Foreword

Representative Patrick J. Kennedy

We are at an inflection point in history—an unprecedented stage in human development when life expectancy is almost double what it was a hundred years ago. This is a remarkable and historic achievement. More than half of babies born today in a developed country can expect to live into the triple digits. The largest growing demographic in the United States is the eighty-five and over cohort, many of whom will remain active and engaged well into their nineties. But close to half will suffer from some form of dementia. Others will struggle with chronic illnesses they may not have survived a generation ago. With this increase in longevity comes a growing need for care.

Foreword

As Jody Gastfriend powerfully illustrates in *My Parent's Keeper*, families like yours are providing that care with compassion, dignity, and dedication. You are working mothers struggling to carpool kids and drive your father to the doctor. You are only children with no siblings to share or spar with. You are recently launched millennials caring for an ill or impaired parent. Family caregivers come in all shapes, sizes, and colors. What unites us is greater than what divides us. We share in a common struggle: providing the best possible care to our family members without sacrificing our own health, jobs, relationships, and well-being.

In my book *A Common Struggle*, I share my lifelong quest to end discrimination against mental illness and addiction. This mission is the result of my personal and family history confronting these challenges and absorbing their painful and powerful life lessons along the way. Although I experienced the destructive effects of silence and shame, I was ultimately healed by the redemptive power of love and faith. And I learned that care has a value. It is what saved me. It is what you, as family caregivers, provide to your loved ones every day. But you can't do it alone. The challenges you face may seem unique and private, but they are in reality shared by millions.

My Parent's Keeper takes an unflinching look at the dif-

Foreword

difficulties caregivers face every day—stubborn parents, squabbling siblings, workplace discrimination, and our fragmented healthcare system. Caregivers themselves are at greater risk for depression, addiction, and stress-related disorders. If we ignore our needs as caregivers, we do so at our own peril. Yet there is a path forward and a power to our collective voice. Together, we must demand that workplaces support caregiving employees and speak up when they do not. We must insist that family caregivers are recognized as essential contributors within the healthcare team and not be sidelined. We have to muster the political will to offset the staggering costs of long-term care. We must adapt technology to allow people to age more independently in their own communities. And we must demand funding for Alzheimer’s disease research and eradicate this agonizing and terminal disease in our lifetime.

During my time on Capitol Hill, I authored and co-sponsored a number of bills that addressed the needs of seniors and their caregivers, including the Nurse-Family Partnership Act, the Positive Aging Act, and the Alzheimer’s Treatment and Caregiver Support Act. We need these legislative calls to action—while recognizing that the challenges faced by caregivers cannot be met with policy initiatives alone and must be tackled within real-life families. Most of us will someday be a caregiver or

need care ourselves. We cannot put our heads in the sand and hope to avoid this inevitability. We must also take the bold personal steps of acknowledging that aging and mortality should not be shunned, but rather understood and embraced.

My Parent's Keeper will help to educate and thereby empower caregivers in the trenches—sons, daughters, nieces, nephews, spouses, and partners who struggle to do the best they can with what they have. While each story is different, the burdens and benefits of caregiving have a universal theme. Assuming the care of our aging parents is an experience fraught with uncertainty, frustration, and loss. As the end of life approaches, we may feel a jumble of emotions: sadness, relief, and a resurgence of love and connection. When we bear witness to our parents' final journey from this world, we are left with their essence: memories and life lessons forever embedded in our consciousness.

I know firsthand the pain of losing a parent. Most Americans remember my father, Senator Ted Kennedy, as a dedicated, hard-working public servant. But he also was my dad. At times, it seemed that he was larger than life—that he could fight any battle, take on any foe. When my father was diagnosed with brain cancer, I knew he was facing a formidable enemy. I was with him in the House chamber after President Obama's inauguration when he

Foreword

suffered a debilitating seizure. I watched with reverence as he delivered an inspirational speech at the Democratic National Convention, still reeling from the effects of chemotherapy. At my father's funeral I reflected, "Most Americans will remember Dad as a good and decent hard-charging senator. But I will always remember him as a loving and devoted father." At the end of my father's life there were unforeseen gifts I could not have anticipated. Our relationship, for years often strained and distant, now became closer. My father told me of his great pride in my work on the Mental Health Parity Act. We shared moments of quiet connection. We expressed, often without words, the deep love we felt for one another. As I saw my father weaken from disease, I also saw his strength. Even as his health deteriorated, my father continued to promote causes he believed in. I share his fighting spirit. I've spent my entire career advocating for mental health and substance abuse treatment for all. I fought many hard-won battles in the Congress. At the same time, I was facing the most important challenge of my life—caring for my own mental illness and addictive disease.

My personal struggle and family relationships taught me a great deal about what it means to care and be cared for. It is not so different from your struggle. When confronted with illness and debility, whether your own or a

loved one's, you must open yourself up to vulnerability and help. As caregivers we needn't soldier on in silence. Growing up, I experienced the destructive power of silence during my mother's long struggle with alcoholism. I learned to acknowledge her disease, as well as my own, and build bridges to combat isolation. I grew to understand that our collective voice is strong and powerful. What I also learned, which is echoed through the pages of *My Parent's Keeper*, is that we must reach out for help, seek support so we feel less isolated, acknowledge conflict and talk about it in ways that heal rather than hurt us. We must also be proactive and arm ourselves with information to prepare for the road ahead.

My Parent's Keeper will help—providing you with a fundamental understanding of long-term care and how to work within your own family, warts and all, to avoid common pitfalls. These compelling stories of overwhelmed caregivers, coping with their loved ones' dementia, chronic illness, and the difficult journey through end of life care, may resonate with your own experience. The lessons in *My Parent's Keeper* should be shared with family, friends, coworkers, and colleagues who are caregivers themselves or may someday travel in our footsteps. They too will join a community of dedicated people whose journeys are poignantly unique yet profoundly universal.