With just a memory

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You can fall ill with just a memory.
Paulo Giordano, *The Solitude of Prime Numbers: A Novel*

As a family medicine resident, I was sceptical that simulated office oral examinations were either helpful or realistic. Almost 20 years of supervising them with family medicine residents has erased my youthful arrogance and naïvety. Recently when I was supervising these examinations, the actor played a patient named Jeffrey, a First Nations man, who had experienced the trauma of residential schools and witnessed the sexual abuse of his brother who had recently died in a car accident. Plagued by flashbacks and unable to sleep or concentrate, he was haunted by his memories. Although these skillful family medicine residents were able to name Jeffrey's posttraumatic stress disorder, many shied away from allowing him the full expression of his sorrow. They seemed to think that allowing Jeffrey to tell his story might make things worse.

But such is the power of our patients' stories that they are a bridge to understanding and a gateway to healing.

Tony Judt was a historian and the author of *Postwar,* a history of Europe after World War II, which was runner-up for the Pulitzer Prize in 2006 and regarded by many as one of the best history books of the past decade.[1] In 2008, Professor Judt was diagnosed with amyotrophic lateral sclerosis. By the autumn of 2009 he was paralyzed from the neck down. He died at home on August 6, 2010. Against all odds, during the last 2 years of his life he was incredibly productive. One of the gifts he left us is a remarkable book, *The Memory Chalet.*[2] In describing the steady progression of amyotrophic lateral sclerosis he writes:

> The salient quality of this particular neurodegenerative disorder is that it leaves your mind clear to reflect upon past, present and future, but steadily deprives you of any means of converting those reflections into words. First you can no longer write independently, requiring either an assistant or a machine in order to record your thoughts. Then your legs fail and you cannot take in new experiences, except at the cost of such logistical complexity that the mere fact of mobility becomes the object of attention rather than the benefits that mobility can confer.
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> Next you begin to lose your voice: not just in the metaphorical sense of having to speak through assorted mechanical or human intermediaries, but quite literally in that the diaphragm muscles can no longer pump sufficient air across your vocal chords to furnish them with the variety of pressure required to express meaningful sound. By this point you are almost certainly quadriplegic and condemned to long hours of silent immobility, whether or not in the presence of others.[2]

In the silence of his immobility, especially as he lay awake through the lonely nights, Professor Judt constructed his memory chalet, populating its rooms with his memories, thoughts, and ideas before dictating them to his assistant the next day. Out of this exercise arose a collection of stories ranging from his childhood in London, England, riding a favourite bus route, the Green Line; to his discovery of America; to how he met and married his wife, Jennifer. Interwoven throughout are his reflections on the difficulties of living with a relentless and progressive neurodegenerative disease.

If we agree that it is only by listening to patients' stories that we can come to more fully understand their lives and their experiences of illness and loss, how can we ensure that in the midst of our busy days we allow people the opportunity to share their stories? Just as important, how can we ensure we are teaching medical students and family medicine residents this crucial aspect of our work as family physicians? How can we teach them to ask the right questions and to have the confidence to know that by allowing our patients to tell us their stories they are not going to make things worse, but better?

One of the most useful tools that I have found to achieve this is an article by Peterkin.[3] He makes 15 simple and practical recommendations that help us to practise more effective narrative-based medicine. All of them are valuable, but there are a couple that are both powerful and neglected in our practice. The first is to include a final *S* in your SOAP notes—for *suffering*—and to ask yourself if you have allowed room for the patient to talk about their distress at each visit. The second is to ask open-ended questions. Upon meeting a new patient, Rita Charon begins by asking, "What would you like me to know about you?"[4]

Tony Judt was a unique and remarkable person with the force of will, the intellect, and the necessary love and support of family, friends, and colleagues that allowed him to tell his stories so that we can share in them. As family physicians, we have the unique opportunity to allow our patients too to share their unique and meaningful stories.

Cet article se trouve aussi en français à la **page 10.**

Competing interests
None declared

References
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2. Judt T. *The memory chalet.* New York, NY: Penguin Books; 2010.
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