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#### AGING (ife CARE™ A S S O C I A T I O N

Formerly National Association of Professional Geriatric Care Managers

## EDITOR'S MESSAGE The White House Conference on Aging One Year Later

Jennifer E. Voorlas, MSG, CMC

The White House Conference on Aging (WHCOA), held in July 2015, marked the historic 50th anniversary of Medicare, and included many hopeful discussions about better ways to support seniors and their families. Over the years, this national event has been responsible for a number of significant changes in public policy. The first conference was held in 1950, when President Harry S. Truman ordered the Federal Security Agency to hold a national conference on aging. The 1961 Conference led to the development of the 50 state units on aging as part of the Older Americans Act; and in 1971 the WHCOA led to the creation of the Social Security Insurance program.

Fast forward to July 13, 2015, and as Author Gretchen Alkema of SCAN describes, this conference was "for the first time onsite at The White House and celebrated in the East Room, utilizing a more modern approach to community engagement via extensive social media." President Obama's attendance and remarks elevated the importance of the event and served as a call to action." She notes that it "was laser-focused on four specific issues: elder justice, healthy aging, long-term services and supports, and retirement security."

However, "Despite the positive dialogue at the conference, there was a topic glaringly absent from the day: a clear-eyed discussion of current and future long-term care costs [the elephant in the room], which is the largest and most unpredictable factor eroding retirement security for individuals and families." While the WHCOA was a forum for advocating resources and programs which allow seniors to age in place in the comfort of their own homes, Aging Life Care Managers<sup>™</sup> are keenly aware that affordability for some does not mean most; as the majority of those seniors with increased health care needs and lower socioeconomic status are often thrust prematurely into long term care arrangements.

Presenting options to finance long-term care, Author Eileen Tell in her article delves into educating care mangers on the different types of policies in existence, as well as the "hybrid" policies that are now in the market place, weighing the benefits and risks, including helpful tips for care managers working with their clients. Continuing the dialogue, Helene Bergman addresses the impact of overtime laws in a diverse compilation of anecdotes from Aging Life Care Managers and home care agencies across the country, underscoring the impact on care managers, home care agencies, and ultimately the elders we care for.

In alignment with the National Institute of Health and National Institute on Aging, the WHCOA advocated for initiatives to increase healthy aging via physical exercise, and a "stepped up" effort of the National plan to address Alzheimer's disease and related dementias. In keeping with these goals, Dr. Steven Castle's article introduces his fall prevention program, how it has been instituted on a state and national level, and how care managers can play an important role to encourage exercise for

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## Reflections on the 2015 White House Conference on Aging: One Year Later and Much More Work to Do

Gretchen E. Alkema, PhD, LCSW

Nearly every decade since the early 1960s, Democratic and Republican presidents have hosted a convening to deliberate on pressing issues and needs facing older Americans and the families who care for them. This official forum, called "The White House Conference on Aging," has created a focal point for policy dialogue, a presidential platform to bring the highest level of political visibility to challenges and solutions in aging, and a 10-year blueprint for policy and social action. The first White House Conference on Aging in 1961 covered "20 areas bearing on the trends, conditions, and issues affecting America's seniors." It

We choose to do big things here in America. Three generations ago, we chose to end the era where seniors where left to languish in poverty.

identify and prevent elder abuse in alignment with goals of The US department of justice and the National Institute of Health. A clear focus on initiatives to combat elder abuse is explored by authors Amy Berman, Kathrin Lozah, and Dr. Terry Fulmer of the Hartford Foundation. They identify the most vulnerable, at-risk elders, providing information on the signs of elder abuse Aging Life Care Managers need to aware of, and offer information on what care managers can do when they identify

victims of elder abuse in the course of

seniors. In addition, he emphasizes the importance of physical fitness on brain

health, introducing Jennifer Voorlas's article which supports exercise as being "neuroprotective," offering evidence of

exercise as being a potential (and critical) factor in the prevention of cognitive

decline such as Alzheimer's disease and

The topic of elder abuse still remains a national priority which was addressed through discussion of major

initiatives and training programs to

related dementias.

their practices. Finally, while the WHCOA addressed how doctors will now be reimbursed for end-of-life discussions with their patients, absent from the discussion was the value of hospice and palliative care measures included in advanced care planning. Striking this chord is Dr. Nancy Berlinger's article which focuses on the ethics of end-of-life planning as key to long-term care and support of the elderly, which is directly relevant to how care managers can support older adults and their families.

Throughout this edition, each author has contributed to enhancing our knowledge as Aging Life Care Managers about relevant policy issues which impacts the seniors we work with on a daily basis. The articles presented in this issue are not only intended to provide an update on some of the most salient points from last year's conference, but to address their current relevancy, along with a provocative attempt to move and shape the dialogue forward. On behalf of the entire editorial board we hope you enjoy this edition! highlighted economic hardships that older adults and their families faced in paying for medical care. The results were an important force in creating the political will leading to Medicare and Medicaid both becoming law four years later. Subsequent conferences and their presidential decrees raised visibility on issues such as elder poverty and hunger in 1971, the growing diversity and capacity of older adults in 1981, family caregivers as a critical resource in 1995, and Baby Boomer civic engagement and technology solutions in 2005 – all of which led to specific and measurable public and/or private sector action in the years following.

In July 2014, with encouragement from various stakeholders in aging policy and the federal Commission on Long-Term Care, President Barack Obama announced his intent for a 2015 Conference. With Nora Super, the president appointed an executive director who brought an extensive policy and political background in aging, health care, and retirement both inside and outside of government. The team was laser-focused on four specific issues: elder justice, healthy aging, long-term services and supports, and retirement security. While these four issues acknowledge the unique needs of older Americans, the spirit of the event was to move the dialogue on aging away from a fearbased poverty model to one where older adults are a vibrant, natural part of American life. The event logistics further differentiated it from conferences of the past, shifting away from extensive state-based events culminating in a large delegate-driven Washington area meeting in the convention center. This sixth White House Conference on Aging was held for the first time onsite in the

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celebrated East Room on July 13, 2015, and utilized a more modern approach to community engagement via extensive social media. Building on this overall approach, the conference succeeded in three important ways.

First, President Obama's attendance and remarks elevated the importance of the event and served as a call to action. He spoke forcefully on the issues at hand, acknowledging America as both a vibrant nation and one that "maximizes the contributions that older Americans can make to our country." The president further remarked that "one of the best measures of a country is how it treats its older citizens...every citizen deserves a basic measure of security and dignity." Honoring the anniversaries of Social Security and Medicare, he triumphed the American spirit to be bold and the need to carry that vision forward with further reform, stating:

> We choose to do big things here in America. Three generations ago, we chose to end the era where seniors where left to languish in poverty. Two generations ago, we chose to end an age where Americans in their golden years didn't have the guarantee of health care... with the anniversary of those incredible achievements, we need to recommit ourselves to finishing the work that earlier generations began.

Second, the conference outlined a vision to transform how Americans speak respectfully about vulnerable aging as well as what people need to live well and safely when facing chronic health conditions and functional limitations. Experts from academia, entertainment, private industry, health care, labor, philanthropy, and many other sectors focused on the merits of aging, including its opportunity to shape existing and emerging economies for young and old alike. The traditional narrative that aging is synonymous with being sick, poor, and alone was effectively debunked as each speaker reframed aging as a natural part of the human condition shaped by American ideals of honor, purpose, and independence.

Third, the conference moved

beyond a "D.C. Beltway" debate to engaging local communities as well as "grassroots to grasstops" champions. Live streaming and an active social media presence connected 600 community "watch parties" to the conference, with the hashtag #WHCOA coming in at number 3 on Twitter's trending list that day. Showing the power of the Internet to connect, inform, and engage across ages, the 2015 Conference upended the myth of an inherent aging-digital divide.

A final report was released on December 29, 2015, summarizing the year's work and capturing feedback received from stakeholders and advocates across the country. Despite the positive dialogue at the conference and referenced in the final report, there was a topic glaringly absent from the day: a clear-eyed discussion of current and future long-term care costs, which is the largest and most unpredictable factor eroding retirement security for individuals and families.

While Americans today are living dramatically longer than their parents did, they are doing so with more chronic illness and daily functional challenges. Released just days after the conference concluded, a federal report shows that half of all Americans turning 65 today will one day find themselves needing a high level of help with basic daily activities like walking, eating, getting out of bed in the morning, and bathing. One in seven individuals will need a high level of assistance for five years or more – a figure that overwhelmingly affects women who not only are living longer with substantial disability but who also are serving as the primary caregivers to those in need. For older adults and their families, needing this level of assistance can take a sizeable toll on both quality of life and personal finances. The typical American faces long-term care costs in old age averaging \$91,000 for men and \$182,000 for women—but can be much higher, depending on the number of years individuals need high levels of help. This reality creates an unpredictable financial burden. At the same time, the number of aging Americans with high health and daily living needs is projected to grow from 6 million to almost 16 million in the next

several decades.

While each experience is unique, families cover more than half of the total share of long-term care costs through out-of-pocket spending, which can deplete personal savings, retirement accounts, and other assets. In many instances, the costs exceed what families can provide, impacting family members and other unpaid caregivers. While individuals can gualify for Medicaid to cover long-term care needs when their savings are exhausted. they typically incur large out-of-pocket expenses beforehand. Few Americans have private long-term care insurance coverage today due to high premiums and inability to qualify based on presence of preexisting conditions.

Families have little ability to plan for this economic shock, which hits middle-income Americans the hardest. Yet a deeper look at these data demonstrates that long-term care is an insurable risk. Only one-sixth of older adults with severe needs will spend \$100,000 or more, out-of-pocket, on long-term care. Experts agree that our nation's way of financing long-term services and supports is unsustainable, and new realistic policy options are needed to address this problem, which impacts American families, employers, and state and federal systems.

When faced with unpredictable needs and costs, Americans generally use insurance as a tool to mitigate overwhelming financial risk. However, the current long-term care insurance market is effectively broken, leaving few alternatives to finance long-term services and supports. Therefore, to help address the long-term care financing crisis and offer policy alternatives, a project convened and funded by The SCAN Foundation, AARP, and LeadingAge has made new research on insurance options available. The project enlisted the Urban Institute and actuary group Milliman, Inc. to simulate the impact of three insurance options with the same benefit structure. This analysis tested insurance options over three coverage periods, assessing performance across several designs including voluntary or mandatory enrollment. All options could be implemented as private and/or public products. Taken as a whole, the research creates a com-



parative framework for long-term care financing that can help policymakers and thought leaders explore creative solutions using this new "go-to" modeling resource.

Building from the modeling research, three separate bipartisan groups – the Bipartisan Policy Center, LeadingAge, and the Long-Term Care Financing Collaborative – released February 2016 recommendations on how to help working Americans better prepare for their future long-term care needs and associated costs. These recommendations come at a critical time as new information about the extent of the crisis is striking.

The good news is that despite these politically contentious times, these three separate sets of policy recommendations clearly outline a path forward. The SCAN Foundation reviewed each report and found these common threads:

- A multi-pronged approach is necessary—one that requires reimagining the roles of the public and private sectors;
  - Structural changes and reforms in the private market including modifications to the private insurance marketplace to provide lower-priced policies with a better distribution strategy (e.g., in the workplace) to protect against the initial costs once a person needs a high level of support;
- Targeted public solutions to address catastrophic needs—including insurance designs specifically to protect against the longer-term costs for those with high levels of need (e.g., 10 years of support for one with Alzheimer's disease); and
- It's time to refocus Medicaid's role—strengthening this vital

safety net program while lessening its financing role in a reformed, insurance-based long-term care financing system.

Ultimately, these reports show that the whole is greater than the sum of the parts and more refinement work is needed. Taken together, these recommendations clarify the appropriate extent of personal responsibility, create a full and meaningful space for the private market to flourish in covering early stage needs, ensure risk protection for individuals with longstanding needs, and finally take some pressure

off the Medicaid program.

Most of us, as we grow older, will encounter personal challenges, such as managing chronic health conditions, needing help with daily activities, staying active despite chronic pain, failing eyesight, or hearing loss, and worrying about how to pay for care and services.

It has been one year since the 2015 Conference. Much work remains to create a world where older Americans and their families can count on accessing high-quality, affordable health care and supports for daily living delivered on each person's own terms, according to that individual's needs, values, and preferences. Most of us, as we grow older, will encounter personal challenges, such as managing chronic health conditions.

needing help with daily activities, staying active despite chronic pain, failing eyesight, or hearing loss, and worrying about how to pay for care and services. Right now, there is no coordinated and easily navigated system in place to support Americans who want to live independently as they age. The challenge becomes more pressing as the population of older adults increases and costs of various health and longterm care services continue to rise. It is imperative for all of us to become a voice for change so today's generation and those to come can grow older in a world that champions dignity and choice regardless of age, health, or ability.

#### **GRETCHEN ALKEMA**

Gretchen E. Alkema, PhD, LCSW, serves as Vice President of Policy and Communications for The SCAN Foundation. Prior to joining the Foundation, she was the 2008-09 John Heinz/Health and Aging Policy Fellow and an American Political Science Association Congressional Fellow, serving in the office of Senator Blanche L. Lincoln (D-AR). Dr. Alkema advised Senator Lincoln on aging, health, mental health, and long-term care policy during the 2009 health care reform debate.

Dr. Alkema holds a PhD from the University of Southern California's Davis School of Gerontology and was awarded the John A. Hartford Doctoral Fellow in Geriatric Social Work and AARP Scholars Program Award. She completed post-doctoral training at the VA Greater Los Angeles Health Services Research and Development Center of Excellence and was a research associate for the California Fall Prevention Center of Excellence. Her academic research focused on evaluating innovative models of chronic care management and translating effective models into practice.

Dr. Alkema also earned a master's in social work with a specialist in aging certificate from the University of Michigan and a bachelor's degree in psychology from the University of Colorado, Boulder. As a Licensed Clinical Social Worker, she practiced in government and non-profit settings including community mental health, care management, adult day health care, residential care, and post-acute rehabilitation.

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## The Good News and Bad News for Private Financing for Long-Term Care (LTC) Needs

Eileen Tell, MPH

#### Foreword | by Jennifer E. Voorlas, MSG, CMC

The White House Conference on aging in 2015 shed significant light on maintaining the quality of life for seniors and the importance of measures taken for them to "age in place," however one questions remains: How do the majority of seniors continue to pay for their long-term care to achieve this end? Truly, this question has not only become a policy issue but an individual one, as families from differing socioeconomic backgrounds continue to struggle to afford needed care. Long-term care insurance has been one solution to this problem. In this article Eileen Tell goes into great detail to discuss the complexity of long-term care polices and what we need to know as care managers moving forward to best serve our clients.

#### Introduction

Despite the availability of a variety of private finance vehicles to protect consumers from the catastrophic risks of needing long-term care (LTC), most people do not have arrangements in place to help pay and provide for care when the time comes that they need it. New research underscores the importance of planning ahead for ways to address the relatively likely scenario of needing LTC as we age. Specifically, 50% of those age 65 and older will, at some point in their lives, have a degree of loss sufficient to require hands-on help with two or more everyday activities of daily living (ADLs) or supervision due to a cognitive impairment. The average duration of this care need is just under 4 years, with the risk of needing care and the duration of care needed higher for women than for men. Based on today's costs of care, roughly 27 percent of us will see costs of care of at least \$100,000, with costs in excess of \$250,000 for about 15 percent of those who need care. These figures do not include the significant financial and emotional costs of the large portion of

Collectively, probably only about 9 million of the 40 million Americans age 65 and over have one of these private insurance options in place.

care that is provided by unpaid family caregivers.

While there are a variety of private finance options available to provide both financial protection and help finding and arranging for care, for a variety of reasons, few people have chosen to make this type of purchase. These options include:

- Traditional long-term care insurance;
- Hybrid or combination insurance products (combine LTCI with life insurance or an annuity);
- Short-term care insurance;

- Impaired risk annuities; or
- Reverse mortgages

Collectively, probably only about 9 million of the 40 million Americans age 65 and over have one of these private insurance options in place. This falls well below the anticipated "take-up" for what has been shown to be a highly insurable risk. In the 1990s and first half of 2000s, sales of traditional long-term care insurance grew steadily, and products improved significantly. During that time, new product variations emerged to better meet varied tastes and preferences among consumers.

So why has the private finance market for LTC protection stalled so dramatically within the current decade? There are several reasons:

- No single product option today perfectly meets either current or growing needs. Some cost more than many people feel they can pay, some provide only limited or partial protection, and some limit eligibility based on health, income, age or other criteria.
- Today's LTC options also provide limited reach due to the challenges of raising awareness, motiving and enabling planning, and overcoming denial of the need, or the human nature to avoid thinking about and planning for a future of need and dependency. Many people prefer to "take their chances" and hope that they won't need care or hope they will have saved enough to pay for their care needs.

In this article, we explore the good news and the bad news about the private financing of LTC needs as revealed over the nearly three decades of experience with these products. We also highlight "What Every Care Manager Needs



to Know about Private LTC Insurance" to help our audience understand key elements of the product for their clients who have it.

#### Good News for Private Financing of LTC Needs

There have been significant improvements in the design of LTC insurance products since they first emerged. While early products were not well-suited to meet the needs of those seeking care, especially for home- and community-based services, today's products offer comprehensive coverage in all relevant care settings. Most policies have a single pool of benefit dollars from which the insured can select whatever type and amount of care they prefer. So there is no institutional bias with private financing as still prevails with Medicaid. As new options for receiving care (like the growth of assisted living facilities) have emerged, policy design has kept pace with these changes in the delivery system. Most products have an "innovation" provision called an Alternative Plan of Care which gives the policy flexibility to maintain contemporary coverage as service delivery options change over time. Today's products also include many important consumer protections such as early and third-party notification in case of coverage lapse, provisions to reinstate coverage if a payment is missed, a third-party independent review for claims decisions

and more. While early policies relied upon an arbitrary determination of "medical necessity" for when benefits would be paid, today's coverage is correctly aligned with accepted, reliable, and objective measures of functional and cognitive loss as used by Aging Life Care™ / geriatric care practitioners (see Table 1).

As a result of these important improvements in the type of care that is covered, those with private LTC insurance are more likely to be able to receive care outside of a facility which is generally the preference.

#### FIGURE 1 | Enhanced Access to Care at Home with Private LTC Insurance

#### Without LTC Coverage

0/

| Care in Home    | 52% |
|-----------------|-----|
| Assisted Living | 13% |
| Nursing Home    | 35% |

#### With LTC Coverage

| Care in Home    | .65% |
|-----------------|------|
| Assisted Living | .23% |
| Nursing Home    | 12%  |

Source: LTCG, Inc., 2014

In-depth analyses of how these policies work also reveal that claimants and their families are well-served by their coverage. Roughly 95% of all

#### TABLE 1 | How LTC Policies Have Changed Over Time

| POLICY CHARACTERISTIC                 | AVERAGE FOR 2010  | AVERAGE FOR 1990   |
|---------------------------------------|---|--|
| Comprehensive Coverage                | 92%   | 37%  |
| Nursing Home Benefit Amount           | \$154   | \$72   |
| Home Care Benefit Amount              | \$153   | \$36   |
| Coverage Duration                     | 4.8 years   | 5.6 years  |
| Inflation Protection                  | 92%   | 40%  |
| Annual Premium                        | \$2,268   | \$1,071  |
| Benefit Determination                 | Loss of 2 or more<br>ADLs or Severe<br>Cognitive Impairment | Varied across policies;<br>Different ADLs used,<br>inconsistent measures<br>and thresholds,<br>medical necessity |
| Independent Third Party Claims Review | Included in most policies                                   | Not included   |
| Alternative Plan of Care Feature      | Included in most policies                                   | Emerging use   |

claims are paid. Among those in claim:

- 94% had no disagreement with the insurer about that claim;
- 3% had a disagreement that was satisfactorily resolved.
- Most claimants say their policy benefits meet care needs; 90% feel their policy provides flexibility in service choice;
- In the absence of insurance, half the claimants feel they would have to seek facility care or not be able to afford care; and
- Most (77%) do not find it difficult to file a claim.

Figure 2 illustrates some of the non-financial benefits to claimants receiving care under their LTC insurance policy.

The presence of LTC insurance also improves the family caregiving experience. Individuals caring for someone with private LTC insurance are nearly twice as likely to be able to continue to work as those whose loved ones do not have LTC insurance. This working caregiver is also less likely to experience the severe stress and negative physical health outcomes associated with juggling work and caregiving. The care management assistance provided by insurers reduces caregiver stress by providing a valuable resource for respite care, help finding services, and providing paid care when family caregiving is either not feasible or isn't desired. But having LTC insurance doesn't erode the important role that families play in caregiving for their loved ones; it merely changes the nature of the role in a way that reduces the burden of hands-on care and the emotional stress of round-the-clock caregiving.

From a societal perspective, an investment in private LTC insurance also pays off with regard to Medicaid program savings. A recent study estimated the projected lifetime Medicaid savings on nursing home care at just under \$8,000 for each privately insured person with coverage at the levels prevailing in 2010.

Finally, the other good news for private financing of LTC needs is the emergence of a variety of new prod-

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uct configurations that broadens the price points and better tailors coverage to satisfy consumer preferences for different kinds of product options. Specifically, the industry has seen significant growth in the sale of combination products (LTC insurance combined with an annuity and/ or a life insurance product) as well as in less costly, less comprehensive "short-term care." Because it limits the insurance liability, these shortterm care products are often available with more lenient underwriting than traditional LTC insurance. This helps broaden the reach of private coverage to those who might not otherwise be insurable with a traditional product. Industry innovation in product design and pricing means broader market appeal for those who may not feel well served by the concept of a traditional LTC insurance product.

#### And Now for the Bad News

The economic challenges and sustained low interest rate environment of the current decade have negatively impacted both the supply and the demand side of the LTC private financing equation. On the supply side, insurers are not able to realize the profitability on product that they previously experienced, especially given tight regulatory limits on the ability to adjust premiums based on financial and actuarial experience. This means fewer companies offering product, limited resources for education and distribution. Also, for the companies that remain in the market, premium increases, tighter underwriting, or other changes put the product out of reach of a growing number of potential buyers.

Offering coverage through sponsoring emplovers has been an important distribution channel for traditional LTC insurance; but with the emergence of the Affordable Care Act, and the challenging economic climate, the time and attention that employers are able and willing to give to this voluntary benefit is limited. That, combined with some insurer market exits that hit harder in the

employer group market, has cut off what had been an important distribution option, especially for reaching younger buyers where affordability is enhanced. On the flip side, consumers are seeing higher premiums for comparable coverage today compared to a few years ago as companies have needed to seek rate increases. This exacerbates an already challenging value proposition for the buyer. Fewer consumers can justify the investment at a time when portfolios and incomes

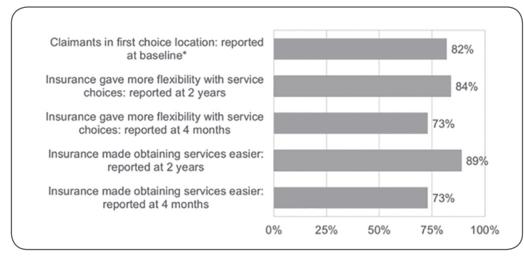
Fewer consumers can justify the investment at a time when portfolios and incomes are challenged in this financial environment. Also, most people who buy LTC insurance are risk-adverse and prefer more comprehensive coverage than perhaps they can afford. are challenged in this financial environment. Also, most people who buy LTC insurance are risk-adverse and prefer more comprehensive coverage than perhaps they can afford. Also, as some companies' attempt to offer lower premiums through reduced coverage (e.g., no longer selling an unlimited lifetime benefit); the market appeal to a primary audience of typical buyers is reduced. The

typical buyer psychology isn't currently compatible with a "some coverage is better than none" mindset, which is behind the emergence of short term care product designs. And while the

emergence of a variety of new product types, including lower cost coverage options is intended to address both the affordability issue and the "use it or lose it" nature of traditional insurance, having more options across and within products adds to the complexity of a product purchase that is already seen as confusing and challenging to many consumers.

Finally, while awareness of the risks and costs of LTC has increased, and the value of planning ahead for LTC needs is gaining acceptance, most consumers still fail to plan. LTC insurance will remain a product that is sold, not bought, as long as the decision to buy or not

#### Figure 2 | Claimant Satisfaction with LTC Insurance Claim Experience



Source: LifePlans, Inc., Calculating the Value of Private LTC Insurance. Presented at the 15th Annual Intercompany Long-Term Care Insurance Conference, March 2015.

buy is a voluntary one, and the incentives for purchase are in a "difficult to imagine" far off future for many.

#### Conclusion: Coming to a New Normal for Solving the LTC Dilemma

There is a growing consensus among both the private and public sector players in the battle to address this LTC financing crisis, that the most viable solution involves creative collaboration between both private and public sectors. Traditional and newly emerging private LTC finance products have an important role to play in defining solutions, but it has become clear over the last challenging decade of flat sales despite product innovation, that these private products, under even the best of circumstances, will remain a niche solution. Even with the current private industry disruption, innovation, reinvention, and redefinition currently underway, private market penetration is likely to remain small. For the first time, both public and private sector thought leaders are working together to identify the respective roles each can play in creating viable and affordable solutions. Previously, the debate about how to solve the LTC dilemma was focused on the "false dichotomy that LTC should be primarily either a public or private responsibility." The conversation today has moved toward a collaborative perspective at least with respect to the fact that the most viable solution(s) will be those in which both private and public sector strategies are combined.

Of course, there is still plenty of room for debate, research, and rhetoric with regard to the best use of both public and private sector resources, and the right way to design products and allocate dollars to address the LTC dilemma. The fact that at both the state and federal level, policymakers and industry are talking about creative solutions, raising consumer awareness, and motivating LTC planning, is a step in the right direction. Rather than focusing on the shortcomings of either a private or a public sector solution, thought leaders are coming together to explore how to work together to create and promote affordable options.

## What Every Aging Life Care Manager™ Should Know about Private LTC Insurance

- Most policies have very robust care management using a network of highly trained, local Aging Life Care / geriatric care managers. They are available to help identify care needs through assessment protocols. They also develop and monitor a plan of care suitable to the insured individual's need and changing circumstances.
- The policy language would typically indicate the nature of the care management or care coordination benefit (See the other types of coverage arrangements sometimes offered described below). If the policy language does not specify how care coordination is provided or paid for, have the insured or their power of attorney call the insurer. With the insured's permission, you can participate in the phone call as their Aging Life Care / care manager.
- Some older policies pay for care management, but don't provide it, so a private Aging Life Care Manager may be able to support the family under the umbrella of their coverage. The details of whether and how the policy covers care management services is typically specified in the policy language.
- A few policies give the insured the choice of using their own Aging Life Care Manager or one affiliated with the insurer. In those situations, the policy may specify a limit (e.g., a dollar amount or number of care management visits) to that benefit when the individual chooses to use their own care manager, but may provide on-going care management as the individual's situation changes, when they use the company's network providers for care management.
- Almost all policies today set a total dollar limit, not a number of days, for how much coverage will be provided. For individuals who have a fixed dollar benefit over their lifetime (e.g., \$250,000), a care manager is an important player in helping the family maximize the value of that private coverage. One strategy for doing this is to identify lower cost care options (e.g., one day of adult day care instead of two in-home care shifts) or days on which there can be family in place of paid care, to help stretch the fixed benefit dollars.
- An Aging Life Care Manager can also help families have lower out-ofpocket costs while they satisfy their elimination period or deductible period. Many policies count calendar days of disability, whether or not paid care is received, for satisfying this one-time waiting period. So, helping the family get lower cost care or go without paid care at the start of the disability, can help them more quickly satisfy the elimination period without a dollar outlay. If an expense is required (this is called a service day deductible), then using less costly care each day will also get the insured to satisfy that requirement with less financial impact.
- For those who are getting near their lifetime maximum dollar limit on their coverage (keep in mind that about 45% of all insured have unlimited/

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lifetime coverage), an Aging Life Care Manager can be important to identify affordable and appropriate care options for the transition off of private insurance. The family may still be able to maintain paying for care, may want to seek out less costly care, or, if income and assets qualify them, they may be eligible for Medicaid assistance.

- Most policies pay for respite care, so helping families provide and arrange for that type of care is important.
- Policies also pay for training for informal caregivers. Aging Life Care Managers can help loved ones identify the best ways they can learn to safely and appropriate provide hands-on care or supervision.
- Care notes are very important to the claim process under a private insurance policy. Helping the family understand the documentation that is needed by the insurer will expedite the process of approving and paying claims.
- Policies differ in terms of the requirements for paying for in-home care. Aging Life Care Managers can help the family identify providers that satisfy the specific requirements of their coverage. Some policies limit coverage to a licensed home health care or home care agency, while others may cover an independent provider (nurse, aide, or social worker) as long as they meet the training and other credentialing requirements identified in the policy. Most policies only pay for family or "informal" caregivers under very limited circumstances so families should read their policy language carefully.
- Most policies also pay for devices, equipment, and home modifications specifically to meet the need of those dealing with loss of functional or cognitive function to be able to remain safely at home. You can assist your clients who have private coverage by identifying for them ways in which

technology or changes in the home can enhance their safety and care needs.

- If you are helping find care for someone with private LTC insurance, make sure you know whether their policy has an inflation provision – this means that the benefit amount paid for care increases at some pre-set rate or amount to keep pace with rising costs. If it does not, then it will be important to help families plan for the growing "gap" between coverage and costs and to help them find less costly care options appropriate to their needs. Most policies today do have automatic adjustments for inflation.
- The premiums that people pay for their LTC insurance may be tax-deductible under certain circumstances, much the way out-of-pocket medical expenses are treated. Many people are unaware of this or may not realize that they might qualify for this deduction. For those that do not have private insurance, tracking expenses they incur for LTC needs is important also since these can be included along with other medical out-of-pocket expenses for tax deduction purposes. Essentially, these items are deductible if they exceed 10% of adjusted gross income (or 7.5% for those over age 65). Other rules apply so of course clients should consult their tax advisor.
- Finally, policies differ in the protocols and policies under an Alternative Plan of Care. Most policies will not use that provision to pay for in-home care if the insured has a policy that only covers facility care. Generally, the alternative care has to be of equal or greater quality and cannot cost more than what the policy would otherwise pay. Other safety and suitability concerns must also be met. The Aging Life Care Manager should work with the insured and their insurer to understand the parameters for this provision and then help identify care alternatives that fit within that, if appropriate.

#### References

Bipartisan Policy Center. Initial Recommendations to Improve the Financing of Long-Term Care. February 2016.

Favreault, MM., Gleckman, H and Johnson, RW. "Financing Long-Term Services and Supports: Options Reflect Trade-offs for Older Americans and Federal Spending." Health Affairs. December 2015.

LifePlans, Inc., "Calculating the Value of Private Long Term Care Insurance." Presented at the 15th Annual Long Term Care Insurance Conference, March 2015.

Stevenson, DG., Cohen, MA., Tell, EJ., and Burwell, B. "The Complementarity of Public and Private Long-Term Care Coverage." Health Affairs. January 2010.

#### Footnotes

- 1. Health Affairs, December 2015
- 2. Bipartisan Policy Center, February 2016
- 3. LifePlans, Inc., op. cit.
- 4. LifePlans, Inc., op. cit.
- 5. Ibid
- 6. Health Affairs, January 2010

#### EILEEN J. TELL, MPH

Eileen J. Tell, MPH, is Principal and CEO of ET Consulting, LLC, a woman-owned business focused on long-term care and aging services. Ms. Tell has more than 30 years of experience and industry thought leadership in long-term care. Areas of expertise include policy analysis, market research, product development, and program management and evaluation. Previously she was Senior Vice President for Product **Development and Analytic Services** at LTCG since the company began in 1990. At LTCG, Ms. Tell directed the consulting division which assisted dozens of leading insurers in the successful design and implementation of LTC insurance products. She also provided public policy research and consulting to state and federal governments. Ms. Tell provided senior leadership guidance to LTCG and won a major LTC insurance case



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seeking Third Party Administration and marketing support. This major case win launched the company's transition from a consulting business to a full-service TPA.

She has extensive expertise in public policy analysis, product design, compliance, market trends, and competitive and regulatory analysis. She has consulted to both insurers and to the public sector including state and the federal governments in the US and abroad on a wide variety of long-term care topics. She has been involved in public policy analysis in long-term care both for states and the federal government. She played a key role in the analysis of the CLASS Act, focusing on consumer behavior and the analysis of best practices in insurance program design, including addressing issues of program integrity and risk management. She has conducted numerous consumer studies on various aspects of long-term care finance and delivery. She was instrumental in the design and implementation of 'Own Your Future," a U.S. DHHS's LTC Consumer Awareness Campaign, including development of the first generation of the National Clearinghouse for Longterm Care Information's new website www.longtermcare.gov. She advices insurers in key product design and implementation areas such as policy language and product features, market entry strategy, marketing and sales, customer service training and support, regulatory and competitive analysis, compliance and market research on long-term care needs and preferences in the senior market.

Ms. Tell has published extensively on a wide variety of LTC topics and has contributed as both a writer and editor to AHIP's Long-term Care Professional Designation book series. Ms. Tell is a graduate of Tufts University and has a Masters of Public Health degree from University of Michigan.

## The Challenge of Aging in Place: The Impact of Overtime Laws

Compiled and edited by Helene Bergman, ACSW, C-ASWCM

The theme of the recent White House Conference on Aging (July 2015) was Empowering Americans as We Age, and many initiatives -- economic and otherwise -- were proposed to better prepare workers for retirement, to support elder caregiving, and to facilitate older Americans to age in place. For elders receiving one-on-one care at home or in a facility, a recent change to the Fair Labors Standards Act (FLSA) may in fact be adversely affecting caregivers and the ability of elders to finance long-term care in the community.

In order to protect the rights of domestic employees, the overtime rule, which requires time and a half be paid to those working over 40 hours weekly, went into effect in October 2015. A prior exemption for agencies offering companionship services was negated and, as a result, many home care agencies along with Aging Life Care Managers™ were impacted in ways that are still challenging their ability to provide affordable services for families and their loved ones who need care.

In order to explore how this has affected professionals from differing geographic areas, a cross section of experienced Aging Life Care Professionals™ (both care managers and home care providers) were asked, "How has the Employment Law affected your care management / home care practice?" They identified how these changes have had an important impact on the worker, the quality and cost of care sustaining a Home Care Agency business, and the role of the Aging Life Care Manager. These factors considered together have led to concerns about premature institutionalization and the quality of life for elders who could otherwise remain at home.

#### Impact on the Worker

Nancy Avitabile, Aging Life Care Manager from New York and ALCA National Board Member, notes that many HHA employees have been seeking additional employment as their hours, and overall pay, have been reduced. One aide complained that her hourly rate was reduced from \$13.00 per hour to \$10.00 per hour. Avitabile says, "We have heard of aides enrolling with one, or even two, additional agencies to make ends meet; each requiring them to attend orientations, routine in-service, and deal with different managers and agency culture. Workers complain of more travel time, juggling two work schedules, and less time to manage their own lives. The new standards seem to be leaving the HHAs with the short end of the stick."

Jeff Friedman, Vice President of marketing for a home care agency in California, offers another perspective. He finds "employees working at different agencies...often going to the highest paying (which is also the highest cost) and most convenient for the employee. The demand is high and the supply is low, essentially giving the employee the influence at this point."

Byron Cordes, an Aging Life Care Manager from Texas and a prior President of ALCA agrees, "Caregivers in the region have long worked 50-60 hours per week to gain a semi-reasonable income. Given the current law, employees can still get more than 40 hours of work but they simply have to piece-(continued on page 12)



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meal their hours together with several agencies." Thus, they are running around from job to job.

Bunni Dybnis, a prior ALCA Board Member and principal of LivHOME, California, writes, "I think we can all agree that workers deserve to be compensated for the work they do and protected against injury and unjust labor practices. Unfortunately, there is also the reality of what those in need of care can afford or are willing to pay for the luxury of safety and remaining at home. In California, with costs for twenty-four hour care over double what is was in the recent past, even those with long-term care insurance are often left short when attempting to age in place."

## Impact on Quality & Cost of Care

Cordes notes that as agencies adhere to the law, many have raised their rates to cover employees who exceed the 40 hours; this obviously has put an increased financial burden on his elderly clients. Some have adjusted their calculations of how long their money will cover their care, and many have cut back on quantity of care, thereby decreasing their quality of life. To illustrate, Cordes presents a case example:

> Mrs. K had twenty-four hour care in her facility from a small group of consistent long-term caregivers/ companions. When the law went into effect, the agency had to add more caregivers to the mix and raise the hourly rate; at the same time the facility noted problems in guality of care. Dealing with so many caregivers led to problems with shift changes, punctuality, and they even found Mrs. K without a caregiver one afternoon. The family decided to save the client's diminishing funds and cancelled the caregivers entirely. The care manager worked with the facility to increase its attention to the client. Although they tried, Mrs. K lost her 1:1 care and her dedicated caregivers lost their employment.

Friedman offers an agency perspective, stating, "Because of the increased wages, overtime, etc., the

cost to the person needing the care has increased exponentially...and these cost increases will continue as minimum wage will increase every year until approximately 2020. Many who need these services are essentially priced out of the market..." He further notes that "people who require 24-hour care will feel the changes the most, and that makes the law a health problem not just a labor issue. The folks who need the greatest amount of care are the most vulnerable individuals with the most acute health care problems. Switching from the one 'live-in' person to two 12-hour shifts or even three 8-hour shifts seems inconsequential at first, but for someone with complex medical issues and/or cognitive problems like dementia, having one more person come to the home can create confusion and frustration. In addition, those with affordability issues must reduce costs and cover with family. This causes increased stressors for the family and potential hazards for the client."

Amy O'Rourke, President-Elect of ALCA and an Aging Life Care Manager in Florida notes, "In Florida, we have been grappling with how to adjust our care in the home with the new labor laws. It has been difficult, because all of us want caregivers to earn a decent wage. We have had caregivers who have been working 50-60 hours per week and whose hours have had to be reduced because the family could not afford the overtime. We have had to use multiple caregivers in the home, which has created stress for the families." She further states, "We are still trying to figure out how to pay for health insurance for our full-time caregivers in addition to complying with the new labor laws. It should not be this expensive to help older adults stay at home. I have had more conversations with families who cannot afford the current rate of caregivers. If the rate goes up (which it most certainly will) I don't know how the aging person will get the care they need. What I envision is premature institutionalization for the elder, which will be an expense borne by overstressed state budgets."

The reduction in hours of longterm workers has had a devastating effect especially on cognitively im-

paired and/or medically complex clients. Avitabile has seen how these changes have jeopardized client care by interfering with continuity and functional working relationships. She has seen increased calls to Emergency Medical Services resulting from new aides assigned who were unfamiliar with a patient's baseline functioning... or personality. "During a recent transition to agency care, our intelligent yet cognitively impaired client, receiving 24-hour sleep-in care, questioned the logic of sending in 'so many new faces.' He called his daughter with angry threats to fire each new aide and cancel all services—services that had been nurtured for over a year. Predictably, the daughter called the Aging Life Care Manager and demanded that the problem be fixed. The care manager ultimately negotiated for two workers, each working three days, and a single worker working for one day, for a total of three workers assigned to the case. Although this was an improvement to 'seeing a new face every day,' both the client and the aides yearned for a better outcome. Ideally, the case should have been staffed with two workers sharing the seven day week; however, this would have increased the agency overtime costs."

#### Impact on Home Care Agencies

Can home care agencies stav in business? Or do they have to modify what they offer? Jack Herndon, the managing partner of a home care agency in Northern California, notes that many home care agencies have stopped offering live-in care, in large part due to the increased costs. Or, those who offer live-in care have seen a dramatic increase in their costs and almost all have raised their daily rates to clients as well. These two changes have prompted a number of clients to seek more guidance from Aging Life Care Managers to compare in-home care with residential care and in many cases moving an older adult prematurely.

Cordes notes, "... many of the agencies we work with have been scrambling to hire additional caregivers to fill an increased number of shifts; instead of two 12-hour shifts,

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they now have to fill three 8-hour shifts (or more). This requires working with multiple staffing coordinators who are now calling the better workers trying to fit them into a jigsaw puzzle with an ever-expanding number of pieces."

O'Rourke further notes that the overtime cost has a multi-faceted catastrophic effect on continuity of care as well as sustaining a home care agency. She says "We have had caregivers working for multiple clients whose hours have had to be reduced because the total of hours worked is over the 40 hour limit. Clients who have been attached to certain caregivers have had to adjust to new staff members; there is no justification to pass on an overtime cost to the clients on a three or four hour shift. We are currently evaluating whether we should discontinue our three hour shift option as it creates overtime for some of our staff. As an agency, we have the added overhead of unemployment insurance, both federal and state workers compensation, and payroll taxes. Paying workers overtime is not a financially sustainable business model. Other agencies are expressing this same view to us. Some of our clients want the security of securing employees through an agency AND they want the continuity of staff as well."

#### What about the Aging Life Care Manager?

According to the panel, the changes have wreaked havoc on the job of the Aging Life Care Manager. Avitabile notes having to disappoint the aides, "We have often had to explain to long-term valuable workers about the reduction to their days or hours. Clients ask us to limit the number of scheduled workers even as agencies request their permission to charge overtime, which is new to them." She cites an example of an alert but cognitively impaired ninety-eight year old woman who had been receiving split-shift care. Prior to her death, she had six home health aides assigned to her care; two workers had been added and the schedule reorganized after November 2015. The HHA staff was upset with the Aging Life Care Manager as they (incorrectly) assumed we had changed their hours. Most upsetting was that the client

could not remember the names of the recent hires and was negatively triggered by new HHAs. Not only was this scenario disruptive to the client, the family and the Aging Life Care Manager struggled with the complications of too many workers vying for extra work (and providing inconsistent services).

Herndon recommends that Aging Life Care Managers understand the changes so that they can ensure their clients are in compliance -- whether the families are employing the care providers directly or working through an agency bound by these laws. Dybnis adds, "There have been seven different bills from both California and Federal law makers that have done away with live-in and long-shift waivers, increased overtime and minimum wage payments, added sick days, and reinforced other employer obligations in terms of employee's designation." Aging Life Care Managers do not want to recommend the services of a home care agency that is not complying with the state and federal laws.

What happens when all fails and funds are exhausted? Dybnis answers, "For the group who despite wanting to remain at home, but need 24/7 support -- we have been assisting in finding appropriate placement."

#### **Possible Solutions?**

Avitabile found a temporary solution:

As a viable alternative, we often use licensed registered employment agencies to provide skilled workers for interview and eventual direct employment by our clients. Because family/ direct hire employers are allowed more flexibility with wages, overtime has been more manageable and it is unnecessary to divide long hours of work among many workers; direct-hire workers have been largely unaffected by the FLSA. In our experience, the workers earn better wages, while our families remain in full compliance with the FLSA rules. There is no third party involvement and the direct-hire employer is not required to pay for time when the worker is sleeping or taking a break (though provisions apply). Our clients experience a strong continuity of care and workers are able to focus on one job and one client. A reduction in

the number of employees in the home and paying a living wage (with overtime) has been especially beneficial to our dementia patients, who thrive on continuity and consistency.

There is a way to comply with the new laws and continue to ensure the best care for our clients. We have found that direct-hire workers give us the loyalty, compassion, and expertise

Fewer consumers can justify the investment at a time when portfolios and incomes are challenged in this financial environment. Also, most people who buy LTC insurance are riskadverse and prefer more comprehensive coverage than perhaps they can afford.

our families expect. Client satisfaction stays high, turnover is reduced, and our practice benefits as well. However, when we work with third party employers, we will continue to advocate for our clients to have the continuity and consistency that is always the hallmark of a high quality Aging Life Care<sup>™</sup> practice.

O'Rourke agrees: "As an Aging Life Care Manager, we advise families on all of the ways they can secure caregivers for their parents; through agencies, privately, or through registries. I think the way the industry is going to go is in support of the private caregiver."

Friedman believes that this approach is not without risk, "The unintended result is the exact opposite of the legitimizing intent of the law. What we're seeing is a lot of 'underground' employment, hiring privately or through registries which increases the risks to the clients."

The differing and similar points of view of the professionals interviewed in this article depicts the complexity of maintaining the idea presented *(continued on page 14)* 

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at the White House Conference on Aging: that elders should be allowed to age in place, and we must make it affordable for all. Ironically, that is not happening as those from middle to lower socioeconomic groups are thrust forward into institutional living. While the overtime law has been rightfully designed to protect the worker, it has caused other inequities that may or may not be resolvable in the quest for all seniors to age in the comfort of their own home.

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## **(i** Exercise at any Age, with any Chronic Condition

#### Steven C. Castle, MD

#### Introduction

Exercise and physical activity for older adults was an important theme discussed at the 2015 White House Conference on Aging. Specific initiatives discussed included the NIH Go4Life campaign and the YMCA initiative to provide intergenerational physical activity. The implementation of exercise and fall prevention programs on state and national levels sheds light on the importance of physical activity as being viewed as the core to healthy aging and preventing and lessening the impact of chronic disease. Exercise is now known as an essential component

of falls prevention, demonstrated by the fact that \$5 million of President Obama's budget is targeted for the National Falls Prevention Resource Center. Moreover, the CDC has also recognized its importance by providing free online webinars on falls prevention, which are currently being used by health care providers like Kaiser Permanente. The reduced health care costs as a result of physical activity as well

as the reduction of the most common form of accidental injury (falls) may also reduce the need for long-term services prematurely.

Everyone has heard that exercise is good for you, right? Of us older

adults, how many are heeding that advice? How many of our primary care providers have spent the time to find out and help us do more exercise to the degree that they prescribe or monitor lipid lowering meds and follow cholesterol levels? One reason why we as a society are falling short, as described below, is because there is a bias AGAINST exercise in older adults that no one is talking about.

#### Why Exercise?

Exercise is essential to improving balance and reducing risk of falls. While the National Council on Aging

Everyone has heard that exercise is good for you, right? Of us older adults, how many are heeding that advice? How many of our primary care providers have spent the time to find out and help us do more exercise to the degree that they prescribe or monitor lipid lowering meds and follow cholesterol levels? (NCOA) has made a list of evidencebased programs, the evidence is not equal, and there may be other programs in the community which are actually more robust in improving balance. A recent review on efficacy of exercise programs in preventing falls identified that 32 multicomponent exercises demonstrated reduction in falls by an average of 30%, while three single component

(either walking or strength training) programs were not effective (Gillespie LD 2012). The multicomponent programs target activities that address balance, strength, endurance, and walking. Among successful programs,



total weekly exercise time ranged from 80 minutes to more than seven hours. The duration of programs ranged from eight weeks to two years, while one review suggested a minimal dose of 50 hours of balance exercise is needed to be effective. Participation was improved by having a convenient location, incorporating social activities, and reimbursement for travel costs (Ganz DA personal communication).

In addition, engaging in physical activity is essential for maintaining mobility as we age. Dr. Debra Rose, Director of the Center for Successful Aging at Cal State Fullerton, defines mobility as "the ability to move oneself independently and safely from one place to another." The ability to walk 400 meters has been defined as an excellent proxy for community ambulation, which is central to aging in place and quality of life. This became the primary outcome measure of the LIFE (Lifestyle Interventions and Independence for Elders) Study (Pahor J, 2014). This study randomized 818 (mean age 78.7 years) to physical activity (2x/week in a center and 3-4x/ week at home) with 817 (mean age 79.1 years) to a health coaching group. Of the physical activity group, 85.3% remained independent in community mobility versus only 80.2% of the health coaching group, for a 28% reduction in the risk of becoming dependent (p=.006).

#### How well are we doing?

Data from the National Health Interview Survey and the Centers for Disease Control (CDC) from interviews of the civilian and non-civilian population show that 42.4% of adults age 65-74 are reporting achieving aerobic activity goals as are 28.1% of adults age 75 and over (goal >50%). Not bad.

However, only 14.4% of adults age 65-74 and only 7.9% of adults age 75 and over are achieving the goal of both the aerobic and muscle-strengthening activities. Why aren't older adults doing more muscle strengthening exercise? Probably because we are not aware of the benefits and have a bias that it will do harm. This is also due to the lack of resources, training, and coaching / supervision needed.

## How much exercise should older adults participate in?

The US Office of Disease Prevention and Health Promotion established physical activity guidelines for "Healthy People 2020" to gain substantial public health benefits:

- Avoid inactivity, some physical activity will provide some health benefits (goal <33%)
- For substantial health benefits, older adults should do aerobic activity.
  - At least 150 minutes (2 hours and 30 minutes) a week of moderate intensity (goal >50%)
  - Or 75 minutes (1 hour and 15 minutes) of vigorous intensity (goal > 33%)
  - Or an equivalent combination, performed in 10 minute increments
  - Extensive health benefits occur when increased to 300 minutes (5 hours) of moderate intensity or 150 minutes of vigorous activity
- Muscle strengthening exercises should be done 2 or more days per week of 8-10 exercises that train all major muscle groups (goal >25%)

Additional Recommendations for older adults from the American College of Sports Medicine:

- Maintain or increase flexibility (stretching) for at least 10 minutes a day, twice a week
- To reduce the risk of injury from falls, perform exercises that maintain or improve balance

#### Why should Grandma and Grandpa perform muscle strengthening (weight resistance) training?

In the paper "Exercise is the Real Polypill" (Fiuza-Luces C 2013), the evidence of the impact of exercise in comparison with medications on reducing chronic conditions such as glucose intolerance, lipids, blood pressure, and risk of thrombosisrelated cardiovascular events (heart attacks and stroke) is discussed. The paper reviews a meta-analysis which demonstrates that weight resistance training in particular was equivalent to the polypill (1-3 blood pressure lowering meds, a lipid lowering med, and aspirin), while other types of exercise had a more modest effect on lowering blood pressure in particular. It also identified that there was lower dropout rates in exercise groups (10%) versus the polypill group (20% dropout versus 10% for placebo pill).

In addition, the paper discusses the release of beneficial myokines and anti-inflammatory substances secreted as a result of muscle strengthening exercise, as well as possible substances associated with longevity and reduced risk of colon cancer. Muscle strengthening exercise provides something different than the more traditional aerobic or cardio-fitness exercises we think of older adults actively engaged in.

What are the components of exercise that help improve balance, reduce falls, and achieve mindful awareness? (Rose D, 2010)

The following are descriptions of the positive outcomes exercise can provide for older adults and how these outcomes can improve balance, reduce falls, and increase safety awareness.

### 1. Posture and control of Center of Gravity

Older adults who experience a decline in posture often develop inaccurate perceptions of true vertical. Curvature of the spine with decline in flexibility was significantly associated with falls (Kasukawa Y 2010). Mindful awareness of vertical targets (doors, windows, corners) is helpful in restoring postural alignment. Progressive improvement in balance from exercises can start with seated, progress to standing activities, and utilize compliant (foam) or irregular surfaces. In addition, posture control strategies using the ankle, knee, or hip should be included in the exercise training.

#### 2. Strength and Endurance

Muscle strength declines as much as 20-40% between age 30 and 80. Weakness in the body core (alignment of low back, pelvis, hips) contributes *(continued on page 16)* 

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to poor balance, and weakness of the muscles in the legs can cause significant challenge in going from a seated to standing position. Strength becomes of increasing importance in individuals with poor balance control. More strength is needed to correct posture to prevent a fall because inappropriate weight shift results in moving the center of gravity off the base of support.

#### 3. Flexibility

Joint range of motion and muscle flexibility decline with age and are associated with impairment in function. Loss of flexibility to perform shoulder or spinal rotation is directly related to functional limitations and increased susceptibility to falls. Reduced flexibility in legs results in less efficient gait (limits endurance) and a decline in balance control (leaning) that also contributes to falls.

#### 4. Gait speed and efficiency

Because of many of the changes described above, stride length and decreased height of each step results in a decline in gait speed. Slow gait results in less stability and shorter steps: shuffling increases the risk of tripping or catching a toe. Exercise programs that require negotiating obstacles and vary surface conditions allow participants to develop a walking pattern that is more efficient, flexible, and adaptive, with more speed to improve stability.

#### What else can we do to improve mobility and balance?

Falls prevention is difficult to achieve, while mobility and balance awareness should not be. For the needed behavior changes for exercise and adaption to changes, mobility and balance awareness provides a platform for patients, family, and care managers. One way to better address mobility and balance awareness is by doing balance assessments, including the 8 foot up and go as part of the Senior Fitness Test, or the more balance-focused Short Form of the Fullerton Advanced Balance Scale (Hernandez D 2008). These objective measures provide the opportunity to discuss changes

in balance which most of us are not cognizant or aware. Most 80-year-olds will recognize their balance is not like when they were 30, but all 60 and most 70-year-olds are not aware of decline at all; and all older adults are not aware of the size of the risk or that they have the ability to improve their balance through a formal balance exercise program or the need to adjust their lifestyle to match.

Once aware of their change in mobility and balance, the next step is to try and have older adults work with their providers to figure out the cause of mobility and balance changes. A practical approach to identifying the underlying causes is by symptom categories:

- D: Dizziness/Vestibular benign positional vertigo, vestibular neuronitis, Meniere's Disease, brainstem infarcts
- LH: Light headed/Postural Hypotension – drop in blood pressure with standing

#### **BB: Bad Balance**

- Frame kyphoscoliosis, leg length discrepancy
- Central infarcts in basal ganglia, central microvascular infarcts, Parkinson's, cerebellar
- Peripheral Peripheral neuropathies, spinal stenosis
- Impaired vision, especially discrepancy between eyes
- Meds sleep aids, neuropathic pain meds, psychotropics
- Barefoot or socks increases the risk of falls 10-13 times vs. wearing shoes w/heel; poor weight transfer to balls of feet (studies have shown that wearing socks or walking barefoot inside increases the risk of falling 10-14 fold.
- W: Weakness MS, focal weakness (stroke, motor neuropathy)
- PA: Poor awareness all of us as we age, dementia (Lewy Body & Vascular in particular)

Visit www.DrBalance.com for more information.

## What this Geriatrician learned from the Gerofit program

The following describes an exercise program, Gerofit, and its proven benefits for its participants. The Gerofit program was started by Dr. Miriam Morey at the Durham VA and for the past 30 years has successfully provided an exercise venue for older adults with chronic conditions (Morey MC, 2007). The program requires a referral from the primary care provider, with a chart review and telephone interview. Then baseline and quarterly Senior Fitness Test assessments (Rikli RE 2013) tell you your percentile ranking by gender and five year age group. This allows a prescribed individualized exercise program that includes exercises for aerobic/ cardio, weight resistance, and balance. Program participants demonstrated a 25% reduction in mortality over five years, and in a related study, those that showed a o.1m/sec increase in usual gait speed had less hospital days and reduced one-year costs (Purser JL 2005).

This author was skeptical of this program and had concerns about its safety. What I learned from exercising with older Veterans, doing assessments, and adjusting exercise protocols was this: besides being a lot of fun, the gym is a true respite from illness. Everybody has chronic conditions, and instead of focusing on them, everyone is working to improve their fitness. Second, I realized I was biased against exercise because I was fearful someone would get hurt. Instead, what I have learned is to assess their fitness, then prescribe an appropriate starting place for cardio, weight-resistance training, and balance based on that assessment. Third, older adults need guidance/reminders to do exercises correctly and to adapt exercise to chronic musculoskeletal conditions, and most importantly, to progress the intensity of the exercises. I also learned it is very hard to predict in whom exercise will really take hold and become life changing. Prior history of some physical fitness training provides a clue, but is not a guarantee; while many with no background in exercise can just as readily take off. Exercise is life changing in this cohort.



Here is an example of a success story from our program:

Grant Blackman, 87 years old, Gerofit Participant (325 pounds when he started): "Before I started Gerofit, I was finished -- on the way out. I had difficulty getting up off the couch and had to pull on the coffee table to get up. Now, I have everything to live for. I feel great and now can walk into the post office or store without even using my rollator."

#### What do we do about exercise in the significant portion of older adults with varying forms of cognitive impairment?

How do we implement an exercise program that includes cardio, muscle strengthening, and some balance exercise in this population? What I have learned from Gerofit is that some of the older adults in a program will develop cognitive decline, some will be unrecognized at time of enrollment but become more obvious when they do not learn exercise routines or technique; and in both cases, they will exercise effectively but need supervision and coaching. Those with moderate dementia can fit well into a group exercise program if there is enough staff support or their caregivers are trained and supervised as well. Folding cognitive impairment participants into a fitness program really provides optimal socialization and engagement when the focus is on fitness and set exercise routines. Participants with dementia with past history of physical activity will have motor memory that exceeds cognitive memory. Regardless, improvement in fitness assessment is the norm if participants engage in the exercise, and there is significant benefit to mood and reduced anxiety.

#### How can an Aging Life Care Manager™ help?

Aging Life Care Managers have an important role in promoting exercise for their older clients. Care managers can facilitate the interaction of older adults, families, and health care providers, making the initiation of an exercise program more possible. Care managers can recommend exercise programs for their clients for fall prevention, but can also help to identify clients that have already fallen that could benefit from exercise as an intervention.

The recommendation by the CDC is that if someone has had two or more falls or a fall with injury in the past year, has decreased activities due to changes in their balance, or has demonstrated at-risk screening measures mentioned above, then the following should be done:

 Address chronic medical conditions that may be contributing to changes in balance, including inadequately controlled hypertension.

> How do we implement an exercise program that includes cardio, muscle strengthening, and some balance exercise in this population?

- Review possible risky medications that may impair balance for indication, efficacy, and safer alternatives. A careful review of how medications are being administered for adequate adherence, and if a blood thinning medication is appropriate given the falls risk, adherence with meds and risk/benefit of the blood thinner.
- Have a thorough mobility and balance assessment, including drop in blood pressure with standing, vision (acuity and peripheral fields) cognition, and gait assessment.
- Be offered a mobility aid, with training from qualified professional.
- Be encouraged to participate in a balance exercise program.
- Address vision, appropriate shoes (no barefoot or socks), lighting and environmental risks.

An Aging Life Care Professional<sup>™</sup> is in a unique position to encourage clients and their families to follow through with these recommendations, and begin or continue exercise programs that meet the guidelines.

We, as care managers and health care providers, need to address our own bias about exercise for older adults, in order to become effective advocates for this essential component of health and wellness.

#### References

2008 Guidelines on Physical Activity. US Office of Disease Prevention and Health Promotion.

http://health.gov/paguidelines/pdf/ paguide.pdf

Gillespie LD et al. (2012) Interventions for preventing falls in older people living in the community. Cochrane Database of Systematic Reviews Issue 9. Art. No.: CD007146.

DOI:10.1002/14651858.CD007146.pub3.

Fiuza-Luces C et al (2013) Exercise is the real polypill. Physiology 28:330-358. Doi:10.1152/physiol.00019.2013

Hernandes D, Rose DJ. (2008) Predicting which older adult will or will not fall using the Fullerton Advanced Balance Scale. Arch Phys Med Rehabil 89:2309-2315. Doi.10.1016/j.apmr.2008.05.020

Kasukawa Y et al (2010). Relationships between falls, spinal curvature, spinal mobility and back extensor strength in elderly people. J Bone Miner Metab 28:82-87. Doi 10.1007/s00774-009-0107-1

Pahor J et al. (2013) Effect of structured physical activity on prevention of major mobility disability in older adults: The LIFE Study randomized clinical trial. JAMA 311(23):2387-2396. Doi:10.1001/ jama.2014.5616

Rikli RE, Jones CJ (2013). Development and validation of criterion-referenced clinically relevant fitness standards for maintaining physical independence in later years. The Gerontologist 53:255-267. Doi.10.1093/geront/gnso71

Rose D. (2010) Fallproof! 2nd Edition. A Comprehensive Balance and Mobility Training Program. Human Kinetics. ISBN-13: 9780736067478 (continued on page 18)



(continued from page 18)

Schiller JS et al. Early release of selected estimates based on data from the January-June 2014 National Health Interview Survey, National Center for Health Statistics. http://www.cdc.gov/nchs/data/ nhis/earlyrelease/earlyrelease201412.pdf

White House Conference on Aging 2016, Final Report. http://www. whitehouseconferenceonaging.gov/2015-WHCOA-Final-Report.pdf

#### Dr. Steven C. Castle, MD

Dr. Steven C. Castle, MD is a Professor of Geriatric Medicine at UCLA, Clinical Director of Geriatrics at the VA Greater Los Angeles, and is a Governor appointee to the California Commission on Aging. He is also the first physician to be certified as a FallPROOFTM Instructor from Cal State Fullerton.

His undergraduate degree is from Miami University and he attended Ohio State School of Medicine. He did his residency in Internal Medicine at Riverside Methodist Hospital in Columbus, Ohio and a Geriatric Medicine Fellowship at UCLA.

He has received over \$2.8 million in total grant funding, including 2 grants from the NIA; for studies on the immune function with aging, and a collaborator on grants from NIA and NSF for developing protective headwear to reduce brain injury in older adults, as well as mobility and balance awareness programs in affordable retirement communities. He has over 60 publications and has over 400 invited presentations nationally and internationally.

Dr. Castle is also President and CEO of DrBalance, Inc; a web-based platform to provide solutions for mobility and balance changes in older adults across the healthcare spectrum.

He has received many awards and honors, including the Clinician of the Year from the American Geriatrics Society, six teaching awards at UCLA and an Advocacy Award for his work in falls prevention from the James A. Haley VA in Tampa, Fl.

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## The Neuroprotective Role of Exercise

Jennifer Voorlas, MSG, CMC

#### Exercise and Dementia | by Steven C. Castle, MD

The White House Conference on Aging (WHCOA) not only addressed the importance of addressing Alzheimer's and related dementias as a national priority, but also identified The National Institute of Health's "stepped up effort" to find more effective ways to treat and prevent this devastating illness (1).

Jennifer Voorlas has provided a very detailed survey on the neuroprotective role of exercise in brain health for older adults. While there are many supplements being marketed to improve cognitive function as we age, and we hear advertisements for "brain exercises" regularly on the radio, there is more evidence to support that exercise has a much more important role in both the prevention and slowing progression of dementia, including Alzheimer's Disease.

In prevention of dementia, lack of physical activity is the most modifiable risk factor for Alzheimer's Disease in the United States, in addition to beneficial effects on midlife obesity. Regular exercise has demonstrated improved cognition with normal aging outside of dementia. This physiologic improvement in cognition is hypothesized to be due to the beneficial adaptations in vascular physiology and improved neurovascular coupling.

#### Introduction

Does physical exercise provide an ameliorative effect on age-related neuronal loss? This is a complex and controversial subject among researchers. Significant brain cell loss is not usually considered an intrinsic part of normal age-related decline. However, it is generally agreed that even healthy people experience some loss of brain cells as they age--particularly after the age of sixty (1). But can exercise perhaps halt or slow down brain cell loss leading to more severe disorders—such as Alzheimer's Disease or other forms of dementia-at least in some individuals? Can exercise have a rehabilitative impact? These questions are particularly relevant when looking at the potential benefits to older adults for improved physical, mental, and cognitive health.

We do know that neuronal loss may occur and can be attributed to genetic predisposition towards Alzheimer's Disease or dementia, but also due to multidimensional factors: including diet, a sedentary lifestyle, or menopause (low estrogen) (1). Increased prevalence of neurodegenerative illness in modern societies has been related to an increasingly aging population (2). A sedentary lifestyle may be a risk factor for neurodegenerative disease, and is associated with a higher risk of cerebrovascular accidents.

Moreover, several studies indicate that exercise may be neuroprotective. In fact, physical activity has been



shown to increase cognitive ability in older adults, attenuate motor deficits, increase new neuron formation, ameliorate neurological impairments, and impede age-related neuronal loss (2).

Cognitive assessments have revealed that regular, moderate-intensity physical exercise enhances mental performance in both young and older adults. Lessons may also be learned in particular from studies of the rat brain, considered very similar biochemically to that of the human. Active or exercised rodents—in comparison to sedentary controls--demonstrate improved spatial learning, enhanced memory retention, reduced escape latency, and diminished age-related declines in spontaneous activity (3).

#### Increase Of Metabolic Capacity

Studies have shown several structures in the brain that exhibit exercise-related plasticity and which are likely to be active during vigorous physical activity: the hippocampus, motor cortex, and stratum (4). In addition to transient fluctuations in metabolism, studies done on rats and on humans show exercise to cause neurochemical and structural plasticity (ability to respond to stress or demand) in the hippocampus and striatum, the areas of the brain involved in contextual behavior and decision making (4). Again, drawing on rat models, specific metabolic and neural activity can be detected that shows, during exercise, metabolism increases in the hippocampus, striatum, and the motor cortex (4). These studies lend credence to the argument that by stimulating these critical areas of the brain by exercise there are real potential benefits in slowing the progression of neurodegenerative changes in the brain by avoiding being sedentary.

#### **Exercise as Neuroprotective**

The effect of exercise on how insulin-like growth factor 1 (IGF-1) impacts brain cells also suggests another positive line of study. Because we customarily produce less IGF-1 as we age, understanding how IGF-1 plays a role in supporting the growth of cells/cellular structures in the adult brain may help in understanding how neurodegenerative diseases such as Alzheimer's or stroke affect the brain. Research in the role played by circulating IGF-1 as a possible neuroprotectant in the brain could reveal that exercise is a buffer against more severe insults on the brain (5), so that that if you do produce more beta amyloid (the abnormal protein that is increased in deposits in people with Alzheimer's), the brain is relatively protected by additional circulating IGF-1.

Exercise is also found to stimulate the up-take of the neurotropic IGF-1 from the bloodstream into such specific targeted areas as the hippocampus. By analyzing the specific role of circulating IGF-1 on brain function under physiological conditions, researchers are trying to understand if physical exercise can result in an increased uptake of circulating IGF-1 by muscles and the brain.

It has also been shown that exercise will increase the number of new neurons in the adult hippocampus. Peripheral administration of IGF-1 results in increases in the number of new neurons in the hippocampal region of hypophysectomized rats (rats without the pituitary gland).

It is speculated that circulating IGF-1 might be facilitating the stimulatory effects of exercise on the number of new hippocampal neurons (in normal adult rats) (4, 5). There is now a general consensus that these new neurons are, in fact, produced on an ongoing basis in the hippocampal dentate gyrus of adult mammals. These new neurons arise from a local population of progenitor or stem cells in the sub granular zone, a specific layer in this section of the brain associated with dramatic cell loss in Parkinson's and Alzheimer's Disease.

Exercise is considered "neuroprotective" because of increased passage of circulating IGF-1 into the brain; when this passage is blocked, exercise is no longer neuroprotective. Additional evidence suggests that systematic administration of IGF-1 to brain damaged sedentary mice or rats is sufficient to elicit functional recovery. Based on these findings, it is hypothesized that circulating IGF-1 exerts a physiological protective effect on the brain—one that is depressed in sedentary subjects. By extrapolating these results in rodents to humans, since studies show that exercise also stimulates the growth hormone-IGF-1 axis in human beings, it is conceivable that a sedentary lifestyle contributes to the increasing prevalence of neurological diseases (2).

#### **Brain Cell Proliferation**

In order for exercise to be able to increase the number of new hippocampal neurons, circulating IGF-1 is a necessary factor. Studies show treadmill running, significantly increases the number of replicating neuronal cells (that stain for bromodeoxyurdine in the nuclei) in the hippocampus of adult rats, which also replicates recent findings in mice. Therefore, what is found via exercise, is that Circulating IGF-1 increased the amount of neurons in the hippocampal region of the brain in the group that exercised vs. the group that did not.

> Cognitive assessments have revealed that regular, moderateintensity physical exercise enhances mental performance in both young and older adults.

It can also be speculated that such factors as aging or stress (5) decrease the number of new neurons through up-regulation of endogenous (generated within the body) corticosteroids, and may eventually modulate availability of endogenous neurotropic factors such as IGF-1. When we look at this effect on the aging brain, the positive effect of exercise on the hippocampus (the center of learning and memory) can translate into increased reaction time, thinking, and memory skills.

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#### **Brain Injury & Exercise**

It has been found that the peripheral administration of IGF-1 has potent therapeutic effects in several models of brain damage; this supports the idea that exercise could indeed have ameliorative effects on more serious insults to the brain, and is supported by evidence that early exercise in concussion or traumatic brain injury may be protective (Traumatic Brain Injury and Mitochondrial Dysfunction JB. Hiebert, Q Shen, AR. Thimmesch, and JD. Pierce, Am J Med Sci 2015;350(2):132–138).

Moreover, it can be extrapolated that IGF-1 could also prove of therapeutic value in hippocampal-related diseases—particularly those involving memory processes—and offers a promising venue for further research. Further support of the idea that exercise improves cognition is shown by the fact that IGF-1 ameliorates memory deficits in aging rats. This is a possible explanation for the beneficial effects of physical exercise on the response to neurodegeneration in diseases such as Alzheimer's, where IGF-1 levels are significantly altered. More research needs to be done in order to determine the potential of exercise to ameliorate brain injury after a stroke (TBI) as the research indicates that memory, thinking, and depression markedly improved among exercisers vs. non-exercisers (6).

## The Impact of Sedentarism on Brain Health

Another perspective (7) discusses how circulating IGF-1 facilitates the protective effects of physical exercise against brain insults of different etiology and anatomy. As stated, sedentarism increases the susceptibility to neurodegenerative processes attributable to insufficient brain uptake of serum IGF-1. Several models were used of neurodegeneration affecting different brain areas, because exercise-induced capture of serum IGF-1 is widespread. Since IGF-1 receptors are widely distributed in the brain, neuroprotection by exercise-induced brain uptake of IGF-1 should be ample.

Three models of experimental

neurodegeneration affecting different brain areas were utilized to determine whether neuroprotection by exercise includes all types of neuronal populations—or is rather restricted to a few. To test this, three groups of rats were subjected to administration of excitotoxics of various strengths to produce mild, moderate, and severe models of neurodegenerative damage. The purpose was to test both prevention and amelioration of neurodegeneration by exercise.

The results indicated that in all three groups, exercise ameliorated damage-incurred symptoms; many animals recovered substantial function after five weeks of vigorous exercise on the treadmill. When anti-IGF-1 antibody was injected before the exercise, the ameliorative and recovery effects were blocked. Animals receiving the anti-IGF-1 antibody suffered marked neuronal damage similar to that found in sedentary animals.

Thus, exercise was found to not only attenuate the impact of brain insult, but also to impede the progression of ongoing neurodegeneration, as well as functional recovery from insults (7). Exercise reduces or eliminates neuronal death and decreases or entirely blocks behavioral impairment after neurotoxic insult. While knowledge of the mechanisms underlying IGF-1 neuroprotection are scarce -- their possible relation to exercise-induced neuroprotection being unknown--it is speculated that glucose metabolism may be an important factor. Both IGF-1 and exercise may affect glucose metabolism, because energy demands are increased injured neurons. Both IGF-1 and exercise increase demand for available glucose to the brain. In fact, hippocampal damage with domoic acid induces an increase in glucose uptake in the hippocampus (7).

Recent studies indicate that while regular physical activity may be a protective factor against cognitive decline during aging, inactivity, itself, may be a risk factor for dementia. Furthermore, regular physical activity is now recommended as a therapeutic strategy to delay, prevent, or combat neurodegenerative disease (2). However, the molecular mechanisms underlying the advantageous effects of exercise remain unclarified. Specifically, it is somewhat nebulous whether the neurologically favorable sequelae of physical activity extend to neuroprotection.

#### Oxidative Stress & Antioxidants

Scientists have studied these three questions to understand how relevant oxidative stress and antioxidants are in acute or chronic exercise: 1. Does exercise cause oxidative stress in organs? 2. Does chronic or acute exercise show different effects on oxidative stress in various organs? and 3. What is the relationship between exercise-induced oxidative stress and endogenous antioxidants? The hypothesis is that chronic and acute exercise may have important effects on organs such as the brain, as well as on the muscles and heart and that endogenous antioxidants may play an important role in the adaptation to exercise-induced oxidative stress (10).

Extreme exercise is thought to increase oxidative stress (temporarily) and moderate exercise is thought to increase antioxidant levels. Therefore, depending on the type and duration, it is very well possible that someone's "baseline" ability to fight free radical damage to the brain may be elevated. Considering the aging brain, as well as in the case of neurodegenerative diseases, there is a decline in the normal antioxidant defense mechanisms. which increases the vulnerability of the brain to the deleterious effects of oxidative damage (11). If exercise can "counteract" this effect, there may be important implications for older adults already genetically susceptible to Alzheimer's and related dementias.

#### **Translating the Research**

What possible implications do these scientific studies show? What does the impact of exercise on the brain have on potential "at risk" individuals-- those presently suffering from Alzheimer's disease or other types of dementia? Could exercise possibly prevent--or slow down the progression of these conditions? The studies presented confirm that exercise had beneficial effects for those with risk factors for dementia and other types of brain



injury, as the severity of those with the highest level of physical activity was reduced by 50%, along with a 60% decrease in the incidence of Alzheimer's disease (12).

While the studies do not take into account genetic predisposition of Alzheimer's and how that may or may not skew the results, the underlying mechanisms confirm that exercise sustains cerebral blood flow by decreasing blood pressure, lowering lipid levels, inhibiting platelet aggregability, and easing cerebral metabolic demands (12); which implicates that perhaps one genetically at risk may still reap the benefits if they exercise.

As of recently, the benefits of exercise as a preventative measure against more serious neurodegeneration has been studied as a means to prevent, slow down, and/ or ameliorate preexisting conditions for the elderly. However, now the overall beneficial effects of exercise on AD (Alzheimer's) has been shown to include lower body weight, improved diet (including increased consumption of antioxidants, and lower fat intake), mood, improved blood pressure and cardiovascular health, and decreased blood clotting (13).

#### Conclusion

While there is no question that exercise has an overall beneficial effect on the brain--as well as the other areas of one's physiology--exactly how it does so remains a controversial issue. Further areas of research need to include whether or not exercise must be done over a lifetime (cumulative effect) to reap positive rewards, or if one can take up an exercise routine later in life and reap the same positive results. Moreover, the types of exercises health care professionals recommend to their patients need to be appropriate and carefully crafted for seniors with limited mobility and significant health and cognitive limitations.

If Aging Life Care Managers<sup>™</sup> and physicians can work together to come up with appropriate exercise plans tailored to the individual's medical and cognitive ability, significant benefits may be realized. Our challenge as care managers is to take into consideration the many different types of exercise, the appropriate duration, consistency, intensity of specific types of exercise appropriate to each individual's current health condition.

While additional research is needed to understand the complexity and non-linearity of the exact mechanisms by which exercise produces an ameliorative effect, it still appears clear that regular physical activity represents a critical and potent protective factor against cognitive decline and dementia in the elderly, paving the way for further emphasis on prevention by including exercise in each care manager's care plan for each of our clients.

#### References

(1) Schaie, K.W., & Willis, S.L. (1996) Adult Development & Aging. New York: H

(2) Ramsden et al., Exercise increases the vulnerability of rat hippocampal neurons to kainate lesion. Currently in publication.

(3) McCloskey et al., Exercise increases metabolic capacity in the motor cortex and striatum, but not in the hippocampus. Brain Research. 2001; 168-175.

Harper Collins Publishing.

(4) Trejo et al., Circulating insulin-like growth factor I mediates exercise-induced increases in the number of new neurons in the adult hippocampus. Journal of Neuroscience. 2001; 1628-1634.

(5) Carro et al., circulating insulin-Like growth factor I mediates the protective effects of physical exercise against brain insults of different etiology and anatomy. Journal of Neuroscience. 2001; 5678-5684.

(6) Williams, GP & Morris, ME. Brain Injury, Aerobic Exercise Following TBI. Brain Injury: Vol 23 (4) April 2009, pp 307-312.

(7) Berchtold et al., Estrogen and exercise interact to regulate brain-derived neurotropic factor mRNA and protein expression in the hippocampus. European Journal of Neuroscience (2001); 1-14.

(8) Larsen et al., Does long-term exercise counteract age-related Purkinje cell loss? A stereological study of rat cerebellum. Journal of Comparative Neurology (2000); 213-222.

(9) Praag et al., Running increases cell proliferation and neurogenesis in the adult mouse dentate gyrus. Nature Neuroscience (1997); 266-270.

(10) Gomez-Pinilla et al., Physical exercise induces FGF-2 and its mRNA in the hippo-campus. Brain Research (1997); 1-8.

(11) Liu et al., Chronically and acutely exercised rats: biomarkers of oxidative stress and endogenous antioxidants. Journal of Applied Physiology (2000); 21-

(12) Carmelina Gemma, Jennifer Vila, Adam Bachstetter and Paula Bickford: Brain Aging: Models, methods and mechanisms, Oxidative stress and the aging brain (2007);353-354.

(13) Laurin et al., Physical activity and risk of cognitive impairment and dementia in elderly persons. Archival Neurology (2001); 498-503.

(14) Friedland et al, Patients with Alzheimer's Disease have reduced activities in midlife compared with healthy control-group members. PNAS (2001); 3440-3445.

#### Footnote

 White House Conference on Aging National Report: National Institute of Health and Human Services 2015 report

#### Jennifer E. Voorlas, MSG, CMC

Jennifer E. Voorlas, MSG, CMC has been in the field of gerontology since 1996 when she first participated as an intern in the peer counseling program for seniors, at the Center for Health Aging in Santa Monica CA. While completing her Master's degree in Gerontology in 1998 at The University of Southern California, she worked at the Alzheimer's Disease Research Center at USC, coauthoring a training manual for teachers based upon a pilot program she co-created for at-risk seniors in the community called The Memory Enhancement Seminar for Seniors. As co-administrator of this community outreach program, she was able to learn about the unique needs of a diverse group of elders in the community. Further on in her career she worked within a neurology practice for many years as a sole geriatric care manager/consultant. During this time she also started her own geriatric care management practice in 2011 Geriatric Care Consultants LLC in Malibu, California where she currently resides. She can be reached at geriatriccaring@ aol.com.

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### Updates from the White House Conference on Aging about Elder Mistreatment: What Aging Life Care Managers<sup>™</sup> Need to Know

Amy Berman, BS, RN, Kathrin Lozah, and Terry Fulmer, PhD, RN, FAAN

#### Abstract

Elder mistreatment causes undue harm and suffering for the over 1.2 million Americans who are victims annually. Aging Life Care Managers are in an optimal position to help screen, detect, and intervene in this serious clinical syndrome. The 2015 White House Conference on Aging did much to propel this issue to the headlines, noting the problem as a central issue and President Obama specifically called out elder abuse and neglect as an affront to our older citizens. Here we provide information regarding what care managers should know and what they can do to help.

#### White House Conference on Aging (WHCOA) raises Elder Mistreatment as a national priority

The older adult population in the United States is doubling in size, a dramatic increase in the number and proportion of older adults that is largely the result of two factors. First, people are living longer and second, 10,000 baby boomers are turning 65 each day and will continue to do so for the next few decades (Pew Research Center, 2010). However, an increase in life expectancy does not necessarily equate to an increase in the quality of life lived; growth in the population of older adults also means greater numbers of people experiencing elder abuse and mistreatment.

In order to shine a national spotlight on issues impacting older adults, the White House Conference on Aging (WHCOA) is held once every ten years to focus on policy and practice reforms necessary to improve the health and wellbeing of our nation's older adults. The most recent conference, held in July 2015, centered discussions on four focus areas. These four foci are: 1) Retirement Security, 2) Healthy Aging, 3) Long-Term Services and Supports, and most notably – 4) Elder Justice.

Elder justice is defined as efforts, "to prevent, detect, treat, intervene in, and prosecute elder abuse, neglect, and exploitation and to protect elders with diminished capacity while maximizing their autonomy (O'Shaughnessy, 2010)." In order to address elder justice, the WHCOA announced a number of targeted efforts that include improving the science on understanding and preventing elder abuse, protecting older American victims from financial exploitation and crime, and training law enforcement professionals to detect and prosecute elder abuse and mistreatment. These targeted efforts have been described in greater detail below.

#### President Obama speaks about elder abuse

President Barack Obama convened and addressed the WHCOA, offering powerful remarks on the state of aging in America. The President celebrated the strides that have been, and continue to be made, to ensure that every older American is treated with the dignity and respect he or she deserves. President Obama commented that, "the United States has a lot to be proud of," in regards to how it treats its older citizens, citing Medicare, Medicaid, and Social Security as, "some of our greatest triumphs as a nation (Obama, 2015)."

President Obama also reflected on the magnitude of work that has yet to be completed in order to ensure that older adults have the resources and support they need to flourish. The President cited elder mistreatment, the increasing costs of aging, and the lack of home care workers, as challenges for our rapidly aging demographic.

In his address at the White House Conference on Aging, President Obama mentioned specific reforms for the promotion of elder justice stating, "We're going to update quality and safety requirements for thousands of nursing homes, train more prosecutors in how to combat elder abuse, and work with Congress to reauthorize the Older Americans Act [in order to] provide critical support to families and communities (Obama, 2015)."

#### What is Elder Abuse?

According to the Institute of Medicine, "Elder abuse is a violation on older adults' fundamental rights to be safe and free from violence and contradicts efforts toward improved well-being and quality of life in healthy aging (IOM, 2014)." Data suggests that as many as 1 in 10 older adults in America experience physical, psychological, or sexual abuse, neglect, or financial exploitation (IOM, 2014). Yet, sadly, members of the health care team often fail to prevent, assess, identify, report, and ultimately address elder mistreatment.

There are five main types of elder abuse according to the World Health Organization's World Report on Violence and Health. They are: (a) physical abuse, the infliction of pain or injury, physical coercion, or physical or drug-induced restraint, (b) psychological or emotional abuse, the infliction of mental anguish, (c) financial or material abuse, the illegal or improper exploitation or use of funds or resources of the older person, (d) sexual abuse, non-consensual sexual contact of any kind with the older person, and (e) neglect, the refusal or failure to fulfil a caregiving obligation



which is not necessarily a conscious and intentional attempt to inflict physical or emotional distress on the older person (Krug, Dahlberf, Mercy, Zwi, & Lozano, 2002).

According to the 2003 National Research Council report entitled, Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America, elder mistreatment is defined "as (a) intentional actions that cause harm or create serious risk of harm (whether or not harm is intended) to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder or (b) failure by the caregiver to satisfy the elder's basic needs or to protect the elder from harm (National Research Council of the National Academies, 2003)" This definition is a general characterization of elder abuse and mistreatment which basically falls into intentional abuse or unintentional neglect.

#### **Incidence and Prevalence**

According to the National Elder Abuse Incidence Study, between 1 and 2 million Americans age 65 or older have been injured, exploited, or otherwise mistreated by someone on whom they depended for care or protection (National Research Council of the National Academies, 2003). The National Center for Elder Abuse found that 7.6-10% of older adults experienced abuse, not including financial abuse, within the past year (NCEA, 2011). Older adults were more likely to report major financial exploitation (4.1%) than other forms of abuse including emotional, physical, and sexual abuse or neglect (NCEA, 2011). In 2010, senior citizens lost an estimated \$2.9 billion because of financial exploitation and current estimates put the overall reporting of financial exploitation at just 1 out of every 25 cases, suggesting that there may be at least 5 million financial abuse victims each year (Elton, 2012; NCEA, 2005).

Elder abuse is a significant contributor to poor health outcomes and preventable death. Older adults who are victims of violence have more health care problems and higher utilization than other older adults, including increased bone or joint problems, digestive problems, depression or anxiety, chronic pain, high blood pressure, and heart problems (NCEA, 2011). Perhaps most troubling is that elders who experienced any form of abuse are at three times greater risk of death than those not abused (NCEA, 2011). The underreporting and underassessment of elder abuse on the local, state, and federal levels is significant and the needless effects on older adults is unacceptable. Identification of elder abuse must be a priority for Aging Life Care Managers.

## Under Assessed and Under Reported

When abuse is suspected, Adult Protective Services (APS) is available in all 50 states, with reporting of elder abuse mandated in most states. Yet, an overwhelming number of cases of abuse, neglect, and exploitation go undetected and untreated each year. The New York State Elder Abuse Prevalence Study found that for every case known to programs and agencies, an astounding 24 cases were unknown (NCEA, 2011). Research has shown that the vast majority, approximately 90% of abusers, are family members, most often adult children, spouses, partners, and others, and these family members most often have one or more of the following co-morbidities: drugs or alcohol abuse; mental/emotional illness; caregiver burden (NCEA, 2011).

What are the barriers to identification and reporting of elder abuse and mistreatment? Today, there is no uniform, coordinated system that identifies and reports suspected abuse and provides the victims and perpetrators with a consistent set of services to address the abuse. Major barriers include the flow of information across providers and settings of care and dearth of research and funding to develop and spread interventions. The lack of public awareness and healthcare provider education makes elder abuse very difficult to detect, let alone accurately report.

It is crucial that health care professionals recognize the risk factors, behaviors, and patterns of injury, because signs of abuse can be detected in the standard physical examination (Gibbs & Mosqueda). We can no longer be complacent about the current lack of elder abuse assessment and reporting.

#### **Case Study**

Mrs. F is an 89-year-old widow who lives at home with her 65-year-old son G who has a history of alcohol problems. G cares about his mother and does some things to help her but because of his chronic drinking, he is neglectful and at times abusive. Frequently, he uses her Social Security check to buy beer and does not fill her medication prescriptions. He is well known to the adult protective service system and has been referred by concerned neighbors, but Mrs. F refuses to throw him out saying that she loves him and that it is her fault that he is such an unsuccessful adult. The care manager is familiar with Mrs. F and is at a complete loss as to who can help her determine an appropriate plan of care. Does this sound familiar?

#### Recommendations from the White House Conference on Aging

The White House Conference on Aging (WHCOA) produced an important set of recommendations aimed at addressing the national crisis in elder justice. The three key areas of focus and reform in elder justice are:

1) Improvement of the science on understanding and preventing elder **abuse** targets research and screening as avenues for development. President Obama announced the formation of a State of the Science workshop on elder abuse to be hosted by the National Institutes of Health. The purpose is to bring together researchers, clinicians, and other practitioners in the field to renew their understanding of elder abuse prevention and detection, screening tools to detect victims of abuse, as well as other gaps in elder abuse research (FACT SHEET: The White House Conference on Aging, 2015). This State of the Science will identify critical research gaps and make recommendation to move evidence-based best practice into common practice.

2) Protection of older Americans from financial exploitation and elder abuse includes the introduction of both public and private sector actions to combat the rampant scourge of financial abuse in older adults. In the public sector, the Consumer Financial Protection Bureau is releasing an advisory for financial institutions to help prevent, recognize, and report elder financial exploitation and the federal Administration for Community Living is launching a national effort that will establish core principles for Adult Protective Services, a key resource for states (2015 White House Conference on Aging: Final Report, 2015). Additionally, in the private

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sector, the American Banking Association Foundation will release an interactive community mapping tool that works with innovative bank programs to halt financial fraud and exploitation, deliver consumer education, and form partnerships with local state and federal services (2015 White House Conference on Aging: Final Report, 2015).

3) Training elder abuse prosecutors and developing online training for law enforcement is led by the U.S. Department of Justice which has committed to train prosecutors from all 50 states in order to encourage legal action against elder abuse and financial exploitation. This is a necessary step in combatting the elder abuse epidemic. It has been shown that states with mandatory reporting and tracking of reports have higher domestic elder abuse report investigation rates than states that do not, emphasizing the need for a strong, well-equipped law enforcement team that can prosecute financial elder abuse.

In summary, these strategies to address elder mistreatment focus on prevention and response, fostering research on elder abuse and services, and expanding policies that address elder abuse, an opportunity for public and private efforts to move the nation forward.

#### Call to Action: You Can Make a Difference

Aging Life Care Managers can play a significant role in both identification and treatment of elder mistreatment. Why is this important? Morally, it is an opportunity to prevent needless suffering. Ethically, it is the right thing to do. And professionally, it aligns with a number of outcomes that care managers are responsible for supporting such as improved health, prevention of unnecessary healthcare utilization, and decreased hospital readmissions.

Elder mistreatment is a strong predictor of disproportionate utilization within the healthcare system. People who are victims of elder mistreatment show up more frequently in the emergency room. They are admitted to hospitals and skilled nursing facilities more frequently (Dong & Simon, 2013). These avoidable crises of care are often the physical consequences of abuse and neglect.

#### "Are You Safe at Home?"

There are a number of evidence-based screening tools that may be used to assess elder mistreatment. If your organization already uses one, it is best to follow your institution's protocol. If there is no protocol in place, it may be helpful to know that research has demonstrated a single-item screening question, "Are you safe at home?" was shown to be as effective as longer screening tools (Wasson et al., 2000). Whatever the tool, it is important that you and your organization have a consistent way to identify victims of elder mistreatment. It is critical to include screening in the emergency department and on initial visits in the home.

Every member of the health care team is responsible for identifying and addressing elder mistreatment. Yet, victims frequently present themselves to a wide array of clinicians including physicians, nurses, social workers, care managers, pharmacists, and paraprofessionals. While each one may see the same bruises, fractures, timid demeanor in the presence of family, fear and neglect, if an organization has not made a commitment and set clear expectations for addressing elder mistreatment, victimization may continue.

#### Signs of Elder Abuse

It is important to remember that you can recognize signs of physical and emotional abuse during a routine physical assessment. The following chart is a synthesis of the science on the identification of elder mistreatment (Anetzberger, 2005; Gibbs & Mosqueda, 2014; Powers, 2014)

As a care manager, it's critical that you keep your assumptions in check. Not all homes are loving homes. Not all family members are loved ones. If you suspect abuse, you need to speak to the potential victim privately. Ask the family to step out of the room. If you are in the home environment consider asking the family member for a cup of water. You are responsible for creating an environment that allows your patient or client to answer freely.

Call the police or 9-1-1 immediately if someone you know is in immediate, life-threatening danger. If not in eminent danger, and a person screens positive or elder mistreatment is suspected, follow your organization's procedures for reporting. Some health systems have access to a multi-disciplinary team (MDT) of specially trained health care providers to follow up on cases of suspected abuse. All clinicians, including care managers, must follow their state's mandatory reporting requirements. To find out about the reporting requirements in your state, go to Adult Protective Services, Institutional Abuse and Long Term Care Ombudsman Program Laws: Citations by State at (Stiegel & Klem, 2007). http:// www.americanbar.org/content/dam/aba/ migrated/aging/about/pdfs/APS IA LT-COP\_Citations\_Chart.authcheckdam.pdf.

#### **Resources You Can Use**

If you want to learn more about elder mistreatment there are a number of nocost resources for you and your organization. ConsultGeri (https://consultgeri. org/) is a repository of evidence-based educational materials, geriatric assessment tools, and videos developed by The Hartford Institute for Geriatric Nursing at New York University's College of Nursing. Their Try This Assessment Series includes the Elder Mistreatment Assessment (Fulmer) at https://consultgeri.org/try-this/ general-assessment/issue-15 as well as a video produced by the American Journal of Nursing demonstrating how to assess elder mistreatment using Fulmer's Elder Mistreatment Assessment which may be viewed at https://www.youtube.com/ watch?v=L8jzycuoeTo&feature=youtu. be (American Journal of Nursing, 2013).

| Type of Elder Abuse                 | Signs Observed on Physical Assessment   |
|-------------------------------------|---|
| Physical Abuse                      | Bruises, skin tears, fractures, burns or other injuries, vague or<br>implausible explanations for injuries  |
| Emotional or<br>Psychological Abuse | Fear, silence, agitation, depression, confusion, inability to<br>answer questions or inconsistent answers in the presence of<br>family, ever-present or controlling caregiver |
| Sexual Abuse                        | Any or all of the above signs   |
| Neglect                             | Decubitus ulcers, contractures, malnutrition, weight loss, poor<br>hygiene, depression, medication non-adherence, missed medi-<br>cal appointments                            |



Additionally, ConsultGeri offers an elder abuse and mistreatment protocol which may be accessed at https://consultgeri. org/geriatric-topics/elder-mistreatment-and-abuse (Fulmer & Caceres, 2012).

Another important resource is the National Center on Elder Abuse established by the federal Administration for Community Living. The National Center maintains an updated interactive database on innovations by state that can serve as a resource for you and your organization. These resources can help you improve the lives of older adults.

#### Summary

Aging Life Care Managers are in an optimal position to detect and intervene in cases of elder mistreatment. Their unique skills, familiarity with their case load and knowledge regarding community-based services are extremely valuable to resolving difficult cases and following up to ensure they do not recur. The White House Conference on Aging has done much to shine a light on this important issue and our systems of care need to recognize and support the vital work being conducted by care managers daily.

#### References

2015 White House Conference on Aging: Final Report. (2015). Retrieved from http://www. whitehouseconferenceonaging.gov/2015-WH-COA-Final-Report.pdf.

American Journal of Nursing (Writer). (2013). Elder Mistreatment Assessment [Video]. In Terra Nova Films (Producer). Hartford Institute for Geriatric Nursing: American Journal of Nursing.

Anetzberger, G. J. (2005). Clinical management of elder abuse: General considerations. Clinical Gerontologist, 28(1-2), 27-41.

Dong, X., & Simon, M. A. (2013). Elder self-neglect: Implications for Health Care Professionals. CGS Journal of CME, 3(1), 25-28. Retrieved from http://www.canadiangeriatrics.ca/default/index.cfm/ linkservid/6D29E30B-98E7-31DA-625905BE-874BE665/showMeta/0/

Elton, C. (2012). The Fleecing of Americas Elderly. Consumers Digest. Retrieved from https://www.consumersdigest.com/special-reports/the-fleecing-of-americas-elderly

FACT SHEET: The White House Conference on Aging. (2015). The White House: Office of the Press Secretary Retrieved from https://www. whitehouse.gov/the-press-office/2015/07/13/ fact-sheet-white-house-conference-aging.

Fulmer, T. Elder Mistreatment Assessment. Retrieved from https://consultgeri.org/trythis/general-assessment/issue-15 Fulmer, T., & Caceres, B. A. (2012). Nursing Standard of Practice Protocol: Detection of Elder Mistreatment. Retrieved from https:// consultgeri.org/geriatric-topics/elder-mistreatment-and-abuse

Gibbs, L. M., & Mosqueda, L. Medical Implications of Elder Abuse and Neglect. Clinics in Geriatric Medicine, 30(4), xv-xvi. doi:10.1016/j. cger.2014.08.015

Gibbs, L. M., & Mosqueda, L. (2014). Medical Implications of Elder Abuse and Neglect. Clinics in Geriatric Medicine, 30(4), xv-xvi. doi:10.1016/j.cger.2014.08.015

IOM. (2014). Elder Abuse and Its Prevention: National Academies Press.

Krug, E., Dahlberf, L., Mercy, J., Zwi, A., & Lozano, R. (2002). World report on violence and health. Retrieved from World Health Organization Geneva: http://apps.who.int/iris/ bitstream/10665/42495/1/9241545615\_eng. pdf

National Center on Elder Abuse. Prevention Strategies. National Center on Elder Abuse Adminstration on Aging: National Center on Elder Abuse Adminstration on Aging Retrieved from http://ncea.aoa.gov/Stop\_ Abuse/Prevention/Strategies/index.aspx.

National Research Council of the National Academies. (2003). Elder Mistreatment: Abuse, Neglect and Exploitation in an Aging America. Washington, DC: The National Academies Press.

NCEA. (2005). Fact Sheet: Elder Abuse Prevalence and Incidence. Wahington, D.C.: National Center on Elder Abuse Retrieved from http://www.ncea.aoa.gov/resources/ publication/docs/finalstatistics050331.pdf.

NCEA. (2011). National Center on Elder Abuse Statistics/Data. Administration on Aging Retrieved from http://www.ncea.aoa.gov/ library/data/.

O'Shaughnessy, C. V. (2010). The Elder Justice Act: Addressing Elder Abuse, Neglect, and Exploitation. National Health Policy Forum. Retrieved from https://www.nhpf.org/library/ the-basics/Basics\_ElderJustice\_11-30-10.pdf

Obama, B. (2015). Remarks by the President at White House Conference on Aging. The White House: Office of the Press Secretary Retrieved from https://www.whitehouse.gov/ the-press-office/2015/07/13/remarks-president-white-house-conference-aging.

Pew Research Center. (2010). Baby Boomers Retire. http://www.pewresearch.org/daily-number/baby-boomers-retire/ Retrieved from http://www.pewresearch.org/daily-number/baby-boomers-retire/

Powers, J. S. (2014). Common Presentations of Elder Abuse in Health Care Settings. Clinics in Geriatric Medicine, 30(4), 729-741. doi:10.1016/j.cger.2014.08.004

Stiegel, L., & Klem, E. (2007). Adult Protective Services, Institutional Abuse, and Long Term Care Ombudsman Program Laws: Citations, By State. American Bar Association Commission on Law and Aging for the National Center on Elder Abuse: American Bar Association Commission on Law and Aging Retrieved from http://www.americanbar.org/content/dam/aba/migrated/aging/ about/pdfs/APS\_IA\_LTCOP\_Citations\_Chart. authcheckdam.pdf.

Wasson, J. H., Jette, A. M., Anderson, J., Johnson, D. J., Nelson, E. C., & Kilo, C. M. (2000). Routine, single-item screening to identify abusive relationships in women. J Fam Pract, 49(11), 1017-1022. Retrieved from 20543897

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## Beyond Good Deaths and Angry Families: Improving End-of-Life Care in the Community

The July 2015 White House Conference on Aging explored a range of important topics concerning how to structure and finance long-term care and related services to better meet the needs of our aging society. Missing from this policy-oriented agenda, and yet vital to effective policymaking in this area, was a deeper discussion about how policies and services should reflect and respond to the psychological and social realities of the end of life.

As a scholar who studies ethical challenges in the care of people nearing the end of life, I am often asked to talk about these issues as they affect the community, meaning the general public as well as professionals and aides who are employed in the home or other community settings. This brief essay summarizes some of the ethical questions that, in my experience, people are grappling with and find it difficult to resolve. For detailed practical guidance on surrogate decision-making and many other aspects of end-oflife care (see Further Reading).

Let's start by acknowledging that it's difficult to understand that we're mortal. We don't quite believe that death will happen to us even if we've watched someone else die, even if we see this regularly in our work. Let's also remember that we don't have a crystal ball. Unless we've already been diagnosed with a serious illness, or know we're at risk for developing some serious illness, we usually don't know what will be the cause of our own death. When healthy people try to imagine what a good death would be for themselves, they tend to describe their best selves lying down (I'm at home, surrounded by my family, with my dog at my side) or, they describe a

Nancy Berlinger, PhD

sudden death, occurring in their sleep, or while they're doing something they love. What they don't tend to imagine or describe is what, exactly, they will die of: they don't imagine end-stage cancer, or major-organ disease, or Alzheimer's. And yet, these are the three major trajectories toward death in this country and in other wealthy countries. So improving end-of-life care means focusing, specifically, on what people die of, and working to make those

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experiences better, rather than on attaining a good death or avoiding a bad death in the abstract.

It's not quite accurate to say anymore that "nobody talks about death." There is a lot of public interest in this topic, especially among baby boomers. What we have trouble grasping, and talking about, is the timeframe of the last stage of life, which may last years or decades, starting around age 75 or 80, when a person nears or exceeds the average life expectancy in the US. Most of our end-of-life care systems, including palliative care and the Medicare hospice benefit, were designed with the relatively brief end-stage cancer trajectory, and a focus on pain and symptom relief through appropriate medication. This has been a focus of research from the 1990s onward. So when we talk about stopping treatment or letting go, or about whether to keep going, we should remember that we are usually referring to the cancer trajectory.

We have made some progress toward understanding how to provide good end-of-life care to a person on the organ-system-failure trajectory. However since a person on this trajectory may have episodes of illness, followed by periods of stability, it can be hard to grasp when a familiar treatment has become more burdensome than beneficial, or that good palliative care may involve a technology such as ventilation with the goal of comfort and symptom relief. The trajectory we fear the most is the one we understand the least: the long trajectory of frailty and dementia. Because Medicare and other insurers are organized around medical interventions rather than around care itself, the person and family coping with dementia often must pay out of pocket for the basic supplies, equipment, and services that a person with dementia foreseeably needs – adult day care, home care, nursing home care – until assets are spent down to allow a person to qualify for Medicaid.

Recent research has shown that it costs more to die of dementia than to die of cancer or heart disease. This is a fairness problem – an ethical problem – because we cannot choose which trajectory we're on. It is also a reminder that some terminally people cannot choose to stop treatment near the end of life because there is no treatment to stop. So, what would be better, given



that none of us can escape mortality, and few of us can hope to become wealthy after we've been diagnosed with a life-threatening illness? How can we take meaningful steps to improve care for people in the last stage of life?

First, we need to acknowledge that the end of any specific life is difficult. When we talk about dying as if it requires special skills to understand, or saintliness to manage, we make it harder to comprehend that it is, in fact, the natural end of life. Most adults, and many children, can describe the basics of how a person comes into the world, but few of us know much about how we leave it – how long it takes to die, what is happening to the body as it is dying. It is time to help all health care professionals recognize that endof-life care is a normal part of their work, and that they can be good at it. We can each do our part by recognizing that a family who is dealing with dying is a family that is under stress, not an angry family or a family in denial. How can we reach out to a family in this situation? What practical good can we do for them?

We can also do our part by being clear about what we mean by planning. The 2015 White House Conference on Aging announced a large number of public and private sector initiatives intended to help workers plan for retirement so that people who are living longer do not outlive their savings. However, there is also an urgent need for our society to take action to realign our health insurance systems with the needs of aging people and an aging society, so that, in the aftermath of a diagnosis, a person and a family can plan for the care that is actually needed, and have a way to pay for it. This will require political will at every level. For now, we must recognize that a middle class or working class family faced with out of pocket costs for the basic needs of a family member diagnosed with dementia cannot plan to become wealthy. When some form of appropriate care is unattainable due to its cost, we should not suggest that it is a real option.

We can support each other in taking the basic steps to prepare ourselves for what lies ahead. By midlife, we should all know whom we would want to make decisions for us if we were unable to do so for ourselves. We should recognize that appointing our chosen decision-maker formally, as a health care proxy, is a smart idea. We should talk, frequently, with our chosen decision-maker, about what we want and what we don't want, because our preferences, values, and goals change over time, based on the experience of living. We should remember that this is not one conversation, but many; that these conversations are easier to start in some families than in others; and that the need to focus on decision-making concerning one family member often sparks discussions among others. We should talk concretely about what we hope for and what we fear. If we have specific instructions about what we want or don't want, we should help our future decision-maker by documenting these instructions in a way that they, and future health care professionals, can follow.

The tool known as POLST (Physician Orders for Life Sustaining Treatment -- or in some states as MOLST or MOST) is a brief document prepared in collaboration with a doctor (or other authorized professional, such as a nurse-practitioner, or physician assistant) that summarizes a seriously ill person's treatment and care preferences, in the form of signed medical orders that can be followed in an emergency (for state-by-state information, see www.polst.org). Documents are not a magical solution to the problems we have at the end of life, but they do help a decision-maker manage the stress of decision-making. The Medicare advance care planning reform implemented in 2016 may help to make discussions about end-of-life care, and the documentation of what we want and don't want, a more common part of normal health care.

Finally, because our end-of-life care systems rely so heavily on family caregivers and home care workers, we must always keep the non-professional caregiver in view. Reminding an overstretched family caregiver or a low-wage aide to practice self-care is insufficient, even insensitive. Rather, Aging Life Care Managers, and all health care professionals, should aim to partner with family caregivers and experienced non-professionals, to respect their knowledge, earn their trust, and advocate for their interests.

#### **Further reading:**

- Berlinger N, B Jennings, and SM Wolf, The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life: Revised and Expanded Second Edition (Oxford, 2013)
- Wolf SM, N Berlinger, and B Jennings, "40 Years of Work on End-of-Life Care – From Patients' Rights to Systemic Reform," NEJM 372; 7 (2015): 678-82

#### Nancy Berlinger

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