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Caregiver for Life

by Stephen D. Gresham and Glen E. Gresham

My father and I had the same reaction when we looked at our copies of *The New York Times* on a Saturday morning at the end of January. On the front page, just above the fold, was an article entitled, “A Contrarian View: Save Less and Still Retire with Enough.” Had we read that headline correctly? After decades of helping retirees cope with financial and medical issues, our shock and dismay were the same as if a parenting magazine had declared “Let Kids Play in Traffic — It's Fun.”

After her traumatically brain-injured (TBI) son, Jim, had finally settled down and gone to sleep, Adelaide Newton sat alone in her living room to ponder her current situation.

While her two older children were married, had children and were living independent lives of their own, Adelaide, a widow in her early 60s, had to decide how to deal with Jim, 19, once a very promising college student. A skiing accident had left him with permanent mental limitations. She had barely recovered from the loss of her husband from a sudden heart attack when the call had come that Jim was being airlifted to the regional trauma center.

Now, many months later, she had to decide on a long-range plan. Although Jim had done well in rehabilitation and his left-sided spastic muscle weakness improved, his thinking and behavior were still severely impaired. There seemed to be no probability that he would ever be able to live on his own. The social worker had made it very clear: You will have to decide, Mrs. Newton, whether to keep Jim at home with you or start looking for a long-term placement. At the time, Adelaide had smiled and nodded. Now, she resented the fact that she had to cope with this alone. She had searched for another solution but now knew that the social worker was correct, she would have to develop a plan.

During this trying time she had become very familiar with the singular burden borne by the parents of a severely handicapped child not just those with TBI, like Jim, but children with congenital anomalies and disabling conditions of all sorts. Some were less severe than others but they all were life-changing responsibilities for parents who had never expected to be confronted by such a challenge. Adelaide learned about SSDI, Medicare, Medicaid, groups homes, special schools, sheltered workshops, support groups, respite care and devoting the remainder of one's life to the caregiver role. She had not, however, been able to decide which route to take.

It suddenly occurred to her that a college classmate had faced a similar fate with a young daughter due to an automobile accident. On an impulse, she looked up the number in the alumni directory and called.

After a few reminiscences, Adelaide revealed the true purpose of her call. Her friend was empathetic but curt. She had obviously been through the wringer with her own problem and family. “Adelaide,” she said, “quit dithering. Get out and get as much advice from knowledgeable sources as you can find. Then sit down, list your options and, with appropriate help, assign a cost figure to each. Once you feel ready, make your choice. There is no other way.”

BIG CHALLENGES, BIG REWARDS

Families with special needs children are remarkable in many ways. Their profound responsibilities force them to be financially astute decision makers with both short-term practicality and a long-term vision in mind. They are constantly challenged by the need to juggle shifting priorities out of their control as dictated by the needs of their child. And most significantly, there is no end to their job.

The caregiving family has the attributes of the ideal client for your practice. Your responsibility is to share that focus. Connected as they are to other families similarly challenged, the network created by their common issues both bonds and protects the families. You can be either a valued provider or dropped like a hot potato, depending on your level of service and empathy.

BUILDING THE RELATIONSHIP

Assuming you meet the family after the care situation has developed, there are three primary phases of your relationship and your level of responsibility:

Acute Phase

- Early on you must assess all known and potential risks to both the child and the caregiver. Action items:
- Life insurance on the caregiver sufficient to guarantee special needs are met
- Disability insurance on the caregiver
- Advance directives for care of the child, including naming both medical guardian and financial trustee (not the same person)
- Establish a trust to own the existing assets, if substantial and/or to own the life policy

Care Phase

- Health saving accounts and medical savings accounts as available
- 529 plans for educational opportunities

Long-Term Care Phase

- Life insurance for the child, subject to condition and availability
- Longer-term savings via trust in the event of the caregivers demise
- Long-term care for the caregiver
- Locate continuous-care retirement facility (pre-funded)

The increased longevity of both special needs children and their parents force a level of planning unknown to past generations. Your assistance is invaluable and will become known across a network of families. Beyond your income, service to these remarkable families will compensate your soul.

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