

Foreword



I first meet Helen and Allan Carswell in January 2006. It was a time of hope in Alzheimer's research and Allan and Helen were eager to become pioneers along with clinical researchers such as myself.

Allan and Helen had been living with Helen's symptoms of Alzheimer's disease for at least eight years before they found me and, as was generally the case with this disease they still had many unanswered questions. We embarked on a relationship of learning from each other what was possible and how we might bend the future. As a neurologist, passionate to improve outcomes for those with Alzheimer's disease and acutely aware of the partnership that this journey would require, I saw with Helen and Allan, as with all my patients, the precious opportunity to contribute to something greater than ourselves ... and what accomplished partners they were, Allan with his professorial curiosity and Helen with nursing and business prowess and her ever-reassuring smile.

These were early days in Alzheimer's clinical trials. Diagnosis could only be made certain through autopsy and care strategies and technologies to support families and improve quality of life were in their infancy. We had no amyloid scans, no means of measuring tau (the other toxic brain protein in Alzheimer's disease), and no biological markers of risk or of disease progression to give us a true snapshot of where each person stood vis-a-vis this dreaded disease. Similarly, there were no GPS tracking devices, no

museum and art gallery programs, and no formal means of ensuring that the rights of those facing loss of decision-making ability would be adequately protected.

The field would slowly evolve over the ensuing decade toward a more biological approach to Alzheimer's disease and would begin to take aim at the underlying pathological drivers of the disease, not just the symptoms. Eventually, early detection would become a mantra of the field and even the notion of prevention gained traction.

As Allan asked his questions, the field worked in parallel to come up with answers, whether on the topic of diagnostic certainty, better cognitive tools, or better quality of life measures. Allan and Helen's ability to adapt to their evolving situation, however, far outstripped the pace at which neuroscience could provide answers.

Allan and Helen grasped the imperative of clinical research and embraced the process. They participated in not one but three treatment studies over a period of several years, never flinching at the commitments required of them with each study. Through their involvement, they paved the way for the once daily formulation of galantamine, now in widespread use, as well as for Health Canada's approval of memantine, another mainstay symptom treatment in Alzheimer's disease. Countless Canadians have since benefitted from their efforts. Equally significant is the fact that they participated in one of the early disease modifying studies assessing an experimental anti-amyloid agent. While the trial did not show the hoped-for benefit, it yielded important lessons that helped shape

the subsequent wave of anti-amyloid approaches that dominated the next fifteen years of Alzheimer's clinical trials.

Allan's story is one of enormous personal growth over many years as he educates himself about a perplexing disease, hones his caregiving skills, pursues creative solutions to the ever-emerging new challenges, and carefully measures when to fight back and when to accept the inevitable. He combines intellectual curiosity with a nimble adaptability, never losing sight of the humanity that lies within and the primacy of his marriage and family.

For Allan, nothing is too much when it comes to caring for his beloved Helen, whether demolishing and rebuilding their house, acquiring a wheelchair van, or the many other revisions and detours that would allow Helen to be safe and happy and allow Allan and Helen to remain at home together.

This book is full of devotion, kindness, guiding principles, resiliency, and practical advice that ring true to the reader whether naïve to the Alzheimer's experience or intimately acquainted with it. We can all learn from Allan how to live, love, and face challenges head on, with an unwavering resolve to see the glass as half full.

Sharon Cohen, MD, FRCPC
Director, Toronto Memory Program