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White Paper
**Navigating Caregiving
in Uncharted Waters**



Presented by the
Professional Advisory Board of SeniorBridge
and a panel of thought leaders
in the fields of aging and healthcare

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Navigating Caregiving in Uncharted Waters

Professional and Consumer Views on How to Stay Afloat

FOREWORD

As legislative mandates transform the healthcare landscape, family caregivers face fresh uncertainties and unprecedented hurdles. More than ever, a combination of changing demographic patterns and institutional reform is propelling a revolution in eldercare. Recognizing these pressing challenges, SeniorBridge strives to offer practitioners and families the tools, resources, and options needed to make wise choices about caregiving. As a broker of both knowledge and services, we are keenly aware of the value of expert information that translates to positive outcomes for caregivers and their loved ones.

Disseminating reliable and helpful information is one of SeniorBridge's core competencies. We are frequently

cited in the general press and in professional circles as the go-to source for managing eldercare. We provide valuable data and interpretation via small-group presentations, webinars, our e-newsletter *Care Notes*, personal interviews, and documents like this. In particular, sharing the professional findings and insights of national experts has enabled us to stimulate discussions on the best ways to manage complex chronic care.

Responding to a 'Paradigm Shift'

According to the Family Caregiving Alliance, the number of individuals aged 65 and older is expected to double to 70 million people by 2030. Even more notable, the "oldest old" – those 85 years old and over – are the most rapidly growing age group,



currently representing 1.5% of the population and, according to the United States' Census, projected to be 5% of all Americans in 2050. The significance of this expanding population is apparent when one realizes that these are the individuals most likely to suffer from multiple chronic illnesses and functional deficits which will most likely lead to the need for hands-on caregiving. Approximately 44 million people in the United States provide 37 billion hours of unpaid, "informal" care annually to chronically ill adult family members or friends. But, caregiving involves far more than the function of companionship, "adult babysitting," or housekeeping. Furthermore, the growing number of individuals with multiple chronic illnesses and functional deficits now require medical care at home in ways that formerly only a hospital could provide. Their family caregivers –

75% of whom are women – deliver \$375 billion in unpaid services that require broad-based knowledge and a clinical skill set in order to be effective in delivering positive health outcomes and quality of life for the care recipient and caregiver. Limited by resource allocation, however, these family caregivers go it alone without the support of trained, professional partners and resources.

In fact, today seniors account for 13% of the United States' population but nearly half (44%) of hospital revenue. One in five seniors who are discharged from a hospital are back within 30 days. However, only half recall receiving self-care instructions or seeing a doctor the month after they leave the hospital which suggests that a substantial number of hospitalizations could be prevented with adequate discharge planning, education, and follow up.



The Symposium on Caregiving

Meeting on the heels of the passage of historic health care reform legislation, SeniorBridge partnered with Selfhelp Community Services, Inc., to convene a symposium to explore how these demographic and socio-economic changes are influencing the caregiving processes for families. SeniorBridge commissioned a survey of adults who were providing elder care to loved ones in order to assess the challenges, common experiences, and well-being of family caregivers. In April 2010, 4,400 people who identified themselves as a caregiver or paying for someone to care for a person living at home were surveyed about who they were, what they did, and how they felt about caregiving. Jason Karlawish, MD, of the Institute on Aging at the University of

Pennsylvania and a member of the SeniorBridge Professional Advisory Board, reported survey highlights and provided interpretive comments. While reinforcing previous knowledge, the findings provided a stimulus for discussion at the symposium and served as a bridge to the real-world experiences shared by our guest panelists and audience participants.

This symposium also drew on the expertise of other members of the SeniorBridge Professional Advisory Board, the contributions of physicians, nurses, social workers, academic elder care professionals, and the perspectives of three guest panelists who had each authored books about their own caregiving experiences.



These authors were:

- Rosemary Laird, MD, MHSA, Medical Director for The Health First Aging Institute, Director of Leeza's Place, and author of *Take Your Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss*
- Claire Berman, author of hundreds of magazine articles and the book *Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive*
- Jane Gross, former *New York Times* columnist, creator of "The New Old Age" blog and reader forum on caring for aging relatives in the 21st century, and author of *A Bittersweet Season*, a book on her caregiving experiences.

The anticipated goal of this symposium was to develop a White Paper that would serve as a practical resource to support family caregivers, professionals, healthcare institutions, and community-based services.

White Paper

The intent of this White Paper is to explore these uncharted caregiving challenges that families must now navigate and to also suggest priorities.



CAREGIVER SURVEY: A CLOSER LOOK

SeniorBridge commissioned Amplitude Research, a professional research firm based in Boca Raton, Florida, to better understand who caregivers are, for whom they are caring, what caregivers are doing, and how they feel about it. In March and April of 2010, we surveyed approximately 4,400 people who identified themselves either as a caregiver or as someone paying for someone else to care for a person living at home. More than half of the survey recipients were outside of the SeniorBridge client base. The survey garnered 185 self-identified family caregivers who provided their responses to 14 carefully selected survey questions

From a broad perspective, Dr. Karlawish noted that the survey revealed no groundbreaking new data while seeing that as a positive. As he put it, “We have thoroughly burnished the golden statute of what it means to be a caregiver in America right now for someone with an older adult, and I

think the next challenge now is not just simply to describe that world but obviously to change it, to make it a better place.” When introducing the survey results, Dr. Karlawish also commented on the fact that it is only recently in human history that societies have normalized standards for caring for children (e.g., child labor laws). “But here we are today having a conversation about what it means and what it's like to take care of someone at the other end of life, and I think this survey will be illuminating as to both the sort of challenges as well as the opportunities and the fulfillment that people do get from the experience.”

Dr. Karlawish described a standardized approach for measuring life-space mobility, developed by the University of Alabama at Birmingham. Measuring life-space helps predict functional decline, morbidity, and ultimately, death by how confined a person self-reports their mobility, i.e. how they manage to get out of the



house, get out of their town, get out of their city, etc. So, a caregiver survey in which caregivers report and characterize their interactions and interventions with their loved ones

could potentially yield predictive information about those for whom they care.

Survey Results: The following breakdown of survey data reveals trends regarding caregivers, their patients, their tasks, and their own well-being.

The majority of caregivers are still daughters who need help.

- Two-thirds of respondents were female
- 65% of respondents were caring for a parent
- 73% of respondents don't do it themselves

The survey reconfirmed that many older people in need of caregiving suffer from cognitive problems.

- 72% of respondents need help with bill paying and financial management
- 69% need help with medication management

Difficulties with personal care suggest prevalence of severe functional impairment.

- 9 in 10 respondents have difficulty with dressing, bathing, and toileting

Caregivers define their primary responsibilities as helping with personal care and coordinating the complexities of aging.

- 1 in 3 help with cleaning, meal preparation, and laundry
- 1 in 4 help with grooming and dressing
- 1 in 5 help with bathing
- 60% help with arranging ongoing doctor appointments
- Half assist with transportation and shopping



Positive effects of caregiving are balanced by an emotional toll and a lapse in physical and financial well-being.

- 9 in 10 caregivers feel good about returning care for someone who cared for them
- Two-thirds report renewed relationships with loved ones
- 7 in 10 report strain on personal relationships
- 2 in 5 feel alone
- 2 in 5 saw decline in their own physical health
- Half report decline in financial security and describe caregiving as taking up “all my time”

Caregivers describe psychodynamic issues and coordination of healthcare and social services among their most difficult challenges.

- 4 in 5 struggle with their dependent’s emotional or memory problems
- 3 in 4 wrangle with their dependent’s resistance to help and inability to communicate
- Half report family conflicts over providing care
- 80% report difficulties in coordinating resources
- Two-thirds are caregiving from a distance

We can help families by supporting doctors in directing information and services and equipping caregivers with personal care skills & support.

- 84% report a “good relationship” with doctors
- 78% seek information from professionals
- Yet 80% struggle with coordinating health resources
- 90% report difficulty with bathing
- 88% report difficulty with toileting



Despite the fact that the 85 and older age group is the fastest growing segment of the population and that this group has at least a 50% chance of suffering from a dementia related diagnosis, caregivers are remarkably unprepared to cope with and manage the care issues involved which include resistance, behavioral problems, depression, and family conflicts. And, given our fragmented, acute-care-oriented health system, it is no surprise that so many family caregivers struggle with coordinating resources. Additionally, the frail elderly see different physicians to treat different ailments which usually requires multiple medications and increases the chance of a medical error or omission in treatment. Furthermore, when a patient is seen by multiple specialists, problems are compounded during transfers in and out of hospitals, nursing homes, and/or rehabilitation centers. The findings of our survey therefore suggest a strong need for family caregiver education and professional assistance in managing care.

NOTES FROM THE FIELD: A DIGEST OF PANELISTS' REMARKS

In introductory comments, Russell Lusak of Selfhelp Community Services, Inc. provided a portrait of Mrs. Adele Lerner as a human illustration of the people we serve in the eldercare field. About 40 years ago, Mrs. Lerner decided to begin painting, and two years ago, she had her first art show. Twenty years ago she felt it was time to begin working on her bachelor's degree which she subsequently completed. Mrs. Lerner also cooks for

herself and gets around with a walker. Her daughter, Harriet, lives too far away to visit often, but that doesn't stop them from communicating on a daily basis. Using email and a trusty webcam, Mrs. Lerner and Harriet remain very close. Mrs. Lerner puts her webcam to further use to create her own video blog. She is 104 years old.



Moderator Claudia Fine, LCSW, MPH, CMC, one of SeniorBridge's founders, initiated the conversation with some urgency by remarking on the "tsunami" of elderly people who need, and will ever increasingly require, caregivers. "But there are not enough caregivers and there aren't going to be," she noted. "So, we need to educate ourselves" regarding the best options for our loved ones.

Introduced by SeniorBridge's president and CEO, Dr. Eric Rackow, guest panelists Dr. Rosemary Laird, Claire Berman, and Jane Gross shared their experiences and expertise from three notably different perspectives. The following provides a snapshot of their offerings and insights.

Dr. Rosemary Laird

Dr. Laird is Medical Director for the Health First Aging Institute in Brevard County, Florida, and Director of Leeza's Place, a caregiver resource support center. Dr. Laird conveyed her journey toward community involvement which is one of the frequently missing links in the spectrum of elder caregiving. Her

community, Brevard County, Florida, near Cape Canaveral, is home to many NASA retirees and a high percentage of seniors. In 2002, Dr. Laird joined forces with national television newscaster Leeza Gibbons who had established a memory foundation to meet the needs of dementia patients and their caregivers after being thrust into the caregiver role for both her mother and grandmother. Dr. Laird emphasized the importance of obtaining a proper diagnosis and preparing families for the ravages of an illness that may last as much as 10 years. Much of her professional work now addresses the impact of long-term caregiving on the caregiver, and she presented a lecture series that underscored the importance of "caring for the caregiver" and encouraging caregivers to address their own physical well-being so that they can continue to have the capacity to help others. Dr. Laird's lectures ultimately resulted in her book, *Take Your Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss*. "Many books address the emotional side, but not as many the physical," she said.



She also was instrumental in establishing the first community-based care centers in Florida which were among the first of about 12 in the country. Dr. Laird described these centers as a way to fill the “void of connected services” that caregivers desperately need. “Our community centers are meant to be that oasis of help - emotional help, help navigating the health and social system, and help identifying ways for caregivers to address their own physical well-being.

“Services range from a social worker providing navigational and emotional support to a physician like myself and excellent nursing. All of us have helped develop an educational series for family members caring for beginning, middle stage, and advanced stage Alzheimer’s patients. We like to joke at Leeza's Place, if you didn't take 'Caregiving 101' in high school, you have to go through caregiving training. Of course, everyone needs all sorts of caregiving training. My hope is to create a much more expanded view which addresses not only the acute episodic needs but also views

the patient and family caregivers within the context of their history over time. We could improve an overall sense of well-being of our patients and the family caregivers if we provided continuous attention over the span of an illness.”

In closing, Dr. Laird spoke about the role of geriatric care management and it’s vital role in helping families navigate a complex system, identify resources, and share caregiving responsibilities. “One of my goals when working with family caregivers is to make sure people recognize the value of a geriatric care manager.”

Claire Berman

“You must not, you cannot do this alone” is the centerpiece of Claire Berman’s message. The author of hundreds of articles in major magazines and many books, Claire entered this field not by choice but because it found her. Both her mother and mother-in-law simultaneously had become ill; her mother was diagnosed with Alzheimer’s Disease. The subject of their needs and care had become an “obsession” for Claire



and writing the book, *Caring for Yourself While Caring for Your Aging Parents*, was her way to cope.

“It is critically important for you, the professionals, to help us not become the ‘second patient’. And it’s also very important for us, the family caregivers, not to feel that we are failing if we seek professional help. There actually are quite a bit of services available, but families have to be encouraged to accept them and not feel like they are falling down on the job when they don’t do everything themselves. The point is to recognize what we are able to do and then go find the people, the places, and the programs that fill in where we can’t. That’s true for nearby caregivers, and it’s certainly true for long-distance caregivers,” she said.

“You do the best you can,” she emphasized. “If you compare yourself to some theoretical standard or with somebody else, you’ll always fail; you’ll always feel guilty. I have never met a caregiver who did not feel guilty no matter the kind of care they gave.” Berman went on to relate the

vulnerabilities of caregivers ranging from feelings of inadequacy to emotional stress and strains on familial relationships.

“I do see it as a partnership. We have to work together, which means we have to respect one another - our boundaries and our abilities. The family member knows the patient and needs to help the professional understand who that patient was before they became ill or disabled. The professional helps to objectify the disease and facilitates communication among the family members who often need help listening to each other and agreeing on the best approaches to take.” Berman added, “And, with modern technology, all this can be accomplished with a phone conference call!”

Jane Gross

Jane Gross is a former writer and reporter for *The New York Times* where she wrote about the intersection between aging parents and adult children and created the *Times* blog “The New Old Age”, a blog and reader forum on caring for aging



relatives in the 21st century. During the symposium, Gross delivered a deeply personal narrative on caregiving which also was the inspiration for the book she was working on at the time about her experiences. "A Bittersweet Season" was then published in the Spring of 2011 by Alfred A. Knopf.

Gross' experience involved her mother who, though without cognitive impairment, was completely physically impaired. As with Claire Berman, the subject of eldercare found her as a writer. "I might as well be writing about it, other than just driving everyone around me crazy by talking about it all the time." The arc of her mother's story was sudden and catastrophic, including an abrupt move from Florida after a presenting crisis and being thrust into an arena that demanded treatment and care options of great significance.

Gross noted, as did other panelists, that hardly anyone plans for the eventuality of eldercare. "There's sufficient data to suggest that many people are like my friends who have

85 year old parents who are still playing tennis. My friends believe that their parents are going to be playing tennis or climbing Mount Kilimanjaro until two seconds before the end.

Everybody's best-case scenario and everybody's fantasy is that everything is going to be fine and then they're going to die in their sleep - and unfortunately this is everybody's advanced plan." Gross maintains that more typically there is a presenting crisis that demands hard choices for which one is totally unprepared in an emotional, physical, financial, and/or intellectual capacity. "We were absolutely blindsided by the role reversal," she said of the eternal paradox of becoming totally dependent on others at the end of one's life.

She touched on gender roles, family dynamics, and the transformative reward of caregiving. "I am haunted that I don't have a daughter. I mean theoretically who wants their daughter to do this? On the other hand, I can't imagine that there isn't anybody who isn't grateful and reassured knowing when the bad



times come that they have a daughter. I had a very difficult relationship with my mother until the last four years of her life. Like the people who would say that it was, on balance, an experience that they would never give

back, I, too, would never give back these four years of caregiving because my mother and I didn't learn to like each other until that period. I'm very grateful that she was cognitively intact so that we could have it."

PANELISTS' RESPONSES TO AUDIENCE COMMENTS AND QUESTIONS

After the presentation of our three guest panelists, lively exchanges ensued with comments and questions from audience participants and comments from our Professional Advisory Board. The following highlights trends and themes from this phase of the forum.

Gender, Workforce, and Policy

Questions were raised as to the policy implications of the demographic reality that most caregivers are female adult children and how that relates to our current economic issues and workforce shortages. Dr. Terry Fulmer, a member of the SeniorBridge Professional Advisory Board, current dean of Bouvé College of Health Sciences at Northeastern University, and former Erlene Perkins McGriff Professor and Dean of the College of Nursing at New York University,

compared this challenge to preparing for the onslaught of an approaching severe weather system.

"It's like watching a storm from the North while it hits the southern part of the United States. It's coming, it's coming, it's coming! We're all watching CNN when it hits, and we're surprised. Why are we surprised? We've known since the 1970s that there would be lots of old people," she noted. Dr. Fulmer served on the Institute of Medicine's ad hoc



committee on Retooling for an Aging America: Building the Health Care Workforce. She reported how this panel is exploring ways to deploy members of the workforce to help with anticipated caregiving demands we are facing. And in line with that, “Retooling the Workforce” legislation is being considered to support efforts to increase the number of nursing assistants, home health aids, and nurses. However, it was acknowledged that, while workforce retooling is receiving robust attention, the current level of 3 million nursing attendants is about one-tenth of what we need.

On a related front, Dr. Jason Karlawish commented that the same-sex marriage legislation in Vermont really was about addressing some of these issues on a policy scale. Vermont allows adults to enter into contracts that would cover the ability to take care of each other, share resources, take advantage of tax benefits, and avail themselves of the legal norms. He also noted that it was only recently that the federal government permitted same-sex partners to advocate for

each other in hospital settings.

Dr. Robert Butler, who passed away shortly after this meeting, also commented on the inevitable demographic shifts, remarking on the fact that it is often immigrant minorities (who will become majorities) doing the caregiving, with broad policy implications. He cited his work with the International Longevity Center and the Metropolitan Life Foundation exploring compensation, benefits, training, and norms for national certification for paid caregivers. Dr. Butler expressed considerable concern about another issue that negatively affects family caregivers which is the shortage of primary care physicians. He called on medical schools and legislators to rectify this imbalance in the medical field and suggested they offer incentives to those who choose to be in primary care. Dr. Butler also stressed the significance of the roles of non-physician health care professionals such as nurses, social workers, and rehabilitation workers and the importance of a team approach which also includes family



caregivers as an effective way to manage geriatric care.

Dr. Terry Fulmer added that she was optimistic about the future in light of some of her colleagues' initiatives and experiences, but she added, "I don't think the physicians will be the future of primary care. There is a knowledge explosion and cascade effect, and nurse practitioners will do primary care and physicians will continue with specialty care." She saw this as a positive. "In the 1930s, nurses were not allowed to take temperatures. It was considered out of our domain of practice. In the 1940s, we didn't take blood pressure; that was the domain of medicine. Every time we get something new that we know, and usually it's generated out of the world of medical science, there is a cascade effect. So, we have to un-bundle this notion of who owns what scope of practice. We have to understand and look to this whole notion of empowering the family and doing family caregiving." She cautioned that there might be concerns, and that by empowering the family, the professional is abandoning

responsibility for the patient. She also remarked on the need to further address these complex issues.

Complexity, Caregiving, and "Heroism"

Dr. Peter Rabins addressed the complexity of caregiving. "Almost all chronic care is complex. That's one of the great challenges that we face, and as a result, it has to be multidisciplinary. It can't just be medical or social or financial. A whole spectrum of services, short-term and long-term, individual and system-wide, is required." He also emphasized the importance of preserving the unique narrative of each person's story and recognizing the virtues and rewards of caregiving. "Being a caregiver is an act of heroism. One of the things I worry about when all we hear about is the burden of caregiving and all the negatives is that when you talk to many caregivers, no matter what the struggles, there are tremendous rewards in it as well. We should be celebrating people who provide this kind of care. An extraordinary thing about cultures around the world is that everywhere,



no matter how rich or poor a society, ill individuals are cared for primarily by family members.” With that in mind, he asserted that professionals will not provide all the answers to caregiving challenges.

It Takes a Village and More

Members of the panel and the audience referenced the importance of communities taking a greater “lifespan perspective.” For example, New York City and Portland, Oregon, are championing age-friendly programs that will improve the quality of life of older adults. Dr. Peter Whitehouse talked about interplay between the role of natural community connections and the need for purpose in one’s life. Recognizing that in many cases we cannot prevent cognitive decline, he reflected on human stories of community engagement. In one example, at the Shaker Nature Center near Cleveland, Ohio, older adults with cognitive impairment interacted with elementary school students from The Intergenerational School in Cleveland. “The older folks had recent memory problems, but some of them had been active in preserving the Shaker Nature

Center years earlier. The seniors and the students were in nature together and were able to create a community in which stories were shared.” Dr. Whitehouse maintains that this type of shared experience promotes brain health, encourages young people to think about their responsibilities to nature, and enables older adults to recognize their contributions and have pride in their legacy. “When we reinvent communities to be friendlier to older people with cognitive impairment they will also be friendlier to kids and their environment. So I am moving my own health practice into The Intergenerational School that my wife and I started. Part of it will be based in an urban farm where older folks, regardless of cognitive abilities, and younger folks will work together to create a sense of what is important in community - a sense of sustainability, a sense that we've got to take seriously our responsibilities for future generations. That's my vision of what that kind of community might look like.”

Dr. Burton Reifler expanded this theme by stating, “We've known for



some time that it takes a community to raise a child. Today reinforces the idea that it also takes a community to help a caregiver.” But he asked: “What do caregivers want? Is it to decrease the cost of caregiving? Is it to delay the institutionalization of a loved one? Is it to decrease the burden the caregivers may feel?” To formulate an answer, he told a story from the movie *Babette's Feast* about a woman who was a famous French chef and, who by virtue of the circumstances of the French Revolution, was forced to work as a servant. She wins a large amount of money in the French lottery and decides to put on a feast. “After the banquet, someone asked her why she did it? And she said, ‘What the artist wants is simply the chance to do their best.’ We know now that it takes a community to help a caregiver, and I think what caregivers want, given the constraints of their situation, finances, geography, and family relationships, is simply, at the end, to be able to feel that their community gave them a chance to do their best.”

A Continuum of Learning and Caring

Many audience members and panelists touched upon the need for education and training for elder caregiving and specifically education to address multiple areas of need including financial, procedural/logistical, emotional, physical, and even spiritual. Building on notions of intergenerational community “mainstreaming,” several speakers urged education at the earliest stages of life. Others talked of the need for more formal courses, such as parenting classes, offered to high school students or for family caregivers to teach classes about the complex array of skills needed for caring and coping. Most agreed that, whether good or bad, people tend to avail themselves of the proper learning resources only when a caregiving crisis is upon them.

Nevertheless, several educational scenarios were suggested; for example, focusing on secondary prevention, a course could be developed to train people to recognize a problem early on and therefore prevent long-term effects. As Claire Berman noted, “There's a big



difference between what we would like to have happen and what actually happens. People are not motivated to learn until they need the information, and it's at that point where you start teaching, coaching, and offering services. They're not going to seek out information on caregiving just because it's a thing to do on a Tuesday afternoon. They're going to seek help when they can anticipate or experience the need, and I think education begins there."

Dr. Peter Whitehouse reiterated, "In the broader context of enhancing our humanity, actually you must start the education about the importance of reciprocal relationships in childhood.

By having older folks engage with kids early on, we can provide lessons about what it means to be caring human beings and not just being professional caregivers for people with chronic disease. So embedded in that, then I think the education can start earlier."

Echoing this theme, several audience members shared their own intergenerational and mainstreaming experiences in their families, in their professions, or in their schooling. As one person put it, "You do have to expose children to the entire life cycle and not let them be afraid of people with disabilities and people who are elderly."



CONCLUSIONS

Our forum sparked spirited discussion and pointed to the pervasive need for a multi-tiered approach that raises societal awareness of issues related to aging and chronic care needs and cultivates knowledge, skills, and resources which equip professionals and families with geriatric expertise.

Anticipating Chronic Care Needs as Part of the Life Cycle

Despite available statistics and news coverage of the prevalence of chronic illness, disability, dementia, and other functional deficits among the elderly, families are surprised when confronted by the emotional, financial, and physical realities of caregiving for aging loved ones. This common reaction may be a coping strategy for the often overwhelming feelings experienced as a caregiver.

Redefining Wellness

The group concluded that by redefining "wellness" as something relevant for an older person who walks with a cane, as much as it is for a younger person who does not, we can empower family caregivers to acknowledge the challenges associated with aging and to be positive and proactive. With this perspective family members facing physical and cognitive decline of a loved one will be better prepared to support and value what *now is* rather than mourn what *once was*.

Overcoming "Ageism"

Even when older people do not have complex chronic illnesses or significant functional deficits, the participants felt that many people still lack the skills to engage older people or actually avoid interacting altogether. Education and training for elder caregiving should be intergenerational and extend beyond the healthcare and social services professions. Truly effective education and skilled training in preparation for elder caregiving grows along a continuum that spans all ages and involves the community as a whole.



Improving Caregiver Literacy

The sheer magnitude of the problems families face, including the prevalence of multiple chronic illnesses and associated disabilities and the fragmented healthcare system, creates complex problems that require solutions that can only be identified and implemented with focused training and substantial skills. To minimize vulnerability to harm and exploitation, paid and non-paid caregivers should receive professional direction and guidance by qualified care managers with a geriatric background. Seniors see an average of 12 physicians per year, and 30% are taking more than five medications daily. Without a trained advocate to keep the multitude of professionals involved consistently apprised of status changes and interventions, seniors can suffer from dangerous drug errors including drug-to-drug interactions, under- or over-utilization of a drug, duplication of therapies, and incorrect dosages. However, locating the right professionals can be an overwhelming task in itself.

Promoting Big Picture Advocacy

It is now recognized that when people with complicated medical, functional, and cognitive conditions receive support from a geriatric care manager who looks at the entire constellation of factors that contribute to problems and stressors and considers each individual's resources and strengths hospitalizations are substantially reduced and health outcomes are substantially improved.



Equipping Professionals

The role of a geriatric care manager in identifying warning signs of increased needs for elder care and caregiver respite as well as identifying and implementing options and engagement techniques is increasingly being recognized by health professionals, health systems, and insurance companies. However, resistance to outside help is a substantial barrier to delivering quality care to older adults. Regardless of the level of knowledge, interest, or competency, participating family caregivers acknowledged they had a hard time accepting professional support. Geriatric care professionals need to be as cognizant of caregiver issues as they are of meeting the needs of older people. They have to be particularly proficient at overcoming the emotional barriers families may possess regarding acceptance of the help they need.

Summary

While aging is not synonymous with illness, complex chronic illness and functional decline can be predicted for many people as they age. Care for this growing segment of the older population demands an integrated medical, psychosocial, legal, financial, and spiritual approach. However, family caregivers need help embracing professional guidance. A partnership between qualified, skilled professionals and families is critical to obtaining maximum benefits for all, especially given the fragmented and compartmentalized healthcare and social service systems currently functioning with limited resources.





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