

## The art of medicine

### Banking on stories for healthier cognitive ageing

On a cold Christmas Eve in 1985, Bill Keane arrived in the darkened halls of the Neuropathology Laboratories at Johns Hopkins. He and a friend had risked an accident-strewn highway to drive to Maryland from Pennsylvania; we needed what he carried as quickly as possible. Bill's mother had just died after a 12-year struggle with dementia, and he was bringing us her brain.

2 years earlier, having heard of our research interests in Alzheimer's disease, Bill had arranged to donate his mother's brain to our brain bank—a precious repository of generously donated tissues, to which eager neuroscientists from around the world would compete for access. For Bill, handing over his mother's brain produced palpable relief as he ended his journey of caregiving, and marked the beginning of a collaborative friendship and a new way of thinking about Alzheimer's disease. Although at the time we were all hoping for successful biological treatments for Alzheimer's disease, we sensed then that caring trumped curing.

Bill's commitment to his mother and her fellow sufferers, and his subsequent professional contributions to making the culture in the long-term care field less disease-oriented, were inspiring. They helped launch us on a professional trajectory during which we have come to recognise that people's narratives—the faith they put in science to find a cure and the stories they tell to their affected loved ones about the nature of their ailments—are ultimately far more important in understanding their journey from health to illness than the tissues we extract and analyse.

Today, medicine is becoming diminished in almost every measure except its budget and its ego. Massive government investments in the USA and around the world are being made to collect biological specimens, as if the secrets of healing could be found in our component parts. Rather than the more complex brain tissues that we collected, biobanks are increasingly collecting fluids such as blood to harvest cells that themselves contain the even smaller elements, the all-powerful genes, and, beyond them, the essence of life: DNA. It is necessary that we rise above this reductionism and remember the ancient truism that healers serve society (and life) by understanding their own stories and appreciating the stories of their patients. This is the true art of medicine—a core component of the healing and holism that we have lost.

The evangelists of genetics promise a future of personalised cures that will emerge from a mastery of the human genome. Such knowledge is exciting and of potential benefit. Yet no matter how successful medicine is in expanding the frontiers of the genome, an individual's genes will be only one component of a broad, deep social and ecological matrix that affects health over our lives. To understand the multifactorial nature of health and disease in a community, it is essential to explore cultural contexts as well as individual subjectivities, and the best way to do that is through stories. Now is the time for a true personalised medicine rooted in the art of storytelling and the science of biology to assert itself in support of the quality of life of individual patients.

Scientific advances in Alzheimer's disease have led us down a narrow path on the journey to addressing the major societal challenge of age-related cognitive impairment. We need to break down the hyped-up language of exaggerated therapeutic breakthroughs. We now believe that "Alzheimer's disease" is really a heterogeneous set of conditions intimately related to ageing processes that we should consider a family of disorders rather than a single condition. We have also come to recognise major overlaps among conditions previously thought to be discrete entities—most dementias feature mixed pathologies. An unrelenting, largely exclusive pursuit of better molecular understanding of brain ageing has led to greater confusion—the Alzheimer's disease story has stalled out. A closer look at the 100-year old history of the "disease" tells us that even Alois Alzheimer himself did not believe the cases he observed in the early 20th century should be considered as separate disease entities.

So how do we invigorate our scientific and clinical approaches to brain ageing? In Cleveland, we are turning to a new form of banking—that of personal narratives



*Autobiography* (c.1945) by Marc Chagall

from individuals in our community who are affected by brain ageing. The Cleveland Regional StoryBank—a transdisciplinary planning effort of scholars in the health sciences, humanities, social sciences, and ethics—is a project designed to collect, store, and analyse individual stories related to health, illness, and disease to enrich knowledge of subjective health and illness experiences, and ultimately to improve individual and public health in our region and beyond.

There are revealing conceptual parallels between biobanks and our StoryBank. Genes are a smaller component of cells that join together to form tissues. Tissues themselves are contained in organs which are contained in bodies that exist in complex ecosystems. At the highest (and most neglected) level of analysis, an evolutionary approach to medicine can show us how our genes are modified as a function of surrounding environmental conditions. Similarly, stories are composed of words ordered by syntax that form units of meaning. Stories are carriers of meanings, belonging to and forming the essence of individuals who, in turn, are members of local, regional, national, and international communities that originate, protect, and evolve those stories. Narratives change through complex political and cultural processes that at their heart depend on our awesome ability as a species to learn and gain wisdom from experience.

So how do stories affect health? The narrative medicine movement has arisen in the past few decades heralding the belief that each individual's story is unique. Healing emerges from living out an integrated life narrative that promotes coherence and purpose. Doctor-authors such as Oliver Sacks, Arthur Kleinman, Rachel Remen, and Rita Charon promote the power of story to foster understanding and healing. They cite a need for doctors to have a narrative competence (as well as humility) when interacting with their patients. Intuition, clinical experience, and some hard evidence suggest that there are physical, emotional, and mental health benefits conferred on people who share stories about illnesses. Further, stories have the potential to create and strengthen relationships, and also to cultivate empathy and understanding in ourselves and others who bear witness to the words and visages of suffering people.

Many caregivers and people with dementia have begun to communicate their stories in various forms. However, until now, we have never attempted to systematically collect and analyse stories about personal experiences of illnesses such as so-called Alzheimer's disease and analyse them with the same transdisciplinary approaches to tissues that have precipitated biological insights.

Our pilot banking of stories has begun in two areas: what quality of life means for people with dementia and what the perceptions of genetic risk are for those who have family members with dementia. The first set of stories was provided by residents with a diagnosis of dementia at an assisted living facility in Cleveland. These individuals

volunteered to read with children at the Intergenerational School—an innovative charter school in Cleveland. Contrary to the expectations some might have of "Alzheimer's victims", the participants in the study shared a need to maintain a sense of purpose and usefulness in their lives, and expressed that the relationships they formed with children of the school met this need and contributed to their quality of life. Some even identified health benefits that they attributed to working with children: a reduction in psychosocial stress and an elevation of mood.

Our second set of narratives was donated by individuals at risk of dementia by virtue of a family history. They had been tested for the presence of a susceptibility gene and the quantitative research showed that they reported acceptable safety and satisfaction with the information received. Yet their narratives told a more complex story. People often did not understand, remember, or act on what was shared with them about their relative risk. This, in turn, underscores the ethical implications of disclosing vague genetic information to patients in the clinic or via direct-to-consumer companies.

Our clinical experience and StoryBank's pilot data show that good medical care for those with cognitive decline must transcend the current reductionist approach to include and embrace the life stories of individuals. Labels need to be rethought. Alzheimer's disease should be viewed, at first, as a two-word phrase that communicates a frightening cultural story rather than a specific pathology. It is time to reconsider the scientific and cultural story of this disease and imagine new personalised narratives based on a life-long, ecological view of brain health. Our own stories about brain ageing can be informed and enriched by the stories of those with cognitive challenges and their carers.

Almost 25 years ago, we began a journey with Bill shaped by a commitment to science and to care that was embodied by the gift of his mother's brain tissue. Others have enriched our understanding of the value of words and narratives in service of patients and communities. Today is the time to reassert the value of stories and appreciate the power of myths in medicine. With the innovative use of information technology, new media, and hermeneutic approaches, we can improve on the abilities that human beings have shown over the centuries to tell meaningful stories in the service of health, solidarity, and survival. It is our ambition that the concept of StoryBank can create a "big" humanities and social sciences initiative on a par with the "big" biology project of mapping the human genome. At no time in the history of our species has the need for shared storytelling and the potential resultant collective wisdom and action been greater.

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**Further Reading**

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For more on the **Intergenerational School** see <http://www.tisonline.org>

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