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Eldercaring Coordination: A Needed Dispute Resolution Option in California

By: Sarah J. Gross, M.Ed., J.D., LL.M.

Introduction to Family Conflict in Eldercare

The aging of a family member is an inevitable process, and families hope that their aging parent or grandparent will gracefully step into their elder years. For many families, however, this process is not so graceful, and family members are faced with making difficult decisions. While families want what is best for the elder, family members may disagree over what the “best” entails and conflict erupts over who will care for, have access to, and make decisions for the elder. As a result, adult siblings may find themselves in court arguing over decisions for an elder parent.1

Elder mediation has been a growing and increasingly common avenue for resolving elder disputes outside of the courtroom.2 In most cases, (cases involving mild to moderate conflict), mediation is successful in getting parties to set aside their differences and focus on solutions for the elder. In high-conflict cases, however, where family members demonstrate an unwillingness to cooperate even with the intervention of a mediator, a different approach is needed to address the underlying conflict and encourage families to focus their efforts on the care and wellbeing of the elder.

Eldercaring coordination has developed as an alternative dispute resolution (ADR) option for high-conflict elder disputes. The goal of eldercaring coordination is to complement other services such as legal representation and mediation, and to “help manage high-conflict family dynamics so that the elder, family and stakeholders can address their non-legal issues independently from the court.”3 Eldercaring coordination recognizes the incidence of high-conflict family dynamics in disputes involving elders and provides an ADR option for those instances where mediation fails.

Dispute Resolution in Elder Care: Elder Mediation-Benefits

Mediation has developed as a preferred method for resolving disputes involving the care and needs of elders. Elder mediation is effective in handling high family tensions and emotions because the mediation forum offers the opportunity for the elder and other concerned parties to come to a mutual understanding of each person’s values and concerns.4 It preserves the voice and participation of the

1 Fieldstone & Bronson, Eldercaring Coordination in Your Community or Your Law Practice: New Approaches to Dealing With High-Conflict Families, 14 NAELA J. 1, 2 (Spring 2018).
3 Fieldstone & Bronson, From Friction to Fireworks to Focus: Eldercaring Coordination Sheds Light in High-Conflict Cases 24 Experience (2015).
4 Mary F. Radford, Advantages and Disadvantages of Mediation in...
elder, and provides a constructive and secure environment that encourages the participation of all parties to discuss issues pertaining to the elder’s care, including issues arising in the context of a conservatorship petition.\(^5\)

The goal of elder mediation is to provide families access to resources that are not available in court, where the mediator has knowledge of these resources to serve the needs of elders within the relevant community.\(^6\) In encouraging this type of communication, the facilitative approach of elder mediation helps to preserve family relationships and build connections to community resources that families may otherwise be unaware of.

These benefits to mediation make it a viable and important ADR option for disputes involving families and elders, and thus it is an appropriate intervention in the majority of cases. There are situations, however, where the mediator may be limited in his or her ability to address the high-conflict dynamics that can arise in an elder dispute.

**Elder Mediation – Limitations**

Cases involving high-conflict family dynamics often include one or more conditions which indicate that mediation is not an appropriate method to resolve the dispute and, if used, may exacerbate conflict and result in impasse. For example, some cases may involve an imbalance of power if the elder is unrepresented or is not appointed counsel. A party who is unwilling or unable to participate also frustrates the intent of mediation and indicates that the mediation may be unproductive. If a contentious family member demonstrates an aversion to engaging in good-faith compromise and the mediation proceeds, that family member may misuse the mediation as a forum to vent, escalate conflict, and restate absolute positions. This setting can negatively impact the elder, making him or her feel unheard or unsafe.\(^7\)

In situations of high conflict, when family members are not amenable to working cooperatively and cannot focus on the important issues at hand (an elder parent’s care and well-being), families may require a different dispute resolution process that goes beyond what elder mediation can provide.

**Eldercaring Coordination**

Eldercaring coordination is the missing link between elder mediation and the court that serves to manage family conflict, facilitate productive communication, and assist in the implementation of an elder care plan. Elder mediation and eldercaring coordination are both processes aimed at helping families to make informed decisions, but these processes are distinct from one another in the approach to managing high-conflict family dynamics.

The eldercaring coordination process involves eldercaring coordinators (ECs), impartial third persons who assist the parties in a high-conflict dispute to resolve their non-legal issues. An EC is appointed by the court for a term of up to two years to assist a family in making decisions related to the care of an elder. ECs are required to complete training and to have specific qualifications to ensure adequate knowledge and experience to effectively assist families in decision-making under high-conflict conditions.\(^8\)

The work of ECs complements and enhances elder mediation to help families work more productively in resolving high-conflict disputes, as the EC often steps in to assist families after mediation to address subsequent, repeated conflicts. Family conflict may result in a mediation impasse when family members are enmeshed in chronic disputes that take the focus away from the elder and detract from the goal of resolving the dispute. An EC can be an effective intervention when mediation has failed on account of intractable family conflict, or when mediation is likely to fail because of high-conflict indicators such as controlling behavior toward the elder; multiple non-substantive motions to the court; and sibling entrenchment. ECs may use some of the same strategies and interventions that an elder mediator employs to help families work through conflict and are further trained to delve into and address high-conflict dynamics; identify issues of accord and conflict; and assist families on methods of resolving conflicts in order to make better decisions regarding elder care.\(^9\)

When high-conflict dynamics are addressed within the setting of eldercaring coordination in the event that


\(^{6}\) Radford at 243.


\(^{8}\) See ACR Guidelines for Eldercaring Coordination (2014).

\(^{9}\) Fieldstone & Bronson, *Eldercaring Coordination*
mediation fails, families can begin to separate from conflict narratives and focus their energies on the wellbeing of the elder. The resulting benefits include reduced court time and interventions; greater use of community resources; and the needs of families and elders being addressed earlier so that attorneys can more effectively assist clients on legal issues.

Eldercaring Coordination in California

There are several factors that highlight the need for eldercaring coordination in California: 1) the increasing aging population; 2) lack of aggregate data on elder case filings; and 3) the prevalence of elder abuse.

1) Increasing Aging Population

According to the California Department of Aging (CDA) Population Demographics for 2018, an estimated 8,221,985 California residents will be 60 years old or older. In Orange County, California, the CDA projects a 100 percent to 150 percent increase in the aging population. This increase correlates to increased care needs and use of community and court services by elders. Research also indicates that the aging population has a significant impact on court services.

In 2012, a study was conducted on the impact of the increasing elderly population on court services in Orange County, California.10 The study sought to determine the projected increase in caseload relative to the elderly population; whether court programs exist to address the needs of elders; and what court programs Orange County Superior Court (OCSC) can implement to further meet elders’ needs. The study resulted in several findings. First, data indicated an increase in elder abuse cases as well as in conservatorship filings. Second, OCSC does provide services to elders, including physical accommodations and referrals to mediation through Family Court Services, but there is still a need for a specialized court or process to address elder needs.

The eldercaring coordination process serves as a resource to the court and others involved (elder mediator, attorney, therapist) because the primary focus is reducing and managing family conflict on a consistent basis until the family is able to make supported, issue-focused decisions (rather than conflict-focused) and channel their energies into supporting the elder. When interpersonal dynamics are addressed through the eldercaring coordination process, the family and stakeholders are better able to work with an elder mediator, geriatric care manager, financial experts, conservator, elder law attorney, and/or physicians. The EC helps families navigate the difficult transitions of eldercare and prevent conflicts from interfering with other processes such as mediation and court proceedings. The EC is thus a resource for the legal system, allowing attorneys and the court to focus on legal issues without the interference of family conflict.

2) Lack of Data

There is a general lack of aggregate data in California on conservatorships and other elder disputes. Most cases involving elders are characterized as “probate” cases and are filed and heard in the Probate Division. There is a push for greater oversight of conservatorship proceedings which is compounded by the lack of data.

The introduction of a pilot project in California courts, where data is collected and assessed and improvements are implemented, will provide the data on conservatorships and elder cases and oversight of the California conservatorship system that has been lacking. The Eldercaring Coordination Pilot Project includes assessment tools to gauge the success of the program and its effect on the probate court. Implementing the pilot project in California courts will provide an opportunity to not only evaluate the efficacy of eldercaring coordination as an ADR (alternative dispute resolution) process, but also to provide a level of oversight in conservatorship proceedings and contribute to data collection.

10 Vicky Brizuela The Aging Population of Orange County, California and its Impact on Court Services, National Center For State Courts 1 (2012).
3) Elder Abuse

Elder abuse cases continue to be filed as separate cases in criminal and family courts, and allegations of elder abuse arise in conservatorship proceedings. At the same time, many elder abuse cases in California are not litigated due to deficient investigations, challenges posed by an elder’s incapacity, and inadequate legal remedies, among other factors. Identification of elder abuse and safety issues is often a challenge, particularly for those without the knowledge and training to identify and report elder abuse.

Eldercaring coordination helps in the way of identifying and reporting allegations of abuse, neglect, exploitation, and safety concerns. ECs are trained to screen for elder abuse, neglect, and exploitation, as well as family violence, and to follow appropriate reporting procedures and courses of action when safety parameters are needed. Research on ECs in current pilot sites already indicates that risks are addressed and abuse is reported when appropriate; that safety issues are addressed; and that ECs make appropriate referrals. The duration of eldercaring coordination, combined with the ECs’ training, makes it ripe for identifying and reporting allegations of abuse. An EC who works with a family for a two-year term and builds relationships is well-positioned to identify risks, to prevent abuse, neglect, and exploitation, address existing safety concerns, and monitor safety of the elder.

Conclusion

When mediation reaches an impasse in an elder dispute, the default option is to return to court at the risk of ensuing litigation. With eldercaring coordination, the parties have an alternative process at their disposal. Eldercaring coordination addresses the need for a dispute resolution option for high-conflict cases regarding an elder’s needs that complements and enhances existing services. Eldercaring coordination can provide significant support in conservatorship cases and other elder disputes involving high-conflict family dynamics. Its development as an alternative dispute resolution process demonstrates progress in reducing conflict, increasing court efficiency, and addressing safety concerns for elders, with continued progress expected as the process expands in use.

Orange County Superior Court (Orange County, California) is planning to launch its eldercaring coordination pilot site in Spring 2019. Qualified professionals are being trained as ECs, and the legal and dispute resolution community is being educated about the process. Trainings in family mediation (November 2018), elder care mediation (January 2019), and eldercaring coordination (February 2019) are scheduled as part of the eldercaring coordination Orange County initiative.

Please contact the author, Sarah J. Gross, for more information on the Orange County program and efforts to expand the program state-wide throughout California.

About the Author:

Sarah J. Gross, M.Ed., J.D., LL.M. is an attorney licensed in the state of California whose practice focuses on elder law and elder dispute resolution.

She works with the ACR Elder Justice Initiative on Eldercaring Coordination, an initiative dedicated to developing a dispute resolution option for high-conflict cases involving the care and needs of elders.

Ms. Gross spearheaded the development of a pilot program in eldercaring coordination in Orange County, California courts. She currently serves as pilot site administrator. She continues to advocate for court-connected ADR programs as a means of serving the increasing aging population in the United States, and addressing the needs of elders and their families.

Sarah J. Gross

https://www.asaging.org/aging-in-america

Aging in America Conference
April 15-18 | New Orleans, LA
https://www.asaging.org/aging-in-america
Genworth 2018 Cost of Care Survey Available

-Source of good data on health care costs

One of the stumbling blocks to health care planning is the difficulty of finding good data on health care costs. Genworth’s Cost of Care Survey is a treasure trove of data with powerful tools for health care planning.

Since 2003, Genworth has been doing a national survey of service providers from every state in the U.S. The 2018 survey covers 440 regions (Genworth’s “regions” are based on “Metropolitan Statistical Areas” (MSAs) as defined by the U.S. Census/U.S. Office of Management and Budget). Caregivers in these regions submitted more than 15,500 surveys. Genworth created powerful online tools to help interpret and present the data. The survey, and the analytical tools that accompany it, is available at https://www.genworth.com/aging-and-you/finances/cost-of-care.html.

The analytical tools include:

- A heat map which makes it possible to view health care costs over time from both a national, state and regional level. This tool enables users to calculate hourly, daily, monthly and annual cost of care, compare health care costs by state and region, identify trends and project future developments.
- National and state data tables
- Long Term Care Insurance Calculator
- A summary of trends.

In the summary of trends, the authors note that assisted living facility costs have risen by 67% since 2004, and the national median cost per year for a private room in a nursing home in 2018 is $100,375. Figures like these bring home the realization that health care planning will become even more important in the future.

CMS Launches Flu Vaccination Campaign

“Older adults are at higher risk for severe flu illness and complications, but they often face barriers to accessing preventive health services…”

The Centers for Medicare and Medicaid Services (CMS) have launched a campaign to increase awareness about flu vaccinations for low-income Medicare recipients. Older adults are at higher risk for severe flu illness and complications, but they often face barriers to accessing preventive health services, including the annual flu vaccination. CMS has compiled educational resources for consumers, providers, and advocates including customizable postcards, brochures, posters, and toolkits. There are postcards and posters available in many languages.

All of these materials are available on the CalDuals website.

On December 5, you can join CMS on social media to promote flu vaccinations using the hashtags #FightFlu! To encourage vaccination and emphasize the seriousness of flu, CMS is coordinating social media education and outreach with the Centers for Disease Control and Prevention during National Influenza Vaccination Week December 2-8.
Visitation, communication, and interaction under guardianship is an important and complex issue for courts, guardians, and disability and elder rights advocates. The issue is of great importance because contact with family, friends, and community can have a major impact on health and well-being. Over the last several years, the right to visitation has gained attention from the media and some state legislatures when the adult children of incapacitated celebrities such as Casey Kasem and Peter Falk petitioned the courts for the right to visit their parents over a guardian's objections. As the public becomes more aware of the potential risks of guardianship — including isolation from friends, family, and community — more states are debating hotly contested visitation bills.

Preserving a person's ability to visit, communicate, and interact is essential to their quality of life. Unfortunately, estrangement from family, friends, and acquaintances can be a precursor and a consequence of guardianship. The factors that led to the appointment of a guardian — mental illness, dementia, poverty, abuse, and exploitation — may have also led to unwanted isolation. Family, friends, and professionals should be aware of the potentially devastating effects of isolation on the person; loss of ties to friends, family, and social networks can have a negative effect on anyone's physical and mental health. Isolation leads to an increased risk for depression, cognitive decline and dementia, and even premature death.¹

Balancing the Right to Visitation with the Duty to Prevent Harm and Exploitation

The right to visit, communicate, and interact with others invokes the larger debate over guardianship: how can a guardian preserve as much of an individual’s autonomy as possible while ensuring protection from harm and exploitation? Historically, guardianships transferred most

or all an individual’s rights to a guardian, including the right to choose and maintain relationships and connections. Several state statutes, the 2017 Uniform Guardianship Conservatorship and Other Protective Arrangements Act (UGCOPAA), National Guardianship Association (NGA) Standards of Practice, and National Probate Court Standards, reject the wholesale transfer of visitation and communication rights to the guardian. An increasing number of state laws charge guardians with the duty to encourage and support visitation in accordance with a person’s values and preferences.

A guardian may have to weigh the risks and benefits of maximizing independence and self-determination against the guardian’s duty to ensure the safety and well-being of the person. (See NGA Standard 8). Guardians have the duty to “promote social interactions and meaningful relationships consistent with the preferences of the person and encourage and support the person in maintaining contact with family and friends, as defined by the person, unless it will substantially harm the person.” (See Standard 4).

NGA Standards strongly favor encouraging visitation whenever possible. In addition to the guidance cited above, the following NGA Standards of Practice support the guardian’s role in promoting visitation:

- Identify and advocate for the person’s goals, needs, and preferences. (Standard 7).
- Ask the person what he or she wants. (Standard 7).
- Encourage the person to participate, to the maximum extent of the person’s abilities, in all decisions that affect him or her. (Standard 9).
- Acknowledge the person’s right to interpersonal relationships. (Standard 10).
- Consider the proximity of those people and activities that are important to the person when choosing a residential setting. (Standard 12).

State Guardianship Legislation Addressing Visitation

States are increasingly passing laws that address visitation. From 2015 - 2018, several states addressed the right to visitation and communication in legislation, including Arizona, California, Florida, Hawaii, Indiana, Illinois, Iowa, Louisiana, Maine, Maryland, Nebraska, Nevada, New Mexico, New York, Ohio, Rhode Island, South Dakota, Tennessee, Texas, Utah, Virgin Islands, Virginia, and West Virginia.

State laws differ widely in approach. Several states expressly grant the right to visitation to people subject to guardianship. Others do not use the language of “rights” at all, instead focusing on the need to maintain connections. For example, a recent California amendment specifies that “every adult in this state has the right to visit with and receive mail and telephone or electronic communication;” while Arizona’s statutory language provides that “a guardian shall encourage and allow contact between the person with a guardian and other individuals.” State laws address many facets of the right to visitation, interaction, and communication in guardianship, including the right to visitation, evidence of prior relationships, and the rights of families and other interested parties.

The Rights of Family and Other Interested Parties

Addressing the rights of loved ones to visit over a guardian’s objections raises several questions. When should a guardian restrict visitation? Is a suspicion of the interested party’s bad intent sufficient, or should the guardian have some evidence of wrongdoing? If the person does not want to have contact with a loved one, or seeks limited contact, such as phone calls but not in-person visits, the guardian should respect their wishes. Some states grant family members or other interested parties the right to petition for visitation in court if visitation has been denied by the guardian. In Texas, an adult child of an individual subject to guardianship has the right to file an application for visitation in court and request a hearing. Utah’s statutory language prohibits the guardian from preventing a person from associating with a relative or “qualified acquaintance,” and relatives or qualified acquaintances may petition the court to rescind or modify a visitation order. In Arizona and Florida interested parties can ask the court for a contact order or to review the guardian’s decisions about visitation.

In addition to the right to request visits, some states and UGCOPAA guarantee a right to information for relatives and loved ones about significant changes in the condition or circumstances of the individual. For instance, in West Virginia, relatives who have been granted access by court order to the person subject to guardianship are entitled to notice of death and funeral arrangements, admission to medical facility, and change of location.
Bills of Rights that Include the Right to Visitation

Some states have passed broad-based bills of rights for people subject to guardianship that include the right to visitation, interaction, and communication. These rights are not absolute — there are always exceptions when a guardian or court may prohibit visitation if it would cause harm to the person. For example, in Florida a person retains the right to visits and communications, but the court may remove the right to make decisions about “social environment” and delegate decision-making authority to the guardian. Nevada’s “Wards’ Bill of Rights” guarantees the right to telephone calls, personal mail, and visitors, unless the guardian and court determine that correspondence with a particular visitor would cause harm.

Evidence of Prior Relationships May be Sufficient toPresume Consent

Even if the person subject to guardianship cannot consent to visits or express interest in visits, a guardian can still encourage positive relationships. Several state statutes specify that evidence of prior relationships is a sufficient basis to presume consent or refusal to consent to visits. For instance, in South Dakota consent, or refusal to consent to visits, can be presumed based on proof of the nature of the prior relationship with an individual.

The Role of Courts

Traditionally, state statutes gave guardians unfettered authority to restrict visits and communication to protect individuals under their care. However, some jurisdictions now assign not to guardians but rather to courts the authority to set the terms of visitation. In South Dakota, Rhode Island, and Tennessee, the guardian must seek a court order to restrict visitation, with limited exceptions. Rhode Island’s statute specifies that a guardian may move the court to restrict communication/visitation for good cause, including: existence of a protective order; whether abuse, neglect or exploitation of the individual by the person seeking access has occurred or is likely; and any documented wishes of the individual to reject the communication/visitation. And in Tennessee, only the court — not the guardian — may remove the individual’s right to communication, visitation, or interaction.

In several states, the court may sanction, and even remove, a guardian for preventing a person from visiting, communicating, and interacting with others. For instance, in Louisiana, failure of the curator (guardian) to allow visitation can result in removal of the curator. In Rhode Island, sanctions may include an order to pay court costs and reasonable attorneys’ fees of the other party or parties. These sanctions shall not be paid out of the estate of the person subject to guardianship.

Some state statutes also include procedural protections for individuals seeking visitation, including the right to a hearing, time limits, notice, standard of proof, and attorneys’ fees. For example, in Nebraska, a family member who is denied visitation may petition the court. If the individual has a guardian, the petition is to be filed in the county court with jurisdiction over the guardianship case. If the individual’s health is in decline, the court shall hold an emergency hearing.

The Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (UGCOPAA) and the Right to Visitation, Communication, and Interaction

UGCOPPA, passed by the Uniform Law Commission in 2017, prioritizes visitation as important to the well-being of people subject to guardianship. “[R]ecognizing that individuals subject to guardianship and conservatorship benefit from visitation and communication with third parties, the Act sets forth specific rights to such interactions.”

The Act provides protections for the person’s rights on this subject from the initial appointment of the guardian: the person is entitled to receive notice of the right to communicate, visit or interact with others, including in-person visits, phone calls, personal mail, electronic communications, and social media. ($§ 311(b)(6)).

Moreover, UGCOPAA prohibits the guardian from restricting visitation, unless: (A) the restriction is authorized by court; (B) there is a protective order or protective arrangement that limits contact; or (C) the guardian “has good cause to believe the restriction is

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2 See Prefatory Note p. 3. For a detailed description of all the Act’s strong provisions on visitation, communication, and interaction - §§ 311, 314, 315, 316, 502, 503 - see Guardianship and the Right to Visitation, Communication, and Interaction: A Legislative Fact Sheet).
necessary because interaction with a specified person poses a risk of significant physical, psychological or financial harm,” and the restriction is for no more than seven business days if the person with whom contact is restricted has a family or pre-existing social relationship or for 60 days if a family or social relationship does not exist. (§§311(b)(6); 315(c)).

Article V of the UGCOPAA also provides a means for a court to restrict visits when they would cause harm without appointing a guardian. The court can order a “protective arrangement” instead of a guardianship. The court may direct visitation or supervised visitation; or restrict access “by a person whose access places [the individual] at serious risk of physical or psychological harm” – or by a person who uses fraud, coercion, duress or deception and control.

Finally, the Act requires that family members and others to receive key information about important changes in the person's conditions or circumstances. (Prefatory Note, p. 3. See §§310(e); 411(e)).

Other Relevant Topics

The Right to Visitation in Nursing Homes

Federal nursing home regulations specify that the resident has the right to visitation, and the facility must provide immediate access to any resident by immediate family members or other relatives, subject to the resident's right to deny or withdraw consent at any time. The resident also has a right to communicate with a long-term care ombudsman, as well as a representative of a protection and advocacy agency. The law does not specify whether the appointment of a guardian transfers these rights to the guardian. Regardless, the nursing facility cannot prohibit visitation. (42 C.F.R. § 483.10).

The Role of Mediation

A mediator may be able to resolve visitation disputes without going to court. If a dispute cannot be addressed through mediation, a new dispute resolution process called Eldercaring Coordination may be useful in resolving the increasingly common high conflict “family feud” situations. According to the Association for Conflict Resolution, Eldercaring Coordination is “a dispute resolution option specifically for high-conflict cases involving the care, needs and safety of elders.” Coordinators, training protocols, and a court pilot project template are available at [https://www.eldercaringcoordinationfl.org/](https://www.eldercaringcoordinationfl.org/).

Conclusion

Improving and preserving the access of people with guardians to visitation, communication, and interaction can provide great benefit to their quality of life and protect their basic rights. Guardians, courts, family members, and interested parties all play a role in encouraging people with guardians to avoid isolation. Professional standards, the Uniform Law, and many state legislatures recognize the tremendous importance of visitation, communication, and interaction, and charge courts and guardians with supporting it whenever possible.

About the Author:

Dari Pogach is a staff attorney at the ABA Commission on Law and Aging. She specializes in adult guardianship reform and alternatives to guardianship. She has provided direct legal services to indigent clients for several years, including as a staff attorney at Disability Rights D.C. of University Legal Services, the District of Columbia’s protection and advocacy program for people with disabilities and Quality Trust for Individuals with Disabilities. She also has substantive experience in policy and legislative advocacy, and has testified at numerous legislative hearings, provided comments to proposed regulations, and written public reports with recommendations for improving local laws and practices.

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3 See the Association for Conflict Resolution (ACR) Guidelines for Eldercaring Coordination, which includes ethical principles for Eldercaring Coordinators, training protocols, and a court pilot project template ([https://www.eldercaringcoordinationfl.org/association-for-conflict-resolution.html](https://www.eldercaringcoordinationfl.org/association-for-conflict-resolution.html)). See also Bronson and Fieldstone, From Friction to Fireworks to Focus: Eldercaring Coordination Sheds Light in High-Conflict Cases, Experience, Senior Lawyers Division of American Bar Association, Vol. 24, Number 3, at 29 (2015). [Editor’s Note: Please see Sarah Gross’ article on Eldercaring Coordination on page 22 of this publication.]
The Definitive Tool for Creating Advance Directives

Learn Best Practices and harmonize legal instructions with medical practices.

“By bringing the practices of lawyers into better alignment with clinical realities... the Guide enables lawyers to help their clients get medical care that truly honors their values, choices, and preferences throughout all stages of their illness” - Louraine Arkfeld, chair of the ABA Commission on Law and Aging.

This new guide will help lawyers, medical professionals and caregivers write and implement end-of-life health instructions that are clear and effective. It bridges the chasm between lawyers and doctors and helps lawyers provide guidance that fits clinical and family realities. It enriches the relationship between clients and professionals by giving clinicians and lawyers tools to guide patients and clients through the advance care planning process.

It includes a checklist for lawyers, which offers an itemized listing of what is expected throughout the entire process, plus drafting tips, self-help planning tools lawyers can provide to clients, and information on online resources.

Advance Directives: Counseling Guide for Lawyers, is a collaborative work by a team of organizations, lawyers and medical experts from the ABA Commission on Law and Aging, the American Academy of Hospice and Palliative Medicine, the University of California San Francisco Medical School and the UC/Hastings Consortium on Law, Science & Health Policy. The project was funded by The John A. Hartford Foundation with support from The Borchard Foundation Center on Law and Aging.

To download the guide, click here.
**Don't Let Dementia Steal Everything**
By Kerry Peck and Rick Law

Dementia touches the lives of everyone. Every one of us has either a family member, friend, neighbor or colleague living with dementia. The progressive changes in memory and cognition that define dementia have legal consequences. While we urge every adult to plan for incapacity with powers of attorney, and advance health care directives, planning becomes critically important for a person with dementia.

This book starts with a basic description of dementia, its various forms, and how it impacts the person. The second chapter explores how the progressive nature of dementia brings with it increased risks and care needs. It is important for a person living with dementia and their loved ones to work with an attorney familiar with dementia and its unique challenges. The third chapter describes how to find and engage an attorney who is dementia competent. There is an excellent chapter on the basics of planning for incapacity, exploring the capacity needed to engage in planning, and core planning documents such as advance health care directives and powers of attorney. The book offers an honest evaluation of the strengths and weaknesses of each document and offers practice tips on how to make them most effective.

Paying for health care is important for any person with a progressive illness, more so for a person with dementia because of the predictable loss of memory and decision-making ability. Chapters are devoted to understanding both Medicare and Medicaid, offering a fundamental understanding of who is covered under each program and what kinds of care is paid for. The rules for Medicaid vary from state to state. The book offers an excellent overview of Medicaid eligibility on a national basis (not an easy task.) There is a chapter devoted to the Veterans Benefits that help many persons with dementia and their spouses.

Without planning, or if planning fails to work, guardianship may be needed. Chapter nine explores the issues of guardianship, including how to avoid it, when it is needed, and when guardianship goes wrong and becomes a part of the problem. The chapter is a must-read for everyone. Another must-read chapter examines elder abuse and financial exploitation. Scammers and crooks prey on persons with dementia, taking advantage of the decline in judgement and memory.

The greatest wish of most persons with dementia is to remain at home, with care by committed loved ones. The last chapter of the book explores the issues of in-home care and paid caregivers.

The book is an easy read, at about 180 pages. It is written for a consumer audience and would make a good survey overview for professionals new to the area of legal issues in dementia. The chapters have tips and check lists. There are short interviews with key experts throughout the text.

I will keep a copy on my shelf to share with persons and families experiencing dementia.

The book is published by the American Bar Association / Senior Lawyers Division. It is available in the ABA webstore and through bookstores and online retailers. A much-needed Kindle edition will be available sometime in 2019.

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*Books Reviewed by David Godfrey*
Driving Miss Norma: One Family’s Journey Saying “Yes” to Living by Tim Bauerschmidt and Ramie Liddle

When Miss Norma was diagnosed with cancer at age 90, she chose to hit the road and live life to the fullest. At the time she was diagnosed, her husband was dying in the same hospital. Her doctors recommended aggressive treatment for her cancer, but she said no. Instead she chose to travel the country and see and do the things she’d always dreamed of. She traveled with her son and daughter-in-law in a motor home making a grand circle tour of the country.

Her daughter-in-law started posting on Facebook and writing a blog about driving Miss Norma to keep family and friends up to date on what was happening. Word of the blog spread, media interviews came along, and the story of Miss Norma, who chose to live life at the end of life, went viral.

The book is a well written narrative of the experience. The chapters are written by either her son or her daughter-in-law and is equal parts travel narrative, philosophy of life and a description of the journey through Miss Norma’s last year. The authors do an excellent job of describing the self-advocacy and family support that were necessary to make — and stick with — the decision not to seek aggressive treatment. They briefly describe the relief of health care providers when a terminally ill person and their family agree that no treatment is sometimes the best treatment option. Miss Norma’s family took extraordinary efforts to ensure that she knew what the options were and allowed her to make decisions, promising to honor her choices no matter how hard that might be. (They were practicing supported decision-making without knowing it.)

The book, and the family’s journey around the United States, follows the progress of Miss Norma’s illness, and the sometimes subtle, sometime dramatic changes in her ability to do things. Her final illness and death are treated in a tasteful manner. Miss Norma kept a journal through the process, after her death the authors read through the journal. The journal described people, places and experiences, without a single mention of her illness and changes in her health. She wrote about what was important to her — living life.

The choices Miss Norma and her family made were right for her, but they may not be right for everyone. Anyone who wants to do what she did can find inspiration in this book for taking charge and living life to the fullest at the end.

Financial Exploitation by Conservators: A Series of Eight Background Briefs

The National Center for State Courts and its research partners, including the ABA Commission on Law and Aging, have developed eight Background Briefs on Financial Exploitation by Conservators. The recently released Briefs are at http://www.eldersandcourts.org/Other-Resources.aspx. The Introduction to the Briefs, reprinted below, describes the project.

NATIONAL CENTER FOR STATE COURTS

Introduction

FINANCIAL EXPLOITATION BY CONSERVATORS

- A SERIES OF EIGHT BACKGROUND BRIEFS -

Despite the financial and psychological impact of conservator exploitation on victims and their families, there is little information on its extent and consequences. Thus, the U.S. Department of Justice Office for Victims of Crime funded the National Center for State Courts (NCSC), in partnership with the American Bar Association Commission on Law and Aging (ABA Commission), the Virginia Tech Center for Gerontology (VTCfG) and the Minnesota Judicial Branch, to assess the scope of such exploitation and explore its impact on victims. The project team produced eight Background Briefs:

- Examples of Conservator Exploitation: An Overview
- Conservator Exploitation in Minnesota: An Analysis of Judicial Response
- Detecting Exploitation by Conservators – Court Monitoring
- Detecting Exploitation by Conservators – Systemic Approach
- Court Actions Upon Detection of Exploitation
- Innovative Programs that Address Financial Exploitation by Conservators
- Data Quality Undermines Accountability in Conservatorship Cases
- Supporting Victims of Conservator Exploitation

Accompanying the Background Briefs is a list of key resources on conservator exploitation.

Because state terminology varies, it is important to clarify key terms.

- In the project, conservator is defined as an individual or entity authorized by a court to make property or financial decisions for an adult who the court determines is not able to make those decisions. State statutes may use other terms such as “guardian of property” or “guardian of the estate.” Court-appointed conservators include family members and other non-professionals, attorneys, private for-profit and non-profit professionals and agencies, and public guardianship programs.

- A guardian is an individual or entity authorized by a court to make health care and other personal decisions for an adult who the court determines is not able to make those decisions. Sometimes “guardianship” is used as a general term covering both guardians making personal decisions and conservators making financial decisions. A conservator may also be appointed as a guardian.

- A conservator is a fiduciary – someone entrusted with the management of property of another, and who owes a high duty of trust, honesty, care, confidence, and good faith.

- Exploitation is defined by the National Center on Elder Abuse as the illegal or improper use of a person’s funds, property or assets. State definitions vary.

NCSC in 2016 estimated, based on projections, that there are approximately 1.3 million active adult guardianship or conservatorship cases in the United States and at least $50 billion in assets under conservatorships (see Data Quality Brief). Also in 2016, the U.S. Government Accountability Office (GAO) found that “the extent of elder abuse by
guards nationally is unknown due to limited data . . . “

While many conservators are trustworthy, dedicated, and provide critically needed services, multiple media accounts over many years profile instances in which conservators have breached their fiduciary duty – taking advantage of those they were charged with protecting. As early as 1987, the Associated Press landmark report, Guardians of the Elderly: An Ailing System, found “a dangerously burdened and troubled system that regularly puts elderly lives in the hands of others . . . then fails to guard against abuse, theft and neglect.” Subsequent media stories have made similar observations.

The OVC-funded project collected information on conservator exploitation, as well as the laws and practices in place to prevent, detect and act on such exploitation. This series of Background Briefs is intended to bring about greater public awareness and understanding of the issue. The briefs are aimed at a broad audience including practitioners, advocates, and policymakers, as well as courts and judicial staff.

You can view the entire set of eight briefs at http://www.eldersandcourts.org/~media/Microsites/Files/cec/OVC%20Briefs/OVC-Introduction.ashx.

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1 U.S. Government Accountability Office, The Extent of Abuse by Guardian is Unknown, But Some Measures Exist to Help Protect Older Adults, GAO-17-33, November 2016.
SUMMARY OF HEALTH CARE DECISION STATUTES

ENACTED IN 2018
(as of November 1)

Sasha D. Marseille, Legal intern, ABA Commission on Law and Aging, 2018.

In 2018, ten states adopted eleven amendments to their health decisions laws, creating, modifying, and amending rights and procedures affecting health care decision-making. The statutes affect advanced directives, default surrogate laws, Physicians Orders for Life-Sustaining Treatment (POLST), physician aid-in-dying laws, and registries. These summaries are intended to offer selected highlights and do not fully describe the laws in their entirety.

Each piece of legislation is coded to indicate the potential areas of health care decision making affected by the statute. The coding system is:

AD = Advance Directives
DNR = Do Not Resuscitate Orders
DS = Default Surrogate
POLST = Physician’s Orders for Life Sustaining Treatment, or its variants (e.g. MOLST, POST, MOST, and others).
Registry = State electronic registry for Advance Directives and/or POLST
PAD = Physician aid-in-dying legislation (also called physician-assisted suicide)

Alabama
(DNR, AD)
2018 Alabama Laws Act 2018-466 (H.B. 194). Approved March 28, 2018. Effective July 1, 2018. An Act, Relating to terminally ill minors; to amend Sections 22-8A-2, 22-8A-3, and 22-8A-7, Code of Alabama 1975; to add Sections 22-8A-15 to 22-8A-17, inclusive, to the Code of Alabama 1975; to create the Alex Hoover Act; to authorize the parent or legal guardian of a terminally ill or injured minor to execute, in consultation with the minor’s attending physician, a directive for the medical treatment and palliative care to be provided to a terminally ill or injured minor; to require the Department of Public Health, by rule and in conjunction with a task force, to establish a form for an Order for Pediatric Palliative and End of Life (PPEL) Care to be used by medical professionals outlining medical care provided to terminally ill minors in certain circumstances; to provide immunity to health care providers who provide, withhold, or withdraw medical treatment pursuant to an Order for PPEL Care; and to establish a temporary task force to work in consultation with the Department of Public Health to establish an Order for Pediatric Palliative and End of Life (PPEL) Care form.

Connecticut
(AD)
2018 Conn. Legis. Serv. P.A. 18-11 (H.B. 5148) (WEST). Approved May 24, 2018. Effective September 1, 201Under prior Connecticut law, C.G.S.A. § 19a-574, a woman’s health care wishes were automatically nullified if she were pregnant, forcing her to receive medical life-sustaining treatment when permanently unconscious, incapacitated, or terminally ill, despite contrary instructions in their advance directive. A woman filling out their advance directive may now indicate the following:
If I am pregnant:
(Place a check to indicate option (1) or
(2) or specify alternative instructions after (3))
(1) I intend to accept life support systems if my doctor believes that doing so would allow my fetus to reach a live birth.
(2) I intend this document to apply without modifications.
(3) I intend this document to apply as follows:

**Georgia**
(AD, POLST)
2018 Georgia Laws Act 419 (H.B. 803). Approved May 7, 2018. Effective August 1, 2018. The law defines the crime of “trafficking a disabled adult, elder person, or resident when such person, through deception, coercion, exploitation, or isolation, knowingly recruits, harbors, transports, provides, or obtains by any means a disabled adult, elder person, or resident for the purpose of appropriating the resources of such disabled adult, elder person, or resident for one's own or another person's benefit.”

Section 16–5–102.1(f) of the law provides the following exception:
This code section shall not apply to a physician nor any person acting under a physician's direction nor to a hospital, hospice, or long-term care facility, nor any agent or employee thereof who is in good faith acting within the scope of his or her employment or agency or who is acting in good faith in accordance with a living will, a durable power of attorney for health care, an advance directive for health care, a Physician Orders for Life–Sustaining Treatment form pursuant to Code Section 31–1–14, an order not to resuscitate, or the instructions of the patient or the patient's lawful surrogate decision maker.

-Hawaii-
(DS)
2018 Hawaii Laws Act 125 (H.B. 1812). Approved July 5, 2018. Effective October 1, 2018. The purpose of this Act is to clarify that health care surrogates appointed under section 327E–5, Hawaii Revised Statutes, may operate as authorized representatives in order to act on behalf of a patient during the Medicaid application process and for Medicaid related matters.

- • “Surrogate” means an individual, other than a patient's agent or guardian, authorized under this chapter to make a health-care decision or to act as a Medicaid authorized representative for the patient.
- • A surrogate may act as a Medicaid authorized representative, pursuant to federal and state Medicaid laws relating to authorized representatives, on the patient's behalf for the purposes of Medicaid, including but not limited to assisting with, submitting, and executing a Medicaid application, redetermination of eligibility, and other on-going Medicaid-related communications with the department of human services. For the purposes of Medicaid, the surrogate may access Medicaid records of the patient on whose behalf the surrogate was designated to act. For a surrogate to be able to act under this subsection, the surrogate shall agree to be legally bound by the federal and state authorities related to authorized representatives, including but not limited to maintaining the confidentiality of any information provided by the department of human services, in compliance with all state and federal confidentiality laws. The surrogate's status as an authorized representative for the purposes of Medicaid shall terminate when revoked by a patient who no longer lacks decisional capacity, upon appointment or availability of an agent or guardian of the person, or upon the patient's death.

-PAD-
2018 Hawaii Laws Act 2 (H.B. 2739). Approved April 5, 2018. Effective July 1, 2018. Establishes a regulated process under which an adult resident of the State with a medically confirmed terminal disease and less than six months to live may choose to obtain a prescription for medication to end the patient's life. Imposes criminal sanctions for tampering with a patient's request for a prescription or coercing a patient to request a prescription.

**Idaho**
(Registry)

- • File numbers, passwords and information in the files of the health care directive registry maintained by the secretary of state under section 39–4515, Idaho Code, are confidential and shall not be disclosed to any person other than to the person who executed the health care directive or the revocation thereof and to persons legal representatives, to the person who registered the health care directive or revocation thereof, and to physicians, hospitals, medical
personnel, nursing homes, and other persons who have been granted file number and password access to the documents within that specific file.

Michigan
(Registry)

2018 Mich. Legis. Serv. P.A. 208 (S.B. 897) (WEST). Approved September 20, 2018. Effective September 20, 2018. This bill directs the Department of Health and Human Services to seek a Medicaid waiver from the federal government that would impose work requirements and a copayment on beneficiaries. Section 105d. (1)(g) of the Act requires that enrollees be informed about advance directives and required to complete a department-approved advance directive unless they exercise option to decline. The advance directives received from enrollees as provided in this subdivision shall be transmitted to the peace of mind registry organization to be placed on the peace of mind registry.

Nebraska
(DS, PAD)

2018 Nebraska Laws L.B. 104. Approved and effective April 4, 2018 (not yet codified). This bill establishes for the first time a default surrogate for health care decisions, allows people to make health care decisions for certain adults and emancipated minors. A patient can designate a surrogate to make health care decisions on his or her behalf in the event that the patient becomes incapacitated by personally informing the primary health care provider.

In the absence of a designation, a member of the patient’s family can act as surrogate in the following descending order of priority: spouse, adult child, parent or adult sibling.

- If no family member is available to serve as a surrogate, an adult who has exhibited special care and concern for the patient and is familiar with the patient’s personal values may be designated as surrogate.

- If multiple people of equal standing assume authority as a surrogate but they disagree on a health care decision, the supervising health care provider will comply with the majority decision.

- A surrogate will be required to make health care decisions in accordance with the patient’s instructions and wishes, if known. Otherwise decisions must be made in the patient’s best interests, taking into account his or her personal values.

- Decisions made by a health care surrogate will not require judicial approval.

The bill specifically prohibits an owner, operator or employee of a health care facility at which the patient is residing or receiving care from acting as a surrogate. An exception can be made if that person is related to the patient by blood, marriage or adoption.

Oregon
(AD)

2018 Oregon Laws Ch. 36 (H.B. 4135). Effective March 16, 2018 (not yet codified). Modifies statutory advance directive form. Creates Advance Directive Adoption Committee (ADAC) consisting of Long Term Care Ombudsman and 12 members appointed by Governor. Requires ADAC to adopt advance directive form and to review form at least once every four years. Establishes components of form that cannot be changed by ADAC. Establishes alternative form that may be used until January 1, 2022. Directs ADAC to submit adopted form to interim committee of Legislative Assembly related to judiciary on or before September 1 of even-numbered year subsequent to adoption of form. Allows advance directive form to be notarized or witnessed by two adults other than health care provider or health care representative. Continues effectiveness of advance directives completed prior to effective date of Act and allows good-faith execution of older advance directive forms.

SECTION 3 of the act states that at a minimum, the form of an advance directive adopted under this section must contain the following elements:

(a) A statement about the purposes of the advance directive,
(b) A statement explaining that to be effective the advance directive must be:
   - Accepted by signature or other applicable means; and
   - Either witnessed and signed by at least two adults or notarized.
(c) A statement explaining that to be effective the appointment of a health care representative or an alternate health care representative must be accepted by the health care representative or the alternate health care representative.
(d) A statement explaining that the advance directive, once executed, supersedes any previously executed advance directive.
(e) The name, date of birth, address and other contact information of the principal.
(f) The name, address and other
contact information of any health care representative or any alternate health care representative appointed by the principal.

(g) A section providing the principal with an opportunity to state the principal's values and beliefs with respect to health care decisions, including the opportunity to describe the principal's preferences, by completing a checklist, by providing instruction through narrative or other means, or by any combination of methods used to describe the principal's preferences

(h) A section where the principal and the witnesses or notary may accept by signature or other means, including electronic or verbal means, the advance directive.

(i) A section where any health care representative or any alternate health care representative appointed by the principal may accept the advance directive by signature or other means, including electronic or verbal means.

**Vermont**

(AD)

2018 Vermont Laws No. 121 (H.690). Approved May 5, 2018. Effective May 5, 2018, amends parts of VT ST T. 18 § 9701 through § 9718. This act amended the institutional signing requirements for advance directives by requiring that, at the time of execution, where the principal is being admitted to or is a resident of a nursing home or residential care facility, the directive is not valid unless one of the following individuals explains the nature and effect of the advance directive to the principal and signs a statement affirming that he or she has provided the explanation:

(A) an ombudsman;
(B) a recognized member of the clergy;
(C) an attorney licensed to practice in this State;
(D) a Probate Division of the Superior Court designee;
(E) an individual designated by a hospital pursuant to subsection 9709(d) of this title;
(F) a mental health patient representative;
(G) an individual who is volunteering at the nursing home or residential care facility without compensation and has received appropriate training regarding the explanation of advance directives; or
(H) a clinician, as long as the clinician is not employed by the nursing home or residential care facility at the time of the explanation.

For a patient admitted or being admitted to the hospital, the following persons may fulfill this duty:

1) an ombudsman;
2) a recognized member of the clergy;
3) an attorney licensed to practice in this State;
4) a Probate Division of the Superior Court designee;
5) an individual designated by the hospital pursuant to subsection 9709(d) of this title; or
6) a mental health patient representative.

It further specifies that a health care provider may serve as a witness to a principal's execution of an advance directive, as may the individual who explains the nature and effect of the advance directive if the principal is being admitted to or is a patient in a hospital, or is being admitted to or is a resident of a nursing home or residential care facility, at the time the advance directive is being executed.

The act also expands the description of a clinician who may have signed a patient's do-not-resuscitate (DNR) order or clinician order for life-sustaining treatment (COLST) to include a clinician who treated the patient outside Vermont and held a valid license to practice in the state in which the patient was located at the time the DNR/COLST was issued.

**Virginia**

(DS)

2018 Virginia Laws Ch. 565 (S.B. 222). Approved March 30, 2018. Effective July 1, 2018. An Act to amend and reenact §§ 32.1–127 and 54.1–2990 of the Code of Virginia, relating to medically or ethically inappropriate care not required. Requires that each hospital that is equipped to provide life-sustaining treatment shall develop a policy governing determination of the medical and ethical appropriateness of proposed medical care, which shall include:

- a process for obtaining a second opinion regarding the medical and ethical appropriateness of proposed medical care in cases in which a physician has determined proposed care to be medically or ethically inappropriate;
- provisions for review of the determination that proposed medical care is medically or ethically inappropriate by an interdisciplinary medical review committee and a determination by the interdisciplinary medical review committee regarding the medical and ethical appropriateness of the proposed health care; and
- requirements for a written explanation of the decision reached by the interdisciplinary medical review committee, which shall be included in the patient's medical record. Such policy shall ensure that the patient, his agent, or the
person authorized to make medical decisions pursuant to § 54.1–2986 (a) are informed of the patient's right to obtain his medical record and to obtain an independent medical opinion and (b) afforded reasonable opportunity to participate in the medical review committee meeting. Nothing in such policy shall prevent the patient, his agent, or the person authorized to make medical decisions pursuant to § 54.1–2986 from obtaining legal counsel to represent the patient or from seeking other remedies available at law, including seeking court review, provided that the patient, his agent, or the person authorized to make medical decisions pursuant to § 54.1–2986, or legal counsel provides written notice to the chief executive officer of the hospital within 14 days of the date on which the physician's determination that proposed medical treatment is medically or ethically inappropriate is documented in the patient's medical record. 

- If, at the end of the 14–day period, the conflict remains unresolved despite compliance with the hospital's written policy established pursuant to subdivision B 21 of § 32.1–127 and the physician has been unable to identify another physician or facility willing to provide the care requested by the patient, the terms of the advance directive, or the decision of the agent or person authorized to make decisions pursuant to § 54.1–2986 to which to transfer the patient despite reasonable efforts, the physician may cease to provide the treatment that the physician has determined to be medically or ethically inappropriate subject to the right of court review by any party.

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