

MENTAL HEALTH ISSUES OF PARTICULAR GROUPS:
(1) THE DICHOTOMIES OF CAREGIVING: MENTAL HEALTH
CHALLENGES
OF INFORMAL CAREGIVERS

by

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Life as a caregiver

When I developed the outline for this article, I thought the hardest part was over. After all, I had been for 14 years a caregiver for my father – a man who suffered from mixed dementia, crippling arthritis, incontinence, aphasia and dysphasia, a man who ended a proud, accomplished long life in a faceless long term care facility. I had been through it all and believed I understood caregiver emotions and what it's like to have one's mental health and well-being compromised because of love for another.

But as I began to unravel my thoughts and memories, I realized that it's as difficult for me today as it was then to understand what went on in my mind and how these thoughts and emotions changed my life completely.

Logic tells us that caregiving today should be easier than ever. Yes, our health care system is under huge stress; yes, our population is aging rapidly and yes, we live in an age where there is too little time to think about life and our obligations to others and ourselves. But what about the never-ending advances in medical technology, miracle drugs and aids and equipment that allow seniors to live healthier, more independent lives? Don't these realities make up for all caregiving difficulties we face in today's world?

The answer is definitely no. My caregiving experience taught me that because of the long list of physical and cognitive deficits endured by my father, I ended up adding spouse, parent, personal care aide, friend, chauffeur, decision-maker, advocate, personnel manager, financial manager and funeral planner to my role as daughter, How could anyone fill all these roles and emerge unscathed?

There are 4.5 million caregivers in Canada today who are sacrificing all or part of their lives to care for chronically or terminally ill loved ones. No matter where care is provided – in the home or in an institution – caregivers invariably end up paying for products and services out of their own pockets. In fact, informal caregivers' financial contribution – in the form of subsidizing the cost of services delivered to the home, and in casual expenditures (food, laundry, gas, parking etc.) – totals about \$100 million a week or more, suggesting that caregivers spend at least \$5 billion a year. Many caregivers report they have had to cut back on their personal budgets, use up their savings or borrow money to meet their caregiving financial obligations (Berger Monitor Special Report 1999).

The economic value provided by family caregivers is enormous. It is estimated that help given to seniors alone saves the public system over \$5 billion per year (Fast, Forbes & Keating, 1999) and is equivalent to the work of 276,509 full time employees. (Keating, Fast, Frederick, Cranswick, 1999).

Yet there are no formal, customizable and accessible training programs for caregivers, no 24-hour help lines, no national policies for financial support or job protection and certainly no formal recognition or thanks for putting our lives on hold.

Of course there is help available to caregivers. But what and how much often depends on what province you live in, or whether you live in the city or the country. Getting help also depends on our connection to our community, on knowing the questions we need to ask as well as on our awareness of what we are owed by society and governments. But getting depends mostly on our ability to ask for it.

I have heard professionals say over and over: “Why don't caregivers ask for help?” “Why do they tell us in surveys what they need and then ignore the services that we develop?” I believe the answer is this: being a caregiver is like walking a tightrope. As long as you hold on to your pole - your support – and maintain your concentration, you may wobble but you will keep your balance and remain upright – physically and emotionally. You don't feel you need help. But as soon as something begins to shift and your pole becomes unbalanced you start to lose control, you lose your balance and you fall. You still don't ask for help because you now think it's too late to fix the impossible. There is no escaping this reality where there are problems that can't be solved, questions that can't be answered and complexities that can't be understood — where the only relief comes in someone's death.

When I read Webster's definition of dichotomy - a separation into two parts that differ widely from, or contradict each other – I knew I was seeing the essence of caregiving. When you look at most caregivers, you can almost see two people precariously existing within the body of one. You experience a person wrestling with contradictions that sometimes even she does not see or accept, a person struggling to rationalize extreme polarities.

What are some of these caregiving dichotomies that demand such a delicate balancing act?

Sense of accomplishment vs. hopelessness and despair

Caregiving is a task-oriented and emotional minefield. Most of us can do the physical job. We even take pride in learning how to assist another with dressing, eating or transferring. On a good day we feel useful, even capable, and positive to the point of believing our expert care may in fact influence the course of the illness. We revel in our accomplishments.

But then a fall happens — in the home that we so carefully modified to prevent just such a catastrophe. Our euphoria turns in an instant to despair. We admit the unthinkable: Who am I trying to kid? I can't change things at all; in fact I barely cope from day to day.

Our fatigue permits us to surrender to the emotional turmoil that is always just beneath the surface. We are torn between knowing we can do the job better than anyone else and admitting that we lack the tools — knowledge about the diseases we face, treatment options, appropriate medications and, more importantly, the experience to make the right decisions when the times inevitably come to make them. We feel helpless; we become hopeless.

Relief vs. guilt

When I made the decision to place my father in a long term care facility, I was emotionally burned out. I could see no other alternative for either of us. Intellectually I knew my father needed what I could not give him — 24-hour, two-person skilled care in a safe environment. But I was still overwhelmed with remorse.

I had to admit I felt relieved that someone else would now take over the minute-to-minute care and watch over my father's well-being. The other side of me raged at my selfishness. How could I do this to my own father, who was so fiercely independent and had instilled this quality in me? How could I put my needs before those of my father, a helpless, frail shell of a human being? The guilt was inescapable and filled me with a profound sorrow that still lives in me today.

Fortunately, time and a wise fellow caregiver taught me a valuable lesson. Placing my father allowed me to concentrate on loving him and not on worrying about him. I was released from the constant tension of doing, so I could now just be with my father, to sit quietly beside him, hold his hand and comfort him with my presence. I had time to quietly care.

The need to control vs. the ability to accept help

Caregivers are renowned for saying: No one knows my loved one better than I do. I can do the job better than anyone else; it's easier if I just do it. Some of us refuse help because we are perfectionists who don't want others to know that we need any help; others come to fear that the caregiving may be taken away from them, robbing them of their reason for living.

I believe what caregivers are really doing is trying to preserve some degree of control over a situation that has spiraled out of control. We need to do it all, yet we also resent being left totally responsible for the life of another. Whatever goes wrong is our fault because we are not working hard enough.

But something else is also going on here. In today's world we are considered successful if we are capable and independent. As we grow up we learn to regard the need to lean on others as a sign of weakness or as an indication of decline.

Suddenly we become caregivers who are supposed to ask for help, to depend on others. How can we reverse years and years of learned independence virtually overnight without feeling anxiety, confusion and fear — of losing what we have been taught is a requirement for a successful life? Caregivers have lost the war before the first battle is fought. We need to change the rules of the game so that we grow up understanding that we all need others for varying reasons throughout our lives; it's normal and essential.

We must learn to heed the words of one wise old woman who said: "If you accept help you teach the next generation how to give help" (Lustbader 2001).

Anger vs. acceptance

When someone we love falls ill and we know things will only get worse, we get angry. The more we care, the angrier we get because it's all about someone else and not us. Why my father, my mother, wife or husband? We rail against fate, seeing only the injustice of it all, particularly when we must watch a loved one lose his mind to dementia.

Anger is a healthy part of an emotional life. It allows us to admit to and put words to pain so deep it seems unbearable. But when anger consumes, it burns like a raw flame. There is no room for anything positive as everything that we have always cherished starts to die.

Over time, my anger started to give way to acceptance. I learned that I could not change or control what was happening to my father's mind and body; what I could control was the life I learned to build for my father, one in which he felt safe, loved and protected. There were setbacks but I accepted each new challenge, each change in his capabilities and occasionally felt triumph in my own small way over the seemingly impossible, because I finally accepted the fact that my anger was justified.

Loss vs. gain

How we view our caregiving experience can colour our mental well-being for the rest of our lives. Some look back on their caregiving journey and see only pain and suffering; they see themselves and others as failures because no one was capable of changing the course of events. They continue to experience unending loss – lost companionship, lost time, lost opportunities, loss of self.

In the few quiet times we allow ourselves for contemplation, we have the unhealthy habit of repeating over and over: I should have done more; I should have been there more. Caregivers need help understanding that in giving everything they have to another they end up finding themselves. They need help in rejoicing in their huge capacity for love and forgiveness – expressed through the selfless act of caring for another. Without this awareness, they may never recover their initial spirit and zest for life. They risk remaining bitter and inconsolable, unable to ever recognize caregiving for what it can be — an incredible opportunity to give the best of yourself to another and realize that you have made a unique difference in someone else's life, a difference no one else could ever have made.

Self sacrifice vs. self preservation

Although many men provide care for others, most caregiving is still performed by women. We learn to associate caregiving with family, duty, and commitment because we learn caregiving from our mothers who held these values that they absorbed from their mothers.

Most women never entertain the idea of saying no to caregiving. Society expects women to sacrifice themselves for others and so we respond to the call. But the call in today's world is not one that lasts for a few weeks or months but one that can last for twenty years. We struggle to be the accomplished wives, mothers and professionals that society expects us to be while seeing our souls and our spirits slowly being extinguished because we cannot be all things to all people, even ourselves. We rage silently at our self-sacrifice because we are powerless to stop it.

I was once told that depression equals swallowed rage and I now realize how true those words are. I swallowed my rage so many times caring for my father that I was no longer aware I was doing it. I thought I was functioning, managing my life and my father's; I kept telling myself I was OK. Suddenly one summer morning I could no longer function. In the blink of an eye I felt absolutely incapable. I was diagnosed with depression. I had succumbed to the pressure and the worry and the self neglect even though I believed I could rise above them. I became skilled at meeting my father's needs while becoming totally unable to meet my own. Self-sacrifice had won once again.

Grief vs. fulfillment

Grief is a caregiver's constant companion, from the day of diagnosis until after the day of death. It starts with the little things — the inability to go out for dinner or the loss of a weekend trip. But the grief continues to grow as the losses reveal themselves to the caregiver in crisis after crisis. We know death is coming but we are denied the small joys that can keep us going because we will not allow ourselves to grieve for that moment and then continue on. Small sorrows collect and sneak up on us, preventing us from feeling that we are decent human beings doing the best we can.

When our caregiving days have passed most of us feel too little satisfaction at what we have accomplished. How many of us say to ourselves after the death of a loved one for whom we cared: "I am satisfied with what I did." As my friend Sandy admitted after her mother's death: "I think I played the game well but I didn't win the prize". I believe very few caregivers allow themselves the peace that comes from knowing that they did everything humanly possible for the sake of another and that it was enough.

Caregiving and dementia

Caregiving until the end of life leaves few untouched. In most cases the death of a loved one allows caregivers to heal and move forward, wiser in the knowledge that the circle of life continues as it always has. Dementia, however, imposes its own set of unique sorrows upon caregivers because when the dementia journey is supposed to be over, it's not over. After this unspeakable injustice has robbed us, the daughters and sons, of those we love, after we manage to shake off the shock, the fatigue and the disbelief over what we have managed to live through, what remains is the dark terror that we will follow in our parents' genetic footsteps.

If a little knowledge is a dangerous thing, what will too much knowledge do to us who are left behind, year, after year, after year?

Caregivers spend their days walking a fine line between success and failure, joy and grief — between life and death. There is no tougher task in life. We must encourage caregivers to feel and express the dizzying range of emotions that influence their mental health from day to day. By helping caregivers to openly accept their strengths and weaknesses, their own needs and biases, health care professionals can then normalize these feelings and reactions and allow caregivers to better bear the incredible demands made upon their bodies and souls.

References

Enviro-nics Research Group. *The Berger Monitor Special Report: Health Services in the Home and Informal Care Giving*, 1999.

Fast, J.; D. Forbes and N. Keating. *Contribution and Needs of Informal Elder Care Providers in Canada: Evidence from Statistic's Canada's 1996 General Social Survey on Social Supports*. Health Canada, Health Promotion and Programs Branch, Health Systems Division, 1999.

Keating, N.; et al. *Eldercare in Canada: Context, Content and Consequences*. Statistics Canada and Ministry of Industry, 1999.

Lustbader, W. *What's Worth Knowing*. New York: Jeremy P.Tarcher/Putnam, 2001, p. 154.

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