

Coping with Special Needs Along the Continuum: When Aging Parents Need Aid

Special points of interest:

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Lifelines for Care**
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Recently I read a blog post from a parent who said she could never die because who would advocate for her adult daughter with Autism. This is a real worry of many parents all over the country. Down Syndrome, Intellectual Disability (formerly called mentally retarded) and Autistic adult children are now living into old age and can have very old parental caregivers. This new “geriatric population” presents new challenges for professionals and families.

The aging of special needs children presents two problems to society and families: Who will provide care and oversight when the parent is unable or dies? Special programming for these aging adults who had abundant services prior to turning 18 is almost nil after

60 and even in young adulthood not as rich as it was prior to turning 18. We have innovative programs throughout the country but they can serve only a small number of individuals who could benefit by enriched environments.

This population is in need of professionals who can counsel, advocate and guide both the aging primary caregiver and the intellectually delayed child.

Case Studies: Lifelines for Care

Alice is 86 and she is the primary caregiver for a daughter with autism who is 56. There are no other children or local family and she needs advocacy with her changing cardiac condition as well as with the reality of diminished energy in her ability to oversee her daughter’s care. The daughter has chronic medical issues and has become a behavior challenge at the day program causing her mother extreme stress – not good for a cardiac patient. What would Alice do if her daughter was no longer appropriate for the day treatment center? Alice toys with the idea of placement, but always rejects suggestions from the Care Manager of the community services or licensed homes found by the Care Manager.

Jim and Betty who are in their 80’s are concerned with what will happen when their soon to be 50 year-old son, who is diagnosed with schizophrenia, when they become frail or die. Currently they need only occasional advocacy and coaching. They have one other child who lives out of state and is busy with a demanding career and 4 young children. They do not want to burden this child with the responsibilities of overseeing his brother’s care.

There are a growing number of elders in their later years still responsible for the care and oversight of disabled, mentally ill or displaced adult children. Geriatric Care Managers become the lifeline for these families – giving support and guidance to the elders at the same time coaching the parents in skills that reduce behavioral outbursts.



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Preventing Elder Abuse

As Care Managers we are also worried about “elder abuse”, not that the child who is marginal in mental capacity truly understands that term, but when pushed or excited, an adult with special needs can strike out, push or hit the parent who in their 80’s could easily fall and have a negative outcome. The lives of these families are precarious and only one outburst or one serious illness away from blowing up.

Who or what is the link or life-line that keeps these families stable and balanced? It is the Geriatric Care Manager (GCM). However, for the GCM to be effective, he or she must have established a relationship with both the elder and the adult child. This takes time. In order for care management to be effective there must be a frequent and consistent communication stream between the clients and all the providers of services, both social and medical. This communication is critical for interceding in a crisis and even more for preventing a crisis with good contingency planning for those “what ifs”. That means having a plan A and a plan B.

What happens when the caregiving parent starts down the path of dementia and still has to oversee medications, medical appointments and day programs? The picture is not bright without the support and counsel of a trusted professional. The good news is that “Special Needs” trust attorneys are seeing the value of adding care management into their plans of care. This legal document is what parents of these adult children need so they can rest assured that if they have a medical crisis or the child’s needs exceed their abilities to be a primary caregiver, the Care Manager can step in and guide the quality of life for both the elder and the child with special needs.

Not only are these children living longer, they are also afflicted with the issues of aging, but often at a younger age. Those with Down Syndrome are at a 54% greater risk of developing a dementia than the general public at age 60. Those with Down Syndrome are also at greater risk for hearing and visual loss than the general public – so it is imperative of family caregivers or the Care Manager to have regular evaluations of possible sensory losses. It is through our senses that we experience the world around us and to have sensory loss and cognitive loss can greatly restrict the ability to have any quality of life.

The most challenging issue facing the older geriatric parent caring for these individuals is “behavioral” changes. These changes can be brought about by the special needs child sensing the parents inability to care due to age or illness or the reality that the person who had advocated for them no longer has the energy to be their champion when things go wrong. Acting out behaviors such as aggression, agitation, sleep disturbances, anxiety disorders or self-injurious actions can threaten enrollment in a social day program, as well as the safety of the elder caregiver.

This is when the GCM can be a great asset to the family system in diagnosing the environmental changes, health changes or aging related changes of the “special needs” child and be the eyes to the attending physician who oversees and prescribes the psychotropic, anti-agitation or mood disorder medications. It is important that these medications be reviewed periodically to minimize side effects.

The knowledge base needed in the Care Manager that is going to work with the aging cognitively delayed client and/or aging caregivers include the following to name a few...

- Awareness of entitlements and benefits.
- Awareness of community services for both those with life long cognitive challenges as well as for family caregivers.
- Knowledge of the legal tools and attorneys to advise and secure a plan of long term oversight for the entire family.



- Knowledge of respite settings to give primary caregivers short term breaks.
- Awareness and knowledge of behavioral interventions that can be effective with aging special needs client.
- Knowledge of medication side-effects.
- Conduit of information on behaviors to primary care physicians.
- Medical advocacy and pro-activity when health status changes.
- Counseling skills to help the primary caregivers with their anxiety, grief and worry.
- Coaching primary caregivers in self-care.
- Knowledge of housing and group home living environments.
- Creativity in finding ways to enhance the lives of all parties based on the families values.

Eldercare Services provides Counseling, Support Groups, Home Care and Care Management to aid Family Caregivers. If you or someone you know could benefit from self-care, give us a call at (866) 760-1808 or email us at Info@EldercareAnswers.com.

It is possible that a 70 year-old caregiver still has their aging parents and an aging “special needs” adult child. The burden of care is great and signs of depression and or exhaustion must be monitored in order for primary caregivers to continue to provide family care. About 80% of all care is provided and managed in the home.

The Care Manager might have to advocate for increased funding for family respite, special medical equipment, and respite camps for the aging adult and other systems that will increase the quality of life for the challenged adult as well as for their family caregivers.

Any and all behavioral changes could be an indicator of a medical problem, depression or a psychiatric disorder and need to be carefully evaluated. The precariousness of these families warrants frequent visits by the Care Manager in order to watch for signs needing immediate attention.

Creating Outcomes Through Specialized Knowledge

Alice’s Care Manager has found a care home that will take the daughter on short notice so that any time her health warrants hospitalization, or she just needs a break; her daughter goes to this home run by a professional who has worked years with the Autistic population. So, plan B is to go to the “Respite Care Home” whenever Alice can’t cope for any reason. The Care Manager then continues to oversee and advocate for both family members.



Jim and Betty just needed to meet the Care Manager and have knowledge about their company so that they can have the services of this company written into their “Special Needs Trust”. Jim wanted the Care Manager to visit twice a year until they felt they could no longer manage their son. Betty also wanted the Care Manager to know their son and a family meeting was arranged on his most recent visit. This case is managed very lightly because that is all that is currently necessary, but they like meeting twice a year and feel a great relief knowing someone as capable as the professional Geriatric Care Manager they have chosen will pick up the pieces should either of them not be able to oversee care.

The dedication and love of these family caregivers is beyond description. Some parents have been providing hands on care and advocacy for 60+ years. Care Managers can bring peace of mind to secure the best future for their special needs children thus increasing the quality of life for the elder caregivers and the aging child. Less stress and anxiety means less illness and/or depression.

Many members of the [National Association of Professional Geriatric Care Managers](http://www.CareManager.org) actually specialize in working with these specialized populations and welcome others interested in this field to join us. More information can be found at: www.CareManager.org.

For a list of what a Care Manager will do for you, contact Eldercare Services at (866) 760-1808 or Info@EldercareAnswers.com