently going on in our lives. Hence no memory is a direct representation of experience, or, put differently, through the reconstruction of memory, experience per se is never available to us unmediated by time and history. As an anthropologist, I find this contextual approach congenial. But as a caregiver and a clinician, I have my existential doubts.

While it may be true of ordinary memories, I wonder if it is the case with the memories of extraordinary times: such as the anguished back and forth between acceptance and denial during the early onset of Alzheimer’s disease; a failure in responding with compassion and restraint to a patient; the moment of not being recognised by a spouse or parent who has dementia; or a death bed vigil. Bad things happen in care, as in the rest of life, that we regret and find unforgettable and unforgiveable: we act with indifference; we explode in anger; we lose hope and give up in despair; we run away. I believe we can directly experience these exceptional states even decades after they occur.

Yet the very feelings and relations that are injured are what we have to work with to restore care and remake our lives. The result is that caregiving contains within it those difficult existential struggles that constrain what it can be. Much of this struggle is worked through imaginatively in memories. Caring for memories is both a rehearsing of these incomplete and limiting experiences and a way of reordering them into a coherent narrative that makes sufficient sense of triumphs and failures alike to enable our safe passage through those life stages that remain to be lived.

Whether mediated or directly accessed, this is the gift of memories, even those that haunt and hurt. They bring caregiving right into the centre of our lives, offering the opportunity to affirm and acknowledge who we are, including even those parts of ourselves that are troubled or broken. And they can, I believe, do the same for relationships, past and current.

While caring for memories is most readily understood as a form of family caregiving, it is also an influential part of the experience of the physician and nurse. Clinicians remember patients and their own caregiving practices. We work through memories of successes and failures. We can and do learn from these memories, especially when we face them and critically self-reflect on them. The lessons form a practical wisdom about how to conduct the art of living and how to practise professionally. This process might even be thought of as part of the emotional and moral core of professional practice. Left to themselves, however,
memories can work their own way through us with unexpected and undesired consequences like inappropriate emotional reactions. Clinicians can enquire about patients’ and family caregivers’ memories of care so as to better understand what is at stake for them. But we also can contribute to the caring for memories through more systematic representation of their content and consequences for medical practice.

Guilt, sadness, anger, love—all are present in memories of deceased care recipients. So can be denial, obsession, blindness, and avoidance. Like other aspects of care, we can do an appropriate or inadequate job of caring for these memories. My intention here is not to provide a method of care, but instead to help each of us to confront this usually silent caring. What can we do as clinicians and family carers to assist the caring for memories? What do we owe those whom we have cared for who have passed over into our memories? What do we want or need from such care? This subject, I feel, leads us to the very soul of caregiving and care receiving.

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