

# Journal of AGING (i)fe CARE™

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A S S O C I A T I O N

Formerly National Association of Professional Geriatric Care Managers

EDITOR'S MESSAGE

# Substitute Decision Making: Who should make decisions and what are the alternatives?

Jennifer Lansing Pilcher, PhD, CMC

Greetings! In this issue of the Journal of Aging Life Care, we tackle the issue of Substitute Decision Making for elder clients. This is an important discussion for Aging Life Care Managers who can be involved with our clients' decision making in many different ways.

Every Aging Life Care Manager (ALCM) will be involved in determining whether a client has appointed appropriate substitute decision makers. As part of an assessment, an ALCM will assess what tools a client already has in place for decision making when they are no longer able to make decisions for themselves.

In addition, ALCMs are frequently faced with issues of whether or not a client has capacity or competence to make decisions on their own. An ALCM can be an essential part of helping families discuss issues of competence with their client's physicians and guiding families through

For clients who have not designated substitute decision makers, Guardianship is sometimes an unfortunate outcome.

the process of invoking these documents, if appropriate. Often ALCMs are tasked with having conversations with adult children about the difference between a loved one making a decision they don't like, or a loved one not having the capacity to make their own decisions.

ALCMs may also be involved in the process of determining whether a client needs a guardian. For clients who have not designated substitute decision makers, guardianship is sometimes an unfortunate outcome. For other clients, there are a variety of reasons guardianship may be necessary, including: revocation of the health care proxy or power of attorney, need for authority to place a person in a nursing home, e.g. This can often be a long, expensive, and arduous process.

One of the debates among our colleagues over the last few years has been whether an ALCM should or should not take on a formal decision-making role for their clients. Some ALCMs have agreed to serve as Health Care Proxy, Rep Payee, or even Guardian for their client(s). In their article "Aging Life Care Professionals® Serving as a Client's Decision Maker: The Pros, the Cons and What

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to Consider,” Fins and Swerdlow discuss the potential risks and benefits of this arrangement. Voorlas and Lorenz, In their article “Who Should Be Paying the Bills, and Managing the Finances?” grapple with issues around an ALCM managing finances for a client and what was learned from that experience.

It is clear that there are conflicts with ALCMs taking on decision-making roles for their clients. However, it is also clear that ALCMs can play an important role for clients in providing education, information, and guidance around health care, housing, and care decisions. Is there a way that ALCMs could be involved in decision making without having to be the formal substitute decision maker?

This issue presents the concept of Supportive Decision Making (SDM), an alternative that is gaining momentum across the country. First, we offer an in depth description of SDM and how it compares and contrasts to Substitute Decision Making. Second, we discuss how this model might work for elders and specifically people who have cognitive impairment or dementia. Third, Granigan and Cohen in their article “The Care Committee™: An Example of Supportive Decision Making” presents an example of SDM in action by detailing how an Aging Life Care Management practice and a law practice have collaborated to make this possible. Most importantly, this issue discusses how SDM can provide Aging Life Care Managers a way to support and participate in the decision-making process without having to be a formal decision maker for their clients.

We hope that this issue will spark discussion and consideration of alternative ways for us as ALCMs to support our clients’ decision making in later life. We would like to thank the authors of this issue for their thoughtful contributions.



### Jennifer Lansing Pilcher, PhD, CMC

Dr. Pilcher was awarded her doctoral degree in Gerontology from the University of Massachusetts in Boston in 2005. Her professional experience has focused primarily on care and housing arrangements for elders with Alzheimer’s disease and related dementias, including policy and fundraising work for the Alzheimer’s Association of Eastern Massachusetts, the Alzheimer’s Association of Utah, and the Massachusetts Association of Older Americans.

Dr. Pilcher also presently serves as President of the New England Chapter of the Aging Life Care Association and is the Editor in Chief of the Journal of Aging Life Care.

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# Ageing Life Care Professionals Serving as a Client's Decision Maker: The Pros, the Cons, and What to Consider

Deborah Liss Fins, LICSW, CMC and Stephanie Swerdlow, LCSW, CMC

**INTRODUCTION:** The question as to whether an Aging Life Care Professional (ALCP) should serve as a client's decision maker can be complicated by a number of issues, including: conflict of interest, liability concerns, individual state laws, and most importantly, ethics.

This is an important topic for discussion because over the years there have been multiple complaints filed against members acting in decision-making roles. Complaints were made by family members or informal caregivers against ALCPs who were working with guardians or as court-appointed guardians who were billing for both guardianship work and care management. At least one ALCP was accused of fraud, misrepresentation, abuse, and extortion. As a result of these complaints, the Peer Review Committee at the Aging Life Care Association (ALCA) requested that the Standards Committee review and potentially revise the ALCA Standard regarding Decision Making.

The Standards Committee worked diligently on revising the appropriate standard and when their work was completed, the Standard was reviewed by legal counsel and approved by the Board. Stephanie Swerdlow has served for many years on both the Peer Review and Standards Committee and Deborah Fins has chaired the Standards Committee for the past several years. Swerdlow and Fins were asked to present a webinar to ALCA members about the Committees' decisions and changes to the current Standard. As part of the preparation for the webinar, Swerdlow and Fins developed a non-scientific survey to send to ALCA members to get a sense of what ALCA members are currently doing with respect to taking on decision-making roles with clients, how they are taking on these responsibilities (if they are), and what should be considered if an ALCP is thinking about adding this service to their toolbox. This article is a report of that survey and the findings of the Standards Committee.

## Common Thoughts and Opinions - For and Against

### Why would ALCPs make good decision makers?

Some would argue that the ALCP knows the client the best and that it is a natural extension of services to move from care manager to care decision maker. In many cases, the client may not have anyone else who is trusted or available. There is the concern of the growing population of "elder orphans" or "solo seniors." Others see serving in this role as a way to expand business by adding a guardianship component.

### Why should ALCPs NOT serve as decision makers?

The cons of taking on these roles

are also compelling. First, at its core, being the decision maker can change the dynamic of the ALCP/client relationship from advocate/supportive decision making to the ALCP holding power or authority over the clients' decisions. Second, there is a huge risk of a conflict of interest, or perception of a conflict. Third, who is going to pay for services? If the ALCP is paying oneself, that could be problematic. What if the ALCP makes decisions that continue the decision-making role for personal financial gain (such as prolonging life against the wishes of the family or medical recommendations)? Fourth, family conflict may be greater than in the typical care management arrangement because the care manager holds the authority. And finally, it is a 24/7 legal responsibility requiring constant

availability in a different way than most ALCPs practice.

## Our Survey - What Did ALCPs Say?

As noted in the introduction, we conducted an informal, non-scientific survey of the ALCA membership to see what members are thinking and doing with respect to taking on decision-making roles. The survey was advertised in numerous e-newsletters and had 139 respondents. Overall, the majority of respondents indicated they would not be willing to take on formal decision-making roles for their clients (only 40% indicated they would be willing to do this).

For those who indicated they would not take on the decision-making role, reasons for not doing so mostly

fell into the following categories:

- Conflict of interest (repeatedly stated)
- Not properly insured
- Liability concerns
- Concerns that it changes the objective relationship
- Individual state laws

would be more likely to take on this role for an existing or ongoing client than for a new client (35% for ongoing clients vs. 28% for new clients).

### Would you accept a decision-making role for a new versus ongoing client?

As a follow up, the ALCPs were asked about the criteria they would use to decide whether they were going to accept a decision-making role for a client. For ongoing clients, most ALCPs mentioned that they would consider this for long-term clients only, for clients that had no other family or friends to accept this role, for clients whose wishes are very clear, and for clients the ALCP knows well.

For new clients, on the other hand, ALCPs defined several other criteria that would need to be met in order for them to accept a decision-making

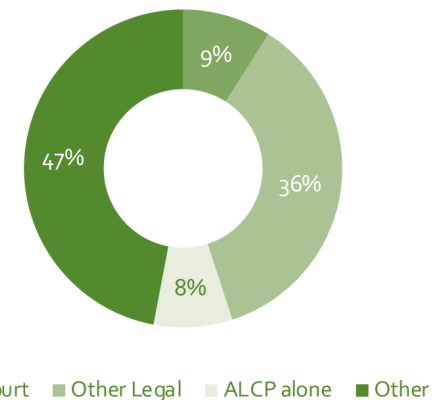
role. These criteria included:

role. These criteria included:

- Client was currently healthy and had no other person to serve
- Limited care management was needed
- A formal evaluation of capacity was or would be completed
- An individual assessment of the situation was or would be completed
- Client would agree to regular meetings
- The ALCP and client had multiple conversations about advanced care wishes

require for clients for whom they were decision makers. Their responses included requiring a set number of visits (monthly to annually) that might vary with the role and needs of the client, contact with family decision makers (if appropriate), and an open and current service agreement. Further, some respondents indicated that they might hire an independent Aging Life Care Manager as well to serve the client. ALCPs taking on this role were asked if and how they were paid for their decision-making services. Thirty-eight percent (38%) of these ALCPs indicated they were not paid or were only paid for care management services, but not decision-making services. However, sixty-two percent (62%) indicated that they were compensated for decision-making services most often being authorized by a legal representative or other representative, such as the client, financial manager, accountant, or trustee (81%). Less

### If so, who authorizes payment?



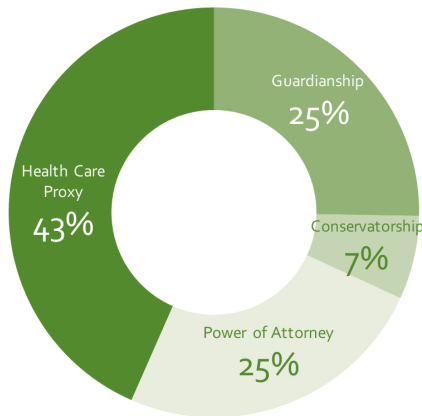
*Other = client, financial manager, attorney, accountant, trustee, e.g.*

often, ALCPs responded that their decision-making services were authorized by another ALCP (4%) or by a court (14%).

A little less than half (48%) of the ALCPs who were acting as decision makers indicated that they were also providing care management services for these clients. Similarly, for payments made for decision-making services, most often the client themselves or their

*(continued on page 6)*

### What authority would you accept?

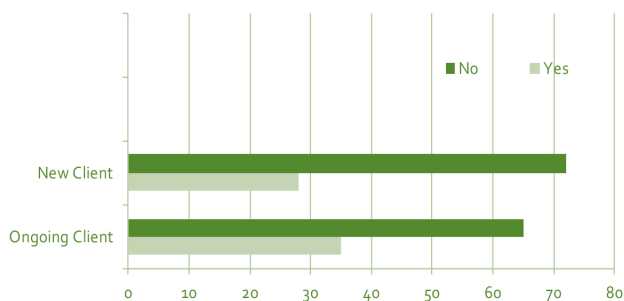


For respondents who indicated they would take on the decision-making role, the survey asked several more specific questions:

First, respondents were asked what type of decision-making role they would be most willing to accept. Interestingly, respondents were more reluctant to accept a financial decision-making role than a role that required health care decision making.

Respondents were asked to comment on how their acceptance of this role would change if it were for a new client versus an existing client. ALCPs who were surveyed answered they

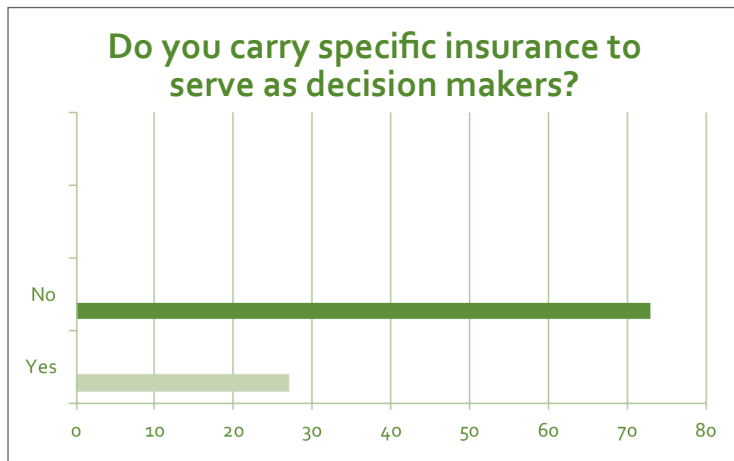
### Would you accept a decision-making role for a new versus ongoing client?



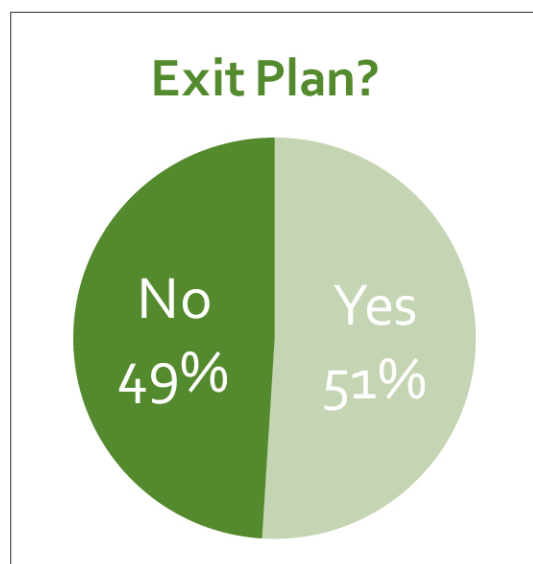
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legal or financial representative (financial manager, attorney, accountant, trustee) were the ones who authorized payments for care management.

The majority of ALCPs that take on the decision-making role do not carry specific insurance to cover them as decision makers (73%). In fact, several ALCPs were unsure if their insurance covered these roles and listed various insurance companies.



Finally, only about half (51%) of the ALCPs who had taken on decision-making roles indicated they had an exit plan if the Aging Life Care Manager needed to retire or leave the case. Of those who indicated they had an exit plan, those plans included turning responsibility over to a distant



relative or successors who were named in documents.

### Summary of Findings

While the sample size of this survey was small, it is still a good illustration of what is happening in the field of Aging Life Care. While most ALCPs are not taking on the role of decision maker for their clients, there is a significant percentage of ALCPs who are doing this or would be willing to accept this

role for their clients. It is clear from this survey that ALCPs are more comfortable taking on the role of health care decision making than financial decision making for their clients. In addition, the survey suggests

that ALCPs are much more likely to do so for on-going clients with whom they have a long-standing relationship, regular visitation, a good sense of their wishes, and for whom no other decision maker is available.

The findings also echo many of the common concerns about this practice. While payment for decision-making services is most often being authorized by a third party, it is not uncommon for the client themselves to be authorizing the payment, leaving the ALCP at risk should the client decide they do not like the decisions that are being made. Further, there are clear concerns about conflict of interest when the ALCP is also providing care management services and/or authorizing payment for either service themselves.

The findings of this survey substantiate the reasons why it was so important for the Standards Committee to review this

issue and make recommendations for the ALCA members.

### THE STANDARDS REVIEW

#### ALCA's Code of Ethics and Standards of Practice

One of the things that sets ALCA members apart from others in the human service professional field, is the strong Code of Ethics and Standards of Practice. They can be found at the ALCA website at: [http://www.aginglifecare.org/alca/about\\_alca/code\\_of\\_ethics\\_and\\_standards\\_of\\_practice/alca/about\\_us/code\\_of\\_ethics\\_and\\_standards\\_of\\_practice.aspx](http://www.aginglifecare.org/alca/about_alca/code_of_ethics_and_standards_of_practice/alca/about_us/code_of_ethics_and_standards_of_practice.aspx)

#### Why are Standards Important?

The Standards of Practice do not dictate how ALCPs run their practices. Rather, the Standards set guidelines for what is considered sound ethical practice. ALCA wants its members to behave in a consistent manner so that the public understands what it is buying when it hires an Aging Life Care Professional. The Standards may be admissible as evidence of a standard of conduct -- a necessary consequence of a meaningful code. However, the violation of the code does not necessarily give rise to a cause of action for negligence or malpractice.

#### Methods for Reviewing Standards

It is important for the reader to understand how the Standards are developed and what can be put into them.

Members of the Standards Committee are seasoned professionals who have been active at the national level. Guest consultants may be invited to address specific standards, if appropriate. The committee meets monthly via conference call.

Standards are reviewed or developed at the suggestion or request of Board members, Peer Review members, legal counsel, ALCA staff, and ALCA members. The Committee may decide to discuss issues that are raised on the listserv, as those are indicators of issues with which members may be struggling. Older standards are also reviewed periodically. Over several months, the Committee drafts a standard, rationale (why the standard is needed), and guidelines for practice. When the standard is com-

pleted, it is sent to the Association's legal counsel for review and approval. The proposed Standard may be sent back to the Committee for editing or sent on to the Board for approval. At that level, it may also be sent back for editing. Once the Board approves, it is announced to the membership and posted on the website. The member-only printable PDF document is then quickly updated.

## The Review Process

In 2016 and 2017, the Committee revised and created two standards on decision-making: "Undertaking Decision-Making Authority" and "Working with Clients under Court Jurisdiction." We will focus here on the issue of undertaking decision-making authority.

For the purposes of the Standard review and the survey, the "decision maker" was defined as:

*"An Aging Life Care Professional who accepts formal decision-making authority on behalf of a client, including but not limited to:*

1. *Guardianship/Conservatorship (recognizing that the titles may vary by jurisdiction);*
2. *Health Care Surrogate/Health Care Proxy/Health Care Power of Attorney;*
3. *Power of Attorney;*
4. *Representative Payee;*
5. *And other similar authority."*

(Note that this definition is not referring to the usual and customary role of an ALCP in helping a client to make a decision. Rather, it refers to a situation where the ALCP actually has the authority to make decisions on a client's behalf).

After months of review, the recommendation of the Standards Committee was that ALCA should discourage ALCPs from serving in these roles. It is now the official position of ALCA that ALCPs should only serve in this role as a last resort and with "extreme caution". (Please see side box for actual wording of the Standard as of the date of this article).

In general, the opinion of the Committee was that there are simply too many potential liability and conflict of interest issues for ALCPs in taking on this role for their clients.

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## Standard: Undertaking Decision-Making Authority

The Aging Life Care Professional who accepts decision-making authority on behalf of a client should do so only as a last resort and with extreme caution. Decision-making authority may include, but is not limited to, healthcare decisions and financial management. The Aging Life Care Professional should act only within his/her areas of expertise and avoid any activities that might suggest a conflict of interest.

### Rationale

When an Aging Life Care Professional becomes a decision-maker, his/her role changes from one of advisor to responsible party.

### Guidelines

- A. The Aging Life Care Professional should know and comply with relevant State and Federal laws and statutes.
- B. The Aging Life Care Professional should have legal documentation of the authority granted.
- C. The Aging Life Care professional who becomes a decision-maker should review the National Guardianship Association Standards of Practice (see [www.guardianship.org/documents/Standards\\_of\\_Practice.pdf](http://www.guardianship.org/documents/Standards_of_Practice.pdf))
- D. When an Aging Life Care Professional is the decision-maker, he/she should clearly differentiate between the decision-making role and the Aging Life Care role. It is important to avoid even the appearance of a conflict of interest or a dual relationship (see Standard "Professionalism of the Relationship."). The Aging Life Care Professional should establish safeguards to avoid impropriety or any possible appearance thereof.
- E. In accepting the role of decision-maker for the client, the Aging Life Care Professional has the responsibility to represent the client's wishes to the greatest extent possible and guard against making decisions based on his/her own values (see Standard "Promoting Self Determination").
- F. The Aging Life Care Professional should avoid, where possible, self-payment. If the Aging Life Care Professional has no alternative than to assist the client to pay for Aging Life Care services, it is recommended that a third party provide oversight for these transactions.
- G. Documentation of all actions should be maintained and made available to authorized parties.
- H. Examples of authority include but are not limited to:
  1. Guardianship / Conservatorship
  2. Health Care Surrogacy / Health Care Proxy / Health Care Power of Attorney
  3. Power of Attorney
  4. Representative Payee, and
  5. Other similar authority

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That being said, it is clear that ALCA members are stepping forward and taking on these roles. As mentioned previously, the recommendations set forth in the Code of Ethics and Standards of Practice are not meant to dictate how ALCPs run their practices, but rather to put forth guidelines for standards of ethical practice in Aging Life Care.

If an ALCP feels it is important or necessary to step into a decision-making role, the authors of this article would encourage the ALCP to do the following:

1. Determine what decision-making authority the ALCP is comfortable accepting and has the skills to administer.
2. Determine a clear process for deciding which clients to accept and under what criteria. Although this will not eliminate your liability, it will at least limit the amount of risk you are inheriting in taking on this role.
3. Determine what supports are in place for the decision maker. Decision making for a client can be a stressful position to be in. Identify and plan around the other stakeholders or supports for the client who can help you when decisions need to be made. Make sure the Client has documented their wishes and filled out the appropriate state forms such as living will or Medical Orders for Life-Sustaining Treatment (MOLST), etc.
4. Develop a clear exit strategy. If you are the decision maker for a client, it is your responsibility to have a plan for what will happen if you are unavailable or unable to make decisions. These strategies should be developed even if you are not close to retirement or don't anticipate leaving your job. Successor decision makers should be identified and discussed with your client to make sure no gap in coverage will occur.
5. Have appropriate insurance cov-

## Deborah Liss Fins, LICSW, CMC

Deborah Liss Fins, LICSW, CMC is the Director of JHC LifeCare Management, a new division of the Jewish Healthcare Center formed in 2019 with the acquisition of Deborah Fins Associates, PC (an Aging Life Care™ management practice founded in 1995). She is a licensed independent clinical social worker and certified care manager. Debbie has lectured extensively in the areas of care options for elders, financing of care, planning for aging parents, caregiver stresses, and guardianship and related matters. She is a member of the Aging Life Care Association® and its New England Chapter. She has served on the National Board of ALCA since 2014, chairs its Standards Committee, and was a recipient of its President's Award in 2018 for service to the organization. She is also a member of the National Association of Social Workers, Massachusetts Guardianship Association, the Worcester Area Geriatric Social Workers (WAGS), the Worcester Alzheimer's Partnership, and Worcester Elder Networking Group (WENG).

Debbie was the director of the Jewish Family Service of Worcester's Guardianship Program for 16 years. This was the first corporate guardianship program in Massachusetts and served as a model for subsequent programs. The program was awarded a Robert Wood Johnson grant in 1989 to create a model for medical decision making for incapacitate elders. As a result of the grant, JFS published one of the first manuals for guardianship programs and an article on decision making. Debbie is an "Elite Feet" individual fundraiser for the Central Mass. Walk to End Alzheimer's. Debbie is a graduate of Brandeis University and the Columbia University School of Social Work.

## Stephanie Swerdlow, LCSW, CMC

Stephanie is a Licensed Clinical Social Worker and an Advanced Professional/Fellow Member of the Aging Life Care Association®. In 2003, Stephanie founded Elder Options, Inc. after working as a Professional Geriatric Care Manager / Aging Life Care Manager since 1995. Stephanie currently serves on the NACCM Board of Directors, served on the Board of the Aging Life Care Association for 6 years, and has also served as the President of the Aging Life Care Association Florida Chapter.

6. Divide the various roles. If you are already the ALCP, appoint someone else to be the decision maker. If you are the decision maker, hire an independent ALCP to provide care management services. It may be tempting to take on both roles, but it can get difficult when those
7. Clarify the payment model and who authorizes payment. Avoid being the person to authorize payment for either decision-making or care management services. Doing so is not only a conflict of interest but could bring into question your motives as a decision maker in the future.

two roles come into conflict with one another.





## Who Should Be Paying the Bills and Managing the Finances?

Jennifer E. Voorlas MSG, CMC and Marguerite Lorenz, CTFA, CLPF

When a senior starts slipping in their ability to manage their own money and pay bills, families often find themselves in the middle of a struggle. They may be in the process of identifying a neurological diagnosis for their loved one, or they are merely seeing the beginning phases of declining capabilities. Moreover, the family may be in a disagreement as to how to solve the problem. As professionals, we know all too well that money is a hotspot in many families as members often have competing agendas or are vying for power. In addition, a senior may worry about losing control and, in many cases, rightfully so. Conversations around finances are often fraught with emotional tension, and, sometimes, suspicion.

Therefore, it makes sense that many family members want to shift the burden off themselves when handling this topic with Mom or Dad. An Aging Life Care Professional (ALCP) may seem like a perfect “neutral” person, someone the elder can trust. At the same time, the family may think they are buying more decision-making time or avoiding competency issues which may extend into legal decision making.

### Who will pay the bills and manage the finances?

It has become more common these days for Aging Life Care Management practices to offer concierge services that include care management in conjunction with bill paying services. However, it is important to examine both the

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### CASE STUDY: “Dan”

“Dan” was a very youthful, athletic 72-year-old who had recently suffered a stroke (CVA) and heart attack. Just three months prior to his CVA, Dan was living independently in a small beach town. Unmarried, Dan spent most of his days riding his bike and nights drinking at the local bar. He was lonely but by no means considered incompetent.

Dan’s prior occupation was in the entertainment industry which included a “fast” lifestyle. Despite his lifelong problem with alcohol, he had become quite successful playing the stock market and had a comfortable portfolio.

Dan initially presented with full range of speech, but he could no longer do his instrumental activities of daily living, such as medication management, driving, cooking, and paying bills. Shortly after his CVA, Dan went into alcohol rehab at the local hospital, but was soon discharged and living in an apartment with 24-hour supervision. Spending the daytime as a mentor to the residents of a local board and care facility where he initially resided after his CVA and evenings at his apartment with his caregivers seemed like the perfect compromise for Dan. Being in control of his money was important to him and although his memory was now impaired, he understood where his money was (at the local bank) and how much he had.

Due to his family’s urging, Dan had recently completed his estate planning, designating his cousin “Dotty” as his power of attorney for finances and health care. Dotty was making the financial decisions about his investments in conjunction with Dan, but she lived 600 miles away. There was another major problem; she traveled most of the time and claimed she just was “not good about paying bills.” Shortly thereafter, the family suffered great tragedies; Dotty’s husband died suddenly, and months later, her daughter got cancer and passed away. It was a terrible and emotional time for the family. I offered to assist Dan in paying his bills during this transition time; but this soon became part of my regular monitoring visits in conjunction with the medical care coordination services I was offering him.

In the beginning of our relationship, Dan was aware of what he was signing and what services he was paying for. I bought a safe Dan could keep in his room which stored his valuables and items like his checkbooks, social security card, brain scans, and health care IDs. I even helped him prepare his expense sheet for his accountant each year and met with his broker when we needed to go over his budget. For accountability, it was important for me to update his family by email.

After a few years passed, it became clear that Dan’s memory was declining further. Pretty soon he had no idea of who he was paying when signing the checks and even less aware of the dollar amount. Dan’s brother approached me after a family funeral, concerned that Dan would outlive his assets he asked, “Who is helping Dan manage his finances and pay bills?” His brother’s wife even expressed concern about Dan’s assets. I knew they were direct beneficiaries of Dan’s estate and while appeared to have good intentions, I could not be sure.

As an ALCP I knew I was getting myself into dangerous territory, and that it was time to alert the family that I no longer felt comfortable in this role. Questions started to enter my mind, “Why did I continue to help pay bills as long as I did?” “What if Dan had been a victim of identity theft? How would I have protected myself?” “Who would have been accountable?”

(continued from page 9)

services ALCPs are qualified to provide and the inherent risks involved with providing those services. This case study is an attempt to educate other ALCPs on how they can examine their current business model and how to make decisions about taking on additional roles. This article uses bill paying as an example of how taking on additional roles without close examination, analysis, and clear communication with the client can create conflicts for ALCPs.

As Aging Life Care Professionals know far too well, deficits in the ability to manage money and pay bills are common especially with patients who suffer from Alzheimer's disease or related dementias. We also know that what starts as a big-hearted attempt to understand what the elder needs (and the family wants) often results into a trap of doing more than we should. The role of the ALCP encompasses many responsibilities related to patient care and oversight. This is why it is especially important not only to be clear with ourselves regarding what services we are willing to offer within our scope of work, but also to recognize when we are stepping outside of our area of expertise and exposing ourselves to unwanted liability.

If an ALCP chooses to offer bill paying services, it is vitally important that they make that decision carefully and consciously in order to protect themselves as well as their client. If an ALCP chooses to take on bill paying responsibilities, they should educate themselves about the potential risks, how to mitigate these risks, and how to ensure they are protected.

While the transition in an Aging Life Care Management practice from solely care managing to bill paying for our clients may seem like a natural progression of "one-stop shopping" and ease for the client, there are real ethical and legal challenges that must be considered before any ALCP takes on this endeavor.

If an ALCP is not sure of their legal and ethical boundaries, they should first check with the family to inquire if they have an estate plan. Estate planning documents, prepared by a client's attorney, allow a client to have control

when life changes. Specific individuals are designated to take responsibility for decision making, and the resulting consequences, based on such written plans. In California, professionals who implement estate plans are California Licensed Professional Fiduciaries ([www.Fiduciary.CA.gov](http://www.Fiduciary.CA.gov)).

Family members, banks and trust companies, and other professionals, such as CPAs and attorneys, may serve in these roles too. If the client already has estate planning documents, and someone designated to pay bills when the client can no longer do so, such as an Agent under the Power of Attorney for Finance, or a Successor Trustee, it may be wise to avoid the complications and liability, rather than trying to do it all.

### Deciding to Provide Bill Paying

What are the issues an ALCP should consider when deciding whether to provide bill paying as an additional service?

First, consult an attorney. As Business and Professional Codes vary from state to state, you will want to be very familiar with these rules before taking on this responsibility. In addition, in some states, Daily Money Management may be a profession for which you will need additional licensure in order to provide.

Second, you and your attorney should review your letter of engagement. The language about bill paying services should be clear so clients know what to expect, especially if there are additional monthly or hourly charges for the service.

Third, the ALCP should consider whether their practice has sufficient bandwidth to cover the time and energy required to provide this service in addition to care management responsibilities.

### How to Limit Liability

What steps should an ALCP take to limit their liability?

1. Talk with your errors and omissions, or general liability insurance carrier to see what coverage you already have and if bill paying or Daily Money Management is coverage that

can be added. Determine the return on investment if this will be a significant cost to your practice.

2. If you are already providing Aging Life Care Management to a family, consider having a separate person on your team providing bill paying to differentiate the roles of the individuals and ensure proper attention goes to each.
3. Decide if you have someone on your team dedicated to accuracy, who has an accounting background or training.
4. Identify the financial decision-maker for the client. If the client has a Power of Attorney or Conservator, you will want to identify this person and interview them to make sure that your working together on finances makes sense.
5. Be thoughtful about how you will handle the issue of paying your own bill. This can create a serious ethical conflict of interest. Decide how you will set up clear communication and transparency about this with your client and/or their family/responsible party.

Consult with the ALCA Standards Committee in order to gain some mentoring regarding your decision to bill pay. Talking it through may help you come to the right decision for yourself and the client.

### Ethical Considerations

According to the ALCA Standards or Practice and Code of Ethics, bill paying presents several ethical dilemmas for ALCPs.

First, if the ALCP will be providing both care management and bill paying services, this will create a "dual relationship" with the client. This is an especially risky situation for both the client and the ALCP as it is likely the medical/health advice and financial management may come in conflict.

Second, providing both services will require the ALCP to pay their own bill. Again, this creates a conflict of interest for the ALCP that puts them and their clients at risk.

Third, in general, the ALCA Standards of Practice and Code of Ethics discourage ALCPs from taking on additional roles due to the potential liability and ethical dilemmas they create.

## When to Say “No” to Bill Paying Services

The safest, least risky alternative for ALCPs is to not provide bill paying services. However, if an ALCP does decide to take on this additional role, there are several situations where the ALCP should *absolutely not* take on this additional role.

If a client does not have a Power of Attorney or Conservator already designated, the ALCP should not agree to provide bill paying services. If the client is paying the ALCP independently and has no alternative decision maker, the ALCP could easily find themselves in a role where they did not have the proper authorization to provide bill paying services, putting themselves at great legal risk.

Additionally, if a client does not have a clear estate plan that designates the account(s) from which to pay bills, this would also present a serious risk for the ALCP. Rather, the ALCP should not agree to take on bill paying service for these clients unless or until they have alternate decision makers assigned and have a clear estate plan.

Further, if in your role as bill payer, it is not recommended that you sign contracts on behalf of the client, as it could present more than financial liability for an ALCP. An ALCP should always consult with an attorney and insurance provider regarding these issues.

Lastly, if you are already the client’s legal decision-maker for health care decisions, also taking on the role of bill paying would pose an even greater risk to the ALCP for both legal and ethical issues.

## How to Avoid Being Asked to Provide Bookkeeping Services

As mentioned at the beginning of this article and as demonstrated in the case study, the transition from care management to bill paying can be progressive. It may not be something the ALCP identifies at the beginning of the case but will become a need over time.

The following are suggestions on how an ALCP can avoid being asked to take on such roles in the future:

1. If client will be paying their own bill initially, have a third party set up to be responsible when a client can no longer do so independently. This could be a family member, power of attorney, conservator, or professional bookkeeper.
2. Seek out and identify local professionals who do the work you cannot do and create a list of resources to offer your clients as needed (bookkeeping service, fiduciary, power of attorney).
3. Identify clients that may need this service during the assessment process in order to refer early and have these services set up in advance. Make this discussion part of your intake process.
4. Consider refusing clients that do not have alternate decision makers or require a secondary guarantor of payment. Some practices have policies about not accepting such clients so that they can avoid this potential conflict in the future.

## Summary

The overall recommendation of the authors and Aging Life Care Association is that ALCPs should consider saying “No” to handling funds. If an ALCP decides this is an important service to provide to their clients, they should move slowly and thoughtfully using the issues raised in this article as their guide for decision making.

Ideally, the team approach to managing a client’s needs is always best. When a family can afford an attorney, fiduciary, and Aging Life Care Professional this is the best allocation of balancing risk. The best way to avoid being put in a position of being asked to provide bill paying services is to plan ahead. An ALCP may not be able to play every role for a client, and that is okay. As devoted professionals, ALCPs must take care of themselves while also looking after their clients.

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Jennifer started her career at the Alzheimer’s Disease Research Center at the University of Southern California in Los Angeles in 1998, where she received her Master’s degree in Gerontology. It was there she assisted in the implementation of a community outreach program for “at-risk seniors” with Dementia/Alzheimer’s. This Memory Enhancement Seminar for Seniors (MESS) was a pilot program and screening tool which involved teaching at-risk seniors proactive strategies to keep their memory sharp, as well as educating them about the differences between normal versus abnormal memory changes.

She started her own practice in 2011, Geriatric Care Consultants LLC, which she could not have done without gaining the breadth of knowledge through her mentors, interning with one of the early pioneers in the field of geriatric care management, and later aligning herself with a well-respected neurologist affiliated with Los Robles Hospital in Thousand Oaks, California. As a consultant and employee of a medical practice, she furthered her understanding of how the medical, cognitive, and psychological challenges intersect and impact those who suffer from Alzheimer’s Disease. Subsequently, she achieved certification (CMC) in care management—awarded by the National Academy of Certified Care Managers (NACCM). She currently authors articles related to caregiving and is interviewed for caregiver and family issues related to elder care.

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# Substitute Decision Making versus Supported Decision Making: What is the Difference?

Jennifer Lansing Pilcher, PhD, CMC, Pamela Greenfield, Esq., Meghan Huber, JD

Older persons are believed to represent a majority of persons under guardianship (Wood, 2006). The aging of the population and the increase in the number of people experiencing Alzheimer's or dementia means that an even larger number of older adults will be at risk of guardianship going forward. The Alzheimer's Association predicts that the annual number of new cases of Alzheimer's and other dementias is expected to double by 2050 (Alzheimer's Association, 2015). The reality of these statistics is that a substantial number of adults will develop cognitive impairment as they age, rendering them incapable of making health care or financial decisions and placing them at high risk for guardianship in later life.

Guardianship, Power of Attorney, and Health Care Proxy are all examples of our traditional model in elder care of assigning a "substitute decision maker" when an elder no longer has the capacity to make decisions for themselves. Until recently, this has been seen by many as the primary remedy for situations when an elder's capacity is in question.

However, Supported Decision Making (SDM), an emerging nationally recognized alternative to adult guardianship, may provide another possibility for thinking about and managing decision making in later life (National Center for Supported Decision-Making, 2014). SDM has been recognized by scholars as having the strong potential for promoting favorable outcomes in the lives of people with disabilities and older adults, and studies are underway to further verify such outcomes (Blanck & Martinis 2015; Whitlatch 2017).

That being said, although SDM has gained traction in advocacy for adults with disabilities, it has only recently begun to expand its model to include helping older adults. As a result, it has not yet taken hold in the elder care field in the United States. However, that may be changing thanks to efforts by groups like the National Resource Center for Supported Decision-Making, the American Bar Association, the Uniform Law Commission, the National Council on Disability, the National Guardianship Association, and Quality Trust for Individuals with Disabilities. In addition, in a November 2018 report, the United States Senate Special Committee on Aging specifically recommended that, among other reforms, states promote less-restrictive alternatives to guardianship, including Supported Decision-Making (United States Senate Special Committee on Aging, 2018).

The following is a discussion about the differences between our traditional models and SDM, the benefits and limitations of both, and how this model might be incorporated into future models for decision making for older adults.

## The Traditional Model: Substitute Decision Making

### Proactive Substitute Decision Making - Health Care Proxy and Power of Attorney

Health care proxies and durable powers of attorney are examples of proactive ways of voluntarily appointing or assigning a substitute decision maker. When developing such legal tools, the individual must have capacity to knowingly and voluntarily execute these documents. Usually,

the individual appoints one or more persons to act as his or her decision maker in the event he or she does not have capacity to do so in the future. While this does empower the individual to choose the person they want to make decisions, these documents are often only invoked once an individual becomes incapacitated.

### Reactive Substitute Decision Making: Guardianship

(Note: Different states have labels and requirements for Guardianship of Person versus Guardianship of Estate or Property. For the purposes of this article, we will simply refer to both as Guardianship).

Guardianship is a reactive state law process which occurs in court. It is the legal system's response to an adult who is alleged to be mentally incapacitated or deemed unable to make legally binding decisions. Guardianship is frequently seen as a means of protecting the incapacitated adult through the court appointment of a substitute decision maker. Examples of people who may be subject to guardianship include older adults with cognitive decline, people with intellectual disabilities, and people with psycho-social disabilities, among others.

Guardianship has serious consequences. If a guardianship is deemed necessary, the individual loses some-to-all decision-making power, which frequently includes the right to choose where they live, how to spend money, with whom they spend their time, and with whom they have relationships (National Council on Disability 2018). An individual who has a guardian frequently cannot enter into contracts, authorize access to their own medical

records, or make health decisions.

In our experience, guardianships are typically sought for older adults when a relative, friend, or institution believes either some legally binding decision needs to be made and the person is thought not able to make it; or the person is making decisions that are thought to be irrational and/or harmful to themselves.

When Guardianship functions as intended, substitute decision makers act responsibly and in keeping with the individual's wishes. If done consistent with best practices, guardianship can be used to increase well-being and encourage preferences and choice. In fact, the National Guardianship Association promotes as one of its standards that the guardian shall "identify and advocate for the person's goals, needs, and preferences" (National Guardianship Association, 2015).

However, many guardianships are not ideal. Despite major reform in many states in the late 1980s and late 1990s, efforts to improve the system seem to have had, at most, limited success due to a lack of implementation (Frolik, Lawrence A, 1998). Among the reforms, two important ideas were introduced. First was the idea of using "least restrictive alternatives," and leaving guardianship as the option of last resort. This reform means that, in general, courts should reject guardianships when a person has in place sufficient alternatives, such as a Power of Attorney or other resources, services, and support to meet their needs. Second was the movement to change the standard for decision making by guardians from "best interest" to "substituted judgment." In other words, guardians should be making decisions based on what the person would have decided if he or she were capable of doing so, rather than what the guardian believes is in the person's best interest. However, questions have been raised as to whether reforms like these have actually been adopted into practice (National Council on Disability, 2018).

But what are the alternatives? Historically, for many older adults, there haven't been any. While assigning a surrogate decision maker while an individual has capacity is clearly preferable

over guardianship, it still requires the appointed person to "substitute" their judgment for that of the elder, rather than supporting the older adult to make their own decisions.

## What is Supported Decision Making (SDM)?

General Continuum of Decision-Making Supports	
COURT APPOINTED GUARDIAN	ALTERNATIVES
<ul style="list-style-type: none"> <li>• Temporary or Permanent</li> <li>• General/Plenary or Limited</li> <li>• Person or Estate or both</li> </ul>	<ul style="list-style-type: none"> <li>• Supported Decision-Making</li> <li>• Advanced Directive &amp;/or Power of Attorney</li> <li>• Representative Payee</li> <li>• Other substitute or surrogate health care decision-maker, depending on state law</li> </ul>

Supported Decision Making (SDM) is a method for supporting adults with disabilities and elders in making their own decision. The National Resource Center for Supported Decision Making describes supported decision making as:

"...where people use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions – is a means for increasing self-determination by encouraging and empowering people to make their own decisions about their lives to the maximum extent possible." (National Resource Center for Support Decision Making, 2016).

Supported Decision Making is a way for an adult with a disability to use their appointed decision makers to:

- 1) Help understand the issues and choices
- 2) Ask questions
- 3) Receive explanations in language he or she understands
- 4) Communicate his/her decisions to others

(Black & Martinis, 2015; Dinnerstein, 2012; Salzman, 2011; Whitlatch, 2018).

Supported Decision Making is not meant to replace measures such as Health Care Proxy or Power of Attorney. Rather, SDM provides a way for the individual to participate in the process

for as long as possible. Through adoption of a Supported Decision Making model, older persons would appoint legally recognized supporters to help them make their own decisions, while also being able to plan for their future through advance planning documents. These supporters may be family mem-

bers, professionals (Aging Life Care Managers, social workers, attorneys, etc.), and others the older person trusts. These advisors are tasked with explaining the facts and issues, offering non-controlling advice, making recommendations, and helping the person communicate his or her choices. Supported Decision Making may be formal or informal and may be documented through the use of release-of-information forms (e.g., HIPAA forms), written plans, and, in some states, statutorily recognized Supported Decision-Making Agreements.

Supported Decision Making is hugely important as it has the potential to increase the self-determination of people with disabilities. Multiple studies have shown that people with greater self-determination are more independent, more integrated in their communities, healthier, and better able to recognize and resist abuse (Powers et al, Shogren, Wehmeyer, Palmer, Rifenburg & Little, 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds, 2005; Wehmeyer, Kelchner & Reynolds, 1996). When denied self-determination, people can feel helpless, hopeless and self-critical (Deci, 1975). In addition, people without self-determination experience low self-esteem, passivity, feelings of inadequacy and

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incompetency, and decreased life outcomes (Winick, 1995; Wright, 2010). As a result, Supported Decision Making has the power to make a distinct improvement on a person's quality of life.

The concept of Supported Decision Making is also related to the idea of Patient Centered Care, a theory well supported throughout most of the health care system in the United States. Patient Centered Care focuses on the particular preferences, values, and wishes of an individual in health care and life planning. Patient Centered Care has come to connote a process in which a disabled individual plans for the future by identifying goals and needed support to reach those goals with the assistance of others (Diller, 2016). Thus, this concept laid much of the groundwork for the development of Supported Decision Making in the United States.

Essentially, Supported Decision Making is something that most people utilize every day without realizing it. When adults make decisions regarding issues with which they are not familiar, such as taxes or car repair, they find a trusted individual or professional to inform their decision making. Although the formalized idea of SDM is somewhat new to the United States, the concept is gaining traction (see [www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)). Thus, SDM is something that all professionals who work with individuals who have cognitive impairments should become familiar with and strive to incorporate into their practices. As the National Guardianship Association has recognized, SDM should be considered before guardianship and incorporated as part of a guardianship, if guardianship is necessary (National Guardianship Association, 2015).

## A Shift in Thinking

Early roots of Supported Decision Making can be traced to the 1990s in Canada. At the time, proponents envisioned it as a method for removing legal barriers created by issues of capacity which prevented people with intellectual disabilities from participating in decision making. At this time, advocates proposed a system of support

that would assist persons with disabilities in making decisions, even if that person would have been considered to lack the ability to make a decision under traditional legal standards (Bach & Kernzner, 2010; Brownin et al, 2014; Diller, 2016).

In recent years, there has been discussion about whether or not persons with disabilities should retain the right to legal capacity, even if they need support in decision making. Diller (2016) argues that people with disabilities should have the legal right to make decisions, regardless of his or her perceived ability to make decisions on their own.

One of the biggest indications of this shift in thinking on the international stage was the adoption of Article 12 of the United National Convention on the Rights of Persons with Disabilities (CRPD) in 2014.

Article 12 specifically states: "Parties [to this treaty] shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" (G.A. Res, 2006). Further, the Committee on the Rights of Persons with Disabilities issued General Comment to explain how Article 12 should be adopted and implemented (CRPD General Comment, 2014). The General Comment specifically states:

"The Committee reaffirms that a person's status as a person with a disability or the existence of an impairment...must never be grounds for denying legal capacity or any of the rights provided for in article 12. All practices that in purpose or effect violate article 12 must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others."

This statement by the CRPD was an important first step in establishing the right to legal capacity for people with disabilities. The CRPD implies a shift from a system of substitute decision making, to a system of supported decision making. Proponents of Supported Decision Making see it as a "liberation" for people with disabilities who have up to now not been able to participate in the decision-making process (Bach & Kernzner, 2010; Diller, 2016). Although the United States has not ratified this treaty, the CRPD has

been used to promote SDM in legal advocacy discourse (e.g., Dinerstein, 2012) and case law (e.g., *In re Dameris L.*, 2012, available at <https://caselaw.findlaw.com/ny-surrogates-court/1619828.html>).

This shift in thinking has also begun to be statutorily recognized in U.S. states which have adopted laws regarding supported decision making. As of May 2019, the states that now formally recognize SDM agreements include Alaska, Delaware, Wisconsin, Texas, D.C., Missouri, North Dakota, Indiana, and Nevada (Whitlatch 2019). Texas was the first state in U.S. to pass a Supported Decision Making Statute. This statute allows an individual with a disability to authorize a supporter who can assist the individual in making and communicating decisions. The statute is clear that the supporter may not make decisions for the person, but rather, is authorized to help obtain information to help the individual understand the decision.

## Older Adults and SDM - The Benefits

To date, Supported Decision Making has not taken hold with older adults to the same degree as it has with adults with non-age-related disabilities, either in theoretical discussions or in practice. For example, in Canada, while Supported Decision Making agreements have become popular in the intellectual disability community, it has not been as readily embraced by elder law practitioners or by the aging community (Diller, 2016).

In a 2016 article, Diller makes the argument that a shift away from guardianship to a right to legal capacity and the development of supported decision making should apply to older adults. Diller argues maintaining legal capacity and developing Supported Decision Making models for older adults will also preserve the autonomy of older adults as it has for younger disabled adults.

As with younger people with disabilities, older adults can benefit from greater autonomy and self-determination. Empirical literature on decision making and older adults shows that maintaining control over decisions of daily life is correlated with better physical and mental health outcomes (Diller, 2016).

Supported Decision Making could reduce the number of older adults under guardianship based on capacity determinations that are inconsistent at best. In order to have a guardianship put in place, often a determination of incapacity is required which can be subjective, not entirely accurate, costly, and time consuming.

Further, wider availability of SDM could reduce the number of guardianships that are pursued in order to solve practical problems. For example, guardianship can be used by a nursing home to deal with obstacles to discharge planning, personal fund management, Medicaid eligibility, or payment disputes with relatives. Diller (2016) argues that by using support like SDM, these issues may be able to be solved without stripping older adults of their rights.

Even though SDM has not been embraced officially, many older adults are practicing SDM informally by using family and friends for support in important decisions (Diller, 2016). Many older adults ask advice, seek explanations, or designate someone to interface with an agency on their behalf (Martinis & Blanck, 2015).

### Why Lack of Adoption with Older Adults?

If that is the case, why is it that SDM has not been more widely adopted by older adults and their families? First, there is a lack of advocacy and movement about the struggle for rights of self-determination and legal capacity for older adults. This is understandable given that advocates for older adults may be more focused on the urgent need for research, resources, the demands of caregiving, and the prevention of elder abuse (Diller, 2016). As a result, older adults and their family members may be largely unaware that Supported Decision Making is an option for planning for later life decision making.

Second, older adults at risk of losing capacity are in a different position than younger cohorts. The idea of Supported Decision Making does not always resonate with the experience of older adults who have had decades of exercising and establishing their

legal rights. An older adult is experiencing the possibility of requiring support for the first time in their lives, while young adults are developing the skills to become capable of decision making (Diller, 2016). This difference means that the process of setting up SDM may feel more empowering to a younger person with a disability than to an older adult who would rather not discuss the potential of losing their decision-making ability. As a result, older adults and their families may be more reluctant to adopt these practices out of denial or a wish to avoid the topic of risk of guardianship.

Third, Supported Decision Making can be seen as more time-consuming than other legal options. One Canadian study hypothesized that older adults are more likely to turn to advanced directives such as power of attorney because it is quicker and more efficient than the process Supported Decision Making requires (Diller, 2016).

Fourth, older adults can be more isolated and lack family or community support. This can mean they do not have people they can identify as supporters or as a health care agent under a power of attorney (Bach & Kerzner, 2010). Also, it can mean they are not aware of needing to assign a decision maker and will be at greater risk for guardianship due to not having a health care agent or POA in place prior to a finding of incapacity.

Fifth, some raise concerns that Supported Decision Making could make older adults more vulnerable to abuse. With guardianship, guardians are (at least in theory, although perhaps not in practice) (NCD 2018) monitored by the court and required to submit financial statements and plans of care. If an older adult has issues with the way his guardian is operating, he or she likely has the right under state law to ask the court to replace his guardian. With Supported Decision Making, however, there may be limited ways that the older adult can seek remedy for abuse or harm by a decision maker (Diller, 2018). The statutes in both Texas and British Columbia have language and requirements that attempt to address this issue. Still, more empirical data is needed to see how effective these mechanisms will be.

Lastly, there are concerns about how Supported Decision Making works with people who already have a diagnosis of dementia. Some believe that while SDM can work well with people with dementia to a point, it is still a question about how people with cognitive impairment might be able to continue to engage in SDM as their disease progresses. Kitwood (1997,1993), Sabat (2002), and others have urged against making assumptions that people with dementia cannot participate in person-centered care. Similarly, the National Resource Center for Supported Decision-Making also makes the case that people with dementia can participate in SDM. Diller (2016) and Whitlatch (2018) argue that with improved communication techniques and different forms of support, an individual with dementia may be able to participate in SDM for much longer than one might typically expect. Lastly, as dementia progresses, the individual's supporters will be able to not only look back on a history of decisions and preferences, but also will have had a history of practicing SDM that will prepare them for making decisions when the individual is no longer able to participate in the process. (For more information about how SDM can work for people with cognitive impairment, please see additional submissions in this issue).

In summary, SDM is gaining visibility and traction in the elder care industry. While SDM provides a positive way for people with disabilities and older adults to participate in the decision-making process, there are challenges that need to be addressed before it will succeed in becoming a widespread practice. These challenges include ensuring appropriate safeguards for people with declining capacity, addressing and battling ageism and perfunctory assumptions of incapacity based on solely on diagnosis, and promoting wide-spread availability of advance planning options earlier in older adults' lives. For Aging Life Care Managers, incorporating Supported Decision Making and similar self-determination principles into their practices should be considered a promising practice, one that is becoming more formally recognized in the United States.

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In 2010, she joined Overlook CARE, a non-profit Care Management practice in Greater Boston, as the Clinical Director. In 2016, Dr. Pilcher was promoted to the position of Senior Executive Director of Care Management and Private Care. In 2018, Dr. Pilcher founded Clear Guidance in order to return to her passion of working directly with clients and their families.

Dr. Pilcher also presently serves as President of the New England Chapter of the Aging Life Care Association and is the Editor in Chief of the Journal of Aging Life Care.

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Ms. Huber is a recent graduate of New England Law | Boston, who recently sat for the July 2019 Massachusetts Bar Exam. Ms. Huber has a passion for planning and helping others in a meaningful way, and sees helping individuals and families plan for their lives as the best way to do that. Ms. Huber currently works as a Law Clerk on estate planning and elder law matters for Greenfield Planning Group.



# Supported Decision Making for Elders with Dementia: A Deep Dive

Jennifer Lansing Pilcher, PhD, CMC, Pamela Greenfield, Esq., and Meghan Huber, JD

Supported Decision Making (SDM) is a person-centered model that can empower an individual to make choices with guidance and advice from trusted advisors. The model starts with the following assumptions:

1. **All individuals have a fundamental right and ability to make choices.**
2. **Adults usually consult advisors to assist with life decisions.**
3. **Well informed decisions of an individual should be honored (Godfrey & Whitlatch, 2017; Martinis, 2015).**

SDM utilizes advisors of the individual's choosing to work with the person to offer advice, information, and guidance. The advisors are tasked with explaining facts and issues, making recommendations, and helping the individual communicate choices and then honoring his or her choices (Godfrey & Whitlatch, 2017).

While this model has been widely embraced internationally as a positive process for helping individuals with disabilities to make decisions, it has yet to take a firm hold among older adults. One of the primary reasons for this lack of adoption is due to concern about how this model will work for older people who are experiencing cognitive decline.

For adults who are experiencing cognitive decline or dementia, the common practice is to take over decision making for them by using substitute decision making. However, advocates of SDM insist that when utilized correctly, the SDM model can empower a person with cognitive impairment to remain engaged in

the decisions that are impacting their lives, even as the disease progresses. Most importantly, the least restrictive support for decision making should be considered first, before assuming that guardianship or substitute decision making is necessary.

## Dementia and Capacity

Advocates of SDM argue that the capacity to make decisions is not an "all or nothing" determination that is based solely on an individual's IQ or diagnosis. Because dementia does not affect people in the same way and the progression can vary significantly, it is possible that people with this diagnosis could engage in SDM well into the disease with proper supports. Kitwood (1997) and others have urged against making assumptions that people with dementia cannot participate in person-centered care such as SDM. Rather, advocates encourage us to "rethink" capacity and what it means for engaging in decision making. Godfrey & Whitlatch (2017) argue that people with

a dementia diagnosis may be able to make some decisions but not others or make decisions at some times and not others. Most importantly, people with dementia may be able to make decisions if they get help understanding the decisions that need to be made.

Further, in their 2017 article, Godfrey and Whitlatch argue that all people lack some capacity. For example, they point to the fact that while an individual may lack the capacity to fly an airplane, he or she might be able to learn how to fly one with the help of advisors. Even a complex challenge, such as flying an airplane, can be broken down into simple and understandable steps.

## Early Diagnosis & Planning

Many people with early stage dementia will retain the ability to make decisions and execute planning for a considerable length of time. Early planning is critically important for a person experiencing changes in memo-

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### Rethink "Capacity"

#### Capacity is NOT:

"All or Nothing"

Based solely on IQ or Dx

#### People may have "capacity" to:

Make SOME decisions but not others

Make decisions SOME TIMES but not others

Make decisions IF THEY GET HELP UNDERSTANDING the decisions to be made

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ry or cognition. Because dementia may progress to the point that planning is impossible, planning must take place while the older adult can engage in the planning process and has the ability to understand and make choices.

## Assessment Tools

In determining whether an older adult with dementia can participate in the decision-making process, it is important to closely assess not only the individual's capacity and skills, but also a variety of other factors. For example, the older adult's life experiences, environment, preferences and interests, available supports, and other individual and situational variables. In addition, an attorney, Aging Life Care Manager, or other party assessing an older person's ability to make decisions should be asking the following questions:

- 1) What kind of decision needs to be made?

- 2) How much risk is involved?
- 3) How hard would it be to undo the decision?
- 4) Has the person made a decision like this before?
- 5) Is the decision likely to be challenged? (Godfrey & Whitlatch, 2018)

In addition, there are tools that can be used to assess the ability of older adults with dementia to participate in SDM.

### Everybody Communicates: Toolkit for Accessing Communication, Assessments, Funding and Accommodations

One such tool, developed by the Autistic Self Advocacy Network and published by the Office of Developmental Primary Care (<https://odpc.ucsf.edu>) lays out a clear process for doing so. The toolkit suggests that the first step is to assess what challenges the adult may be facing in communication.

First, is the older adult experiencing sensory impairment such as hear-

ing loss, auditory processing, visual impairment, visual processing, and/or proprioception (knowing where his or her body is in space)?

Second, does the person have any loss in motor skills that should be assessed including: motor strength, motor skill, dyspraxia/apraxia, and/or motor planning and initiation?

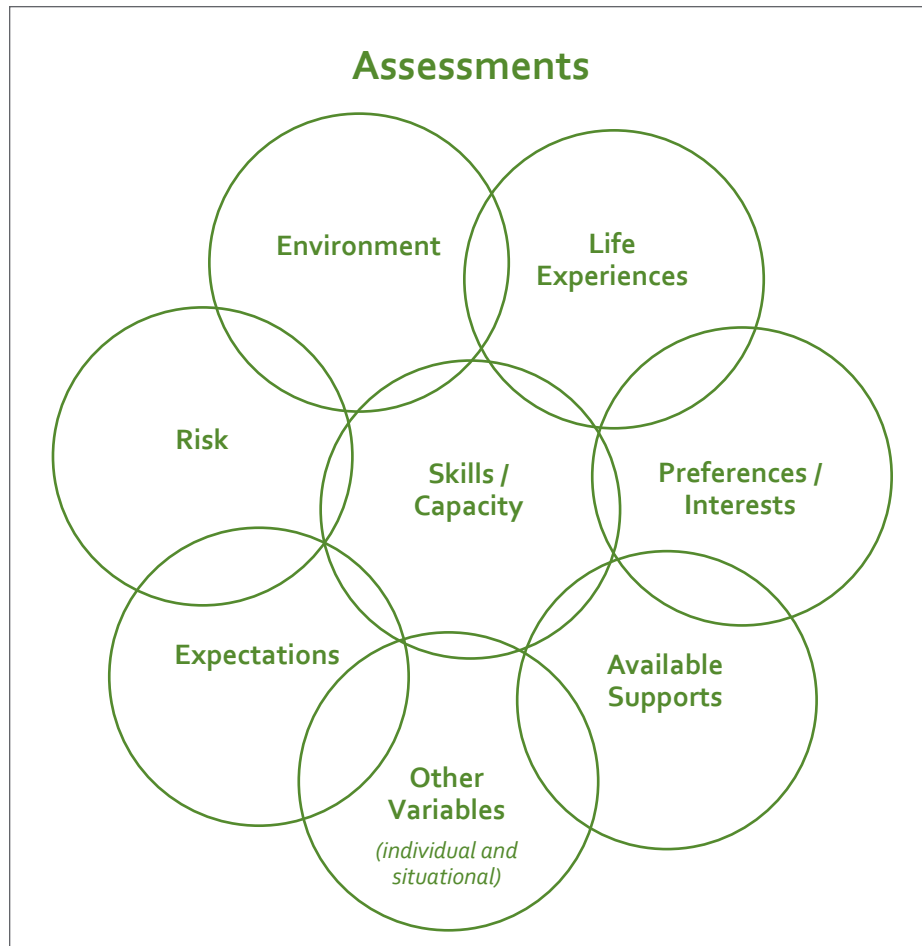
Lastly, cognitive functioning should be assessed. Questions about cognition should include:

- Can the individual remember and recall words and their meanings? Does the individual need extra time for recall?
- Can the individual recognize letters and symbols?
- Can the individual follow complicated sentences or instructions?

It is important that the sensory and motor skills are assessed first as these can easily be mistaken for cognitive impairments. It is critically important in developing strategies for communication that all three of these assessments are done. (For more information about this Toolkit, please visit <https://odpc.ucsf.edu/communications-paper/1-introduction-and-how-to-use-this-toolkit>)

## PRACTICAL Tool

A second tool, called the PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making, is a joint product of four American Bar Association entities with guidance from the National Resource Center for Decision-Making. It is designed to help lawyers identify and implement decision-making options that are less restrictive than guardianship for people with disabilities, including older adults. While it is designed for attorneys, it has been used to provide guidance to social workers and other professionals. This tool uses the acronym PRACTICAL to demonstrate the nine steps an attorney should use to identify decision-making options:



**PRESUME** guardianship is not needed

**REASON.** Clearly identify the reasons for concern

**ASK** if a triggering concern may be caused by temporary or reversible conditions

**COMMUNITY.** Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations

**TEAM.** Ask the person whether he or she has already developed a team to help make decisions.

**IDENTIFY** abilities. Identify areas of strengths and limitations in decision-making

**CHALLENGES.** Screen for and address any potential challenges presented by the identified supports and supporters

**APPOINT** legal supporter or surrogate consistent with the person's values and preferences

**LIMIT** any necessary guardianship petition and order

This tool provides a checklist of items that one should be thinking about in identifying options for their client. For example, under A for "Ask," the checklist includes evaluating whether or not the concerns that have been identified for the client are the result of or related to temporary or reversible conditions such as:

- Medical conditions: infections, dehydration, delirium, poor dental care, malnutrition, pain
- Sensory deficits: hearing or vision loss
- Medication side effects
- Psychological conditions: stress, grief, depression, disorientation
- Stereotypes or cultural barriers

For more information or to see the entire tool and resource guide, please visit [www.ambar.org/practicaltool](http://www.ambar.org/practicaltool).

## Communication Techniques

Diller (2016) and Whitlatch (2018)

argue that with improved communication techniques and different forms of support a person with dementia or cognitive changes may be able to participate in SDM much longer than one might typically expect.

Communicating effectively is one of the challenges of SDM. Although communicating with someone who has a cognitive impairment can be more complicated, it can be done. If possible, open-ended questions are best as they can offer the most insight as to the individual's goals, values, and choices (Godfrey & Whitlatch, 2018). A supporter might start by asking the person what they want or how they feel. When a person has difficulty answering open-ended questions, it is useful to use multiple choice questions and breaking the major issue down into smaller parts.

In addition, according to the Office of Developmental Primary Care, alternate forms of communication should be considered. Other than using spoken words, there are other methods of communication that an older adult might be able to use to get their needs known, such as using gestures, sounds, facial expressions, body language, behavior (moving toward or away from a person or situation, hitting or grabbing), typing or spelling, pointing, and/or choosing pictures or symbols.

If communication impairments are uncovered, then communication supports should be considered in order for the older adult to participate fully in the SDM process. Possible supports include speech-language therapy, physical therapy, occupational therapy, specialized literacy or language instruction, augmentative and alternate communication tools or technology, and low-technology supports including interpreters. These supports can provide tools and techniques for communication as well as training for supporters and family members to improve their communication with the older adult (<https://odpc.ucsf.edu>).

## Establishing Patterns of Decision Making

Engaging people with dementia in SDM is also important in order to learn how the individual makes decisions and

what is important to them. As dementia progresses, the person's supporters will be informed not only on the person's past history of decision making, but his or her stated goals and preferences. SDM can be paired with advance planning documents, such as Advance Directives, Health Care Proxies, and Powers of Attorney. In this way, when a person with dementia is no longer able to communicate decisions, his or her legal agents will be prepared to make them based on what they know from supporting the person using SDM.

## Thoughts for Aging Life Care Managers

This article has attempted to provide information about how SDM can be valuable in promoting independence and self-determination, even for older persons with dementia. The authors hope that the tools provided and ideas about communication techniques will be helpful to Aging Life Care Managers and the Attorneys and decision makers they work with.

It is clear that SDM would be valuable for older adults, particularly those with early-stage dementia. However, Aging Life Care Managers are often sought out by clients, their families, or attorneys long after a diagnosis has been made and sometimes past the point where a client can be engaged in the planning process. Many in the field have taken part in programs and efforts to inspire older adults to plan proactively for aging. While many have seen some movement in this direction, in large part we have yet to see a surge of middle-aged adults and young elders seeking out advice about aging. Advocacy and education are needed for the older population about their options for decision making and how SDM can be a part of that.

Further, it is clear that there is a role for ALCMs to be an "advisor" or "supporter" as part of the SDM team for many older adults. This role would allow for the ALCM to be involved in the education of the elder about the decisions they are making and the possible implications of those decisions. By virtue of their skills, education, training, and experience, ALCMs are

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perfect for this role. As has been done in the past with raising awareness of the need for Advanced Directives such as Health Care Proxy and Power of Attorney, much education is needed for older adults about the possibility of using SDM as a way of avoiding potential guardianship in the future. Perhaps this is one way in which ALCMs can engage with clients at an earlier point in their disease progression.

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### **Jennifer Lansing Pilcher, PhD, CMC**

Dr. Pilcher was awarded her doctoral degree in Gerontology from the University of Massachusetts in Boston in 2005. Her professional experience has focused primarily on care and housing arrangements for elders with Alzheimer's disease and related dementias, including policy and fundraising work for the Alzheimer's Association of Eastern Massachusetts, the Alzheimer's Association of Utah, and the Massachusetts Association of Older Americans.

Prior to founding Clear Guidance in 2018, Dr. Pilcher has had career long experience working with people with dementia and their families. For seven years, Dr. Pilcher was affiliated with Hearthstone Alzheimer Care Assisted Living programs in Massachusetts and New York, where she held a number of management positions. For 8 years, Dr. Pilcher worked both as a Care Manager and as the Director of Operations for AZA Care Management of Boston, MA.

In 2010, she joined Overlook CARE, a non-profit Care Management practice in Greater Boston, as the Clinical Director. In 2016, Dr. Pilcher was promoted to the position of Senior Executive Director of Care Management and Private Care. In 2018, Dr. Pilcher founded Clear Guidance in order to return to her passion of working directly with clients and their families.

Dr. Pilcher also presently serves as President of the New England Chapter of the Aging Life Care Association and is the Editor in Chief of the Journal of Aging Life Care.

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Attorney Pamela B. Greenfield is the founder of Greenfield Planning Group, LLC. Attorney Greenfield's roots are in elder law and long-term care planning for senior citizens. She has a passion for helping seniors and their loved ones navigate through the continuum of care as they age and advising them on how to properly finance their options. Attorney Greenfield focuses her practice in elder law, asset protection planning, and complex MassHealth applications and appeals. She additionally represents families and skilled nursing facilities in guardianship and conservatorship matters as well as probate and estate administration.

Prior to opening GPG in July 2018, Attorney Greenfield headed up the elder law department at Samuel, Sayward and Baler, LLC in Dedham, Massachusetts, where she continues to see clients and serve as of counsel to the firm. Prior to joining Samuel, Sayward and Baler in 2015, Attorney Greenfield practiced at Oalican Law Group, LLC (formerly Cohen & Oalican, LLP) since 2007. She received her law degree from New England School of Law and her J.B.A. with distinction from the University of Wisconsin-Madison, where she majored in journalism.

Attorney Greenfield speaks frequently at nursing homes, assisted living facilities and senior centers in the Metro-Boston area. She has served as both chair and panelist for various Massachusetts Continuing Legal Education (MCLE) programs. Attorney Greenfield is an active member of the National Academy of Elder Law Attorneys, Massachusetts Chapter, where she currently serves as vice president to the Chapter (2019).

### **Meghan Huber, JD**

Ms. Huber is a recent graduate of New England Law | Boston, who recently sat for the July 2019 Massachusetts Bar Exam. Ms. Huber has a passion for planning and helping others in a meaningful way, and sees helping individuals and families plan for their lives as the best way to do that. Ms. Huber currently works as a Law Clerk on estate planning and elder law matters for Greenfield Planning Group.





# The Care Committee™: A Planning Tool for Clients Without Families

Steven M. Cohen, Esq. and Kate Granigan MSW, LICSW, CASWCM

Many elders are aging alone. According to the Administration on Aging, today almost one third (28%) of all elderly individuals live alone. Further, the combination of an increased mobile society, declining marriage rates, and the often-referenced aging baby boomer generation means that we will see an even greater number of elders living alone in the next 25 years. These clients do not have the network of family, friends, or personal connections that many of us take for granted. This begs the question, who will make decisions on their behalf?

An Elder Law and Aging Life Care Management practice in Greater Boston has created a model of supportive decision making, called a Care Committee™, as an alternative to the traditional models of substitute decision making.

## The Traditional Model and Its Limitations

As has been discussed in other articles in this issue, the most familiar model for a client to retain control over medical decisions is to execute a health care proxy appointing an agent and successor agent to act as a substitute decision maker in the event the client is incapacitated. In this model, the proxy should also include a medical directive describing the client's wishes in broad strokes regarding what kind of treatment they would or would not want if she is unable to participate in making medical decisions on her own behalf. Every state has an advanced directive statute regarding health care proxies. Many clients also create living wills that describe in greater detail their wishes regarding end-of-life decisions.

Although this traditional model can work well for many clients, there can be situations where the model does not meet the client's needs. For example, this model will not work for clients who have no family members or close friends to serve as their health care agent. It will also not work for clients with family or friends who are too distant, either geographically or emotionally, to serve.

There are a variety of reasons why family and friends may not be willing to serve as substitute decision makers. They may be reluctant because the tasks associated seem too complicated or overwhelming. Or, they may be over-extended due to taking care of an ill parent while also balancing work and children. Under all of these circumstances the traditional model will not be an effective way to manage a client's care.

Similarly, professionals such as social workers, Aging Life Care Managers (ALCM), and attorneys are often reluctant to serve as health care agents for a variety of reasons. These professionals may be concerned about not knowing the client well enough to be making decisions, or can be concerned about conflicts of interest, time issues, or cost to the client.

The traditional model may not be effective when a client can identify a willing and able health care agent but does not have a successor agent. The initial health care agent may not want to continue serving if the responsibilities become too difficult or time consuming. This is often the case for clients with intermittent capacity because it is particularly challenging to serve as an agent for an individual who,

over the years, repeatedly experiences bouts of temporary incapacity caused by mental illness or substance abuse. If for this, or any other reason, the appointed agent is no longer willing or able to serve, there will no mechanism for identifying another agent or taking steps to have the court appoint a guardian. Such lack of continuity can be extremely disruptive and detrimental to a client's care.

The traditional model may also not work in situations where there is family conflict. Certain family situations give rise to more disagreement over care decisions. For example, there may be tension in a second marriage between a spouse and adult children from the first marriage. Gay and lesbian couples may have tensions arising between the health partner and the parents of the incapacitated partner. In these cases, there are too many competing individuals involved in the client's care. Such conflict unnecessarily complicates important choices about the client's care.

A potential shortcoming of the traditional model is that it may not provide adequate monitoring of the client's care or oversight of the decision maker. No one looks over the shoulder

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of a health care agency to ensure that they are doing a good job. Monitoring and oversight is particularly important to prevent a health care proxy from taking a passive approach or getting involved only when a question or issue is presented. Court-appointed guardians in many states have a statutory obligation to file accountings with the court detailing how they have spent the incapacitated person's money and medical reports outlining a care plan. However, in many states, there is no equivalent obligation that enables the court to monitor a health care agent's decisions.

Finally, some client's care is so complex that it requires delegation beyond that provided by the traditional model. A health care agent may take on too much and make uninformed decisions that would be better suited to a professional. On the other hand, if decisions are being made by a professional such as a Guardian, lawyer or Aging Life Care Manager, they may charge the client for tasks that they should be delegating to a less expensive professional. Most importantly, professional trustees and Guardians strive to earn a robust return on investments for their clients, but may not be skilled or interested in how best to spend money to ensure their client receives proper care, maximizes independence, and improves quality of life.

### **The Potential Solution: The Care Committee™**

Steve Cohen (Elder Law Attorney) and Emily Saltz (Aging Life Care Manager) developed this model by happenstance. In working together, they were seeing more and more cases where the client was never married, had no children, and was not connected to the next closest family members. The concept of the Care Committee™ evolved from these real-life examples of the confusion and lack of clarity for the client about who should be appointed as decision maker.

The Care Committee™ is an alternative approach that includes assigning a health care agent, but also creates a support system for the agent and allows for both professional and

personal perspectives. The concept of the Care Committee™ is based on a team approach to assist clients and includes their appointed agents. The Care Committee™ is not an alternative to the health care proxy, which is a critical relationship to establish.

The Care Committee™ can assist a client in several ways. The client has input from different perspectives, which allows the client the opportunity to consider options and information from a variety of sources and expertise. The client is directing the team as long

The Care Committee™ is an alternative approach that includes assigning a health care agent, but also creates a support system for the agent and allows for both professional and personal perspectives. The concept of the Care Committee™ is based on a team approach to assist clients and includes their appointed agents.

as able, and the information shared with the members allows for a clear message and directive around preferences, goals, and choices. Opinions are heard simultaneously, thus avoiding the problems of the client not correctly remembering what was said. The client is also able to test whether her "team" can work well together. If not, the client has the opportunity to make adjustments. Working with the client benefits the Committee members because they get to know the client, thus avoiding the challenge of trying to make decisions on behalf of an incapacitated person they don't really know.

### **Who should be on the Committee?**

Many people have negative reactions to the word "committee." They may believe committees are unnecessary, time-consuming, or ineffective. Many individuals hesitate to accept a position on a committee for the same reasons. Accordingly, the success of the Care Committee™ depends largely on selection of the right individuals as members. Ideal members are available to the individual as requested, in some cases simply a passive resource while they are well, and more actively involved as needed due to decline or eventual incapacity. They must also be responsible and accountable for seeing actions through. In addition, because any one individual likely will not have the varied skill set required to manage a client's care, it is important to have Care Committee™ members with diverse skills, each of whom contributes something valuable to the Committee.

The Aging Life Care Manager is a key component to the Care Committee™. The Care Committee™ is not a substitute for a health care proxy, but rather the Care Committee™ works along with the proxy and includes an Aging Life Care Manager. Typically, the Care Committee™ members will include the client, the health care agent, durable Power of Attorney or Trustee, an ALCM, friends, and family members. The Care Committee™ is intended to share the responsibilities typically shouldered by the client or by her agent. The Care Committee™ is put in place to advise the agent in making decisions, monitoring the agent's actions and, finally, holding the agent accountable.

Many clients already have an informal Care Committee™ in place that can be formalized. For example, a client who lives in New York City and has a daughter in California and a niece in Connecticut. The daughter hires an ALCM to oversee her mother's care and the niece checks on her aunt on week-ends. Although it is not officially named as such, the Care Committee™ already exists for this client. By naming this network of supports as a Care Committee™ everyone is better able to recognize its importance and how it should function on behalf of the client.

In creating the Care Committee™, the client signs a written document drafted by the attorney. This Care Committee™ Agreement typically exists as a separate document (along with a durable power of attorney, health care proxy, will, and perhaps a trust) as part of the client's estate plan. The client's signature should be notarized, and the Committee members should sign an assent form signifying that they accept their appointment (see sample agreement).

The Care Committee™ document should address the following: defining membership, requiring a minimum number of regularly scheduled meetings, and designating who has the power to appoint and remove members. The document should explain how decisions are made when there are disagreements, definite the Committee's responsibilities, clarify when the Committee ends, and explain the liability and compensation of the Committee members. Finally, the document should reference the client's wishes regarding level of care.

It should be noted that the Care Committee™ Agreement is not a legally binding instrument. It does not carry the same weight as a durable power of attorney or health care proxy. For example, although the Care Committee™ is intended to advise and assist a health care agent, the Committee's decisions are not binding on the agent. In the event of a serious disagreement between the Care Committee™ and the health care agent, the Committee would have to bring the matter to the attention of a court to legally challenge the health care agent's actions.

### When? - Prior to Incapacity

Preferably, the Care Committee™ begins to function while the client is able to participate in Committee discussions in a meaningful way. Healthy clients may sign the Care Committee™ document but delay the Committee's effective date. It may make sense for the client to establish a relationship with an Aging Life Care Manager and have all members of the Care Committee™ meet once to exchange contact information. However, as with other estate planning instruments, even

if the client does not presently need assistance, she should first ask the potential Committee members if they would be willing to serve and share the draft document with the proposed members so they can decide if they want to participate. However, if this is not possible, the Care Committee™ can be created by a health care agent subsequent to the client becoming incapacitated.

Ideally the client leads the Care Committee™ as long as he or she is able to meaningfully participate in the decision-making process. In the event of the client's incapacity, the Health Care Proxy leads the Committee regarding all aspects of care.

### The Care Committee™ and High-Conflict Family Situations

The Care Committee™ is by no means a guaranteed means of resolving conflict over health care decisions. For example, with a second marriage and adult children from a prior marriage, there may be unstated assumptions regarding what would happen if the client becomes incapacitated. The Committee provides a setting for the client to discuss these issues with her family. An Aging Life Care Manager can be key in facilitating and moderating this conversation. The Committee gives the client the opportunity to be heard and to clarify her wishes regarding health care. In addition to signing the Care Committee™ Agreement, it can be helpful to have the family create a "family contract" where everyone signs a written agreement that formalizes what has been discussed. Addressing these issues in the Committee setting may lessen the possibility of future misunderstandings or disagreements. It is important to keep in mind that with some families, agreement is not possible and that having one appointed decision maker may be preferable to involving family in a Care Committee™.

### Other Applications for the Care Committee™

Although the Care Committee™ evolved out of a demonstrated need for clients who lacked appropriate people to assign as their agent, it is

clear there could be many other applications of this concept. For example, it could be used with an elder who is the guardian for their disabled child. The Care Committee™ could be a resource for a successor guardian, making that role far less daunting for a healthy adult sibling to take on. Or consider the couple in their 70s who have no children. This could be a way to begin the conversation with them about how they will handle decision making in the future. Lastly, it is a new method for insulating clients from self-neglect or third-party predators. The Care Committee™ concept is specific, yet broad enough to be adapted to meet the needs of many different populations.

### Aging Life Care Manager Role

The Care Committee™, conceptualized by Saltz and Cohen and expanded and formalized with Cohen and Granigan, current CEO of Life-Care Advocates, presents intriguing possibilities for ways Aging Life Care Managers can be involved in a client's decision making.

First, becoming a member of a client's Care Committee™ allows the ALCM to contribute to the process of decision making without acting as the actual decision maker or agent. As has been discussed earlier in this article as well as others in this issue, this eliminates many of the concerns ALCMs may have about conflicts of interest, self-payment and other ethical issues. Yet, this arrangement allows the client to benefit from the Aging Life Care Manager's knowledge, experience, and personal relationship.

Second, if the Aging Life Care Manager is considering taking on a decision-making role for a client, using a model like the Care Committee™ is one way for the ALCM to feel more confident and supported in making decisions. For example, if the ALCM is the health care agent or guardian, they are not making decisions about the client's health by themselves. Rather, they are discussing all options and information with the other members of the Committee, all of

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whom must work together to decide on the right course of action for the client. While this arrangement does not eliminate all the concerns for an ALCM in taking on a decision-making role, it certainly could allow one to feel considerably more comfortable in taking on this role.

Either way, whether the Aging Life Care Manager is a member of the Committee or the agent for the client, having an ALCM on a Care Committee™ can significantly contribute to the Committee's success. The ALCM can help to provide information about care options and resources, help to understand medical diagnosis or information, help other members of the Committee understand the client's wishes and to help facilitate and moderate difficult or contentious conversations. This role supports what Aging Life Care Managers do best -- articulating what a person wants in a detailed way and taking the guesswork out of understanding a client's wishes.

## Conclusion

The concept of the Care Committee™ goes a long way in addressing many of the concerns related to the traditional model of substitute decision making for a client. The Care Committee™ encourages the inclusion of appropriate professionals to give information so health care agents are not making decisions without accurate information and guidance. In an ideal situation, the Committee sets up a team of people who can be involved with the client for some time and will be knowledgeable about their wishes should incapacity occur in the future. The Care Committee™ formalizes what many clients already have in place informally and gives structure to decision making and processes for decision making that would otherwise not exist.

As a result, the Care Committee™ may help to overcome the reluctance of family members, friends, attorneys, social workers, and even Aging Life Care Managers to step

forward and accept a decision-making role for their clients.

The Committee is intended to share the responsibilities typically shouldered alone by the client or by her appointed agent. The creation of a Care Committee™ also addresses the concern about accountability for health care agents and powers of attorney. In addition to sharing tasks, the Care Committee™ should also advise the agent in making decisions, monitor the agent's actions, and, finally, hold the agent accountable.

Most importantly, the Care Committee™ is one tool that can address what elders want most: choice and control. The Committee is intended to be led by the client whenever possible, allowing him to freely and clearly express his desires for care and end of life, thus empowering him to take control of his future.

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Steven M. Cohen, a partner with Pabian & Russell, LLC, leading the elder and disability law group. He has served as a member of the Board of Directors of the Massachusetts Chapter of the National Academy of Elder Law Attorneys as well as co-chair of elder law committee of the Boston Bar Association. He is co-author of the Nursing Home Medicaid Eligibility Chapter in *Estate Planning for the Aging and Incapacitated Client in Massachusetts* published by Massachusetts Continuing Legal Education.

Mr. Cohen speaks regularly before senior and professional groups including the American Bar Association, the Boston Tax Institute, Massachusetts Continuing Legal Education, the Boston Estate Planning Council, Harvard Medical School, as well as to health care professionals in hospitals and nursing homes. Mr. Cohen has been named a "Massachusetts Super Attorney" by Boston Magazine in the elder law category each year since 2006.

## Kate Granigan, MSW, LICSW, CASWCM

Ms. Kate Granigan is a licensed Independent Clinical Social Worker and received her Master's degree in Social Work from Boston College in 1994. She has worked as a clinician in the field of aging for over 20 years. Ms. Granigan founded C.A.R.E., a Care Management practice, in 1999, and in June 2009 C.A.R.E. merged with Overlook Visiting Nurse Association & Hospice Services, part of the non-profit Masonic Health System. Ms. Granigan was Vice President of Care Management until 2016 when she left to join LifeCare Advocates as Chief Executive Officer.

As Chief Executive Officer of LifeCare Advocates, Ms. Granigan oversees an Aging Life Care Management practice with a team of Life Care Managers, both nurses and social workers, who provide assistance, advocacy, and guidance to elders and their families.

Ms. Granigan is on the Board of Directors of the Aging Life Care Association and an Advisory Board member for the Massachusetts Guardianship Association. Ms. Granigan is a former member of the Board of Directors for the Scituate Council on Aging, Massachusetts Guardianship Association, and previously served as Secretary/Treasurer of National Academy of Certified Care Managers (NACCM). Ms. Granigan is a former member of the Board of Directors and a past President of the New England Chapter of the Aging Life Care Association. In 2015 Ms. Granigan was the recipient of the Aging Life Care Association's New England Chapter "Member of the Year" award.

Ms. Granigan lectures regularly on topics related to aging, caregiving, and elder care.

## Sample Care Committee Agreement

### Care Committee of \_\_\_\_\_

This document describes the conditions for the creation and membership of my Care Committee, (the "Committee"). The purpose of the Committee will be to advise me, or if I am incapacitated, my Health Care Agent appointed under my Health Care Proxy (my "Agent"), and the Trustee of the \_\_\_\_\_ Trust, on the level of medical, nursing, rehabilitative, and comfort care that best provides for my well-being and comfort.

Although this document may not be legally binding, it is my hope that my friends, relatives and all others involved with my care will feel morally bound to follow its mandate. The intent in establishing this Committee is to provide support for me and for others who must make decisions on my behalf regarding my care.

#### 1. Care Committee Creation and Membership

The Committee will begin to function upon my written request or if I am incapacitated upon the written request of my Agent. The Committee will be composed of friends and family that know me well, a licensed social worker, and myself. Upon my incapacity the Committee must always include at least two members, one of whom must be a licensed social worker and one of whom shall be my Agent. From time to time, the Committee may hire a legal or financial advisor for professional advice. The Committee will consult with my physicians and with other friends and family, as necessary. For purposes of this agreement, my Agent shall determine whether I am incapacitated.

In addition to myself, I would like to have the following people serve on the Committee:

\_\_\_\_\_, who are designated Agents and know me well, myself, and a licensed social worker/care manager selected by myself, or if I am incapacitated, by my Agent. The social worker must have professional experience advocating for disabled and elderly clients. I would like to have \_\_\_\_\_, of \_\_\_\_\_, serve as a legal advisor. I also would like \_\_\_\_\_, my \_\_\_\_\_; and \_\_\_\_\_ to serve as consultants to the Committee as deemed necessary by the Committee.

Committee expenses will be paid by me, or if I am incapacitated, by the trustees of the \_\_\_\_\_ Revocable Trust or by my attorney-in-fact pursuant to my durable power of attorney.

At any time I may remove Committee members and appoint additional or successor members. If I am incapacitated, Committee members can be removed and successor members appointed by \_\_\_\_\_, and if she is not living and legally competent, by \_\_\_\_\_.

#### 2. Care Committee Responsibilities

I, or upon my incapacity, my Agent will be responsible to schedule Committee meetings. Upon my becoming incapacitated, the Committee will meet at least monthly. Committee members that do not reside locally, can confer remotely by phone and/or computer and should be consulted on all matters.

The Committee shall propose a care plan that specifies the resources needed to provide for my comfort and well-being at home or in the most home-like independent setting which is appropriate. This plan may include medical, nursing, rehabilitative, resource management, or comfort care in addition to the care requested by my physicians. Section 3 below describes my wishes regarding my desired level of care which should be considered in developing my care plan. If the Committee cannot reach consensus on any decision related to my care I, or if I am incapacitated, my Agent in her sole discretion will make the ultimate decision on behalf of the Committee.

The Committee will provide the proposed care plan in writing to the Trustees of the \_\_\_\_\_ Revocable Trust or to my attorney-in-fact for financial review. If the Trustees find that there are financial constraints that would impact the proposed level of care, these constraints will be shared with the Committee so that the Committee can develop a financially viable alternative plan.

The Committee will review the care plan on at least a monthly basis. The Committee will compare the actual care I am receiving with that in the current care plan. The Committee's review will consider the plan's effectiveness and the Committee's satisfaction with the care provided. The Committee will consider adjusting the care and updating the care plan as needed.

The Committee will delegate any tasks related to my care plan among the Committee members and if necessary identify professionals who should be retained to assist with my care.

The Committee will terminate upon my death.

#### 3. Level of Care

In developing a care plan; I would like the Committee to consider the following:

- (a) My goal is to maintain my independence and current quality of life as long as possible. As long as I am able, I will participate to the extent possible in making decisions about my care and the proposed use of my resources.
- (b) My preference is to remain in a home that I own as long as this is feasible, taking into account both safety and my desire to remain independent. If this preference changes, I will notify the care Committee in writing of my desire for a different living situation, and the reasons for it.
- (c) My preference is to retain my current physicians. If I must change physicians due to a requirement over which I have no control, I wish to have my current physicians recommend the best suited physicians among those available to me. In addition, I wish to have periodic consultations with my current physicians.
- (d) If my condition is such that my best interest will be served by placing me in the care of an assisted living, nursing home or other residential facility, the Committee shall make every effort to select a facility that offers the highest quality of care, comfortable surroundings, allows patients to utilize privately hired personnel, and is accessible to friends. To the best of my ability, I will participate in the selection of the facility.
- (e) Whether at home, in a hospital, in a rehabilitation facility, in a residential facility, or hospice, if I cannot monitor the care myself, the care plan should provide for a care manager who will monitor my care at least weekly and will coordinate any privately hired personnel and services. I also would like a member of the Committee or a friend designated by the Committee to visit me each week and to report any perceived care issues to the Committee. The care manager will provide weekly oral reports to me or to my Agent if I am incapacitated and will provide oral and written progress reports to the Committee and Trustees at least monthly.
- (f) The care plan will recommend the resources needed to provide for my comfort and well-being. At home, these resources may include nurses, caregivers, companions, medical equipment, transportation, and modifications to my home. At other facilities, these resources may include additional privately hired personnel and services if they would enhance my comfort and well-being.

#### 4. Liability and Confidentiality

The Committee members agree to hold all communications and information discussed by the Committee in total confidence, except as authorized and directed by me or if I am incapacitated by my Agent. Members of the Committee who act in good faith shall not incur any liability for their actions to me or to my estate.

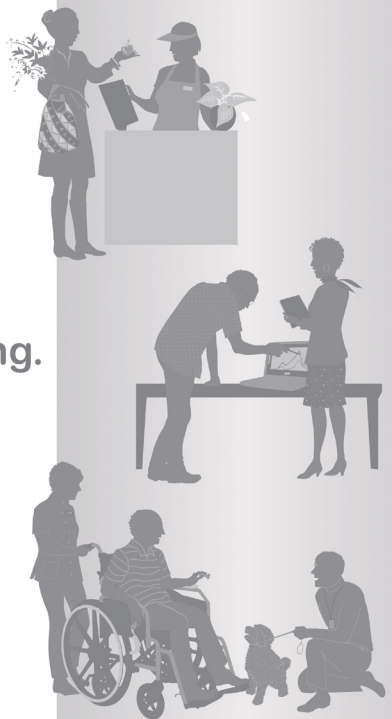
Dated: \_\_\_\_\_, 2014 \_\_\_\_\_

[Notary Statement deleted for space reasons]

The undersigned acknowledges the receipt of the Care Committee of \_\_\_\_\_, and will accept appointment as a member of this Care Committee.

Date: \_\_\_\_\_




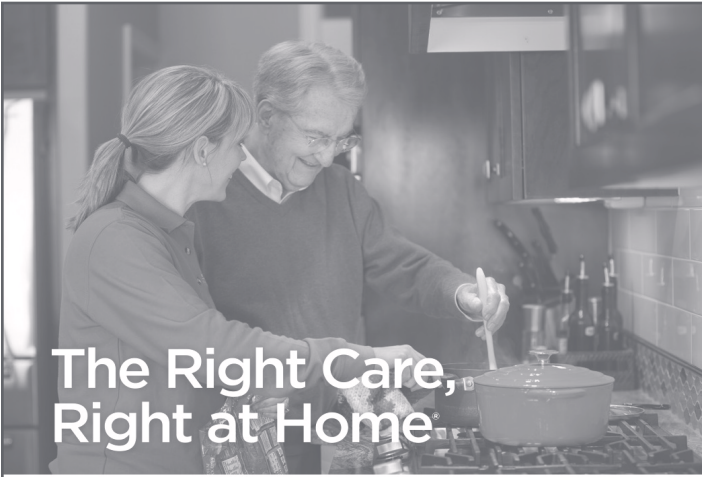


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