

AHLA



**A Guide To
Legal Issues
In Life-Limiting
Conditions**

A GUIDE TO LEGAL ISSUES IN LIFE-LIMITING CONDITIONS

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—From a declaration of the American Bar Association



TABLE OF CONTENTS

I. INTRODUCTION.....	6	L. Resident Rights.....	24	
II. PLANNING FOR THE FUTURE.....	7	M. Costs.....	24	
A. Advance Directives.....	8	N. Family Involvement.....	24	
B. Long Term Care Insurance.....	11	O. Nursing Home Compare.....	25	
C. Family And Medical Leave Act.....	13	VI. WHAT TO EXPECT UPON ADMISSION TO A	HEALTH CARE FACILITY.....	25
D. Elder Care Benefits.....	14	A. Level of Care Required.....	25	
III. INDEPENDENT LIVING AT HOME OR IN A	RETIREMENT COMMUNITY.....	B. Payment.....	25	
A. General Considerations.....	14	C. Admission Policies and Applicable Laws.....	25	
B. Agencies.....	15	D. Admissions Agreements.....	25	
C. Independent Contractors.....	17	VII. PALLIATIVE AND HOSPICE CARE.....	27	
D. Direct Employment of Personal Care Assistants.....	17	A. Physician Orders for Life-Sustaining Treatment.....	27	
IV. LONG TERM CARE OPTIONS.....	18	B. Palliative Care.....	28	
A. Independent Senior Housing Units With or Without Ancillary Services.....	19	C. Hospice Care.....	29	
B. Adult Daycare.....	19	VIII. PACE.....	31	
C. Assisted Living.....	19	A. Available Services Offered Through PACE.....	32	
D. Skilled Nursing Facilities.....	20	B. PACE Participation Requirements.....	32	
V. LONG TERM CARE FACILITY SELECTION.....	21	C. PACE Organization Requirements.....	32	
A. General Considerations.....	21	IX. MEDICAID WAIVER PROGRAM.....	32	
B. Obtaining Referrals.....	21	APPENDIX A.....	34	
C. Facility Visits.....	22	Selected Health Care Glossary.....	34	
D. Licensing and Accreditation.....	22	APPENDIX B.....	41	
E. Location.....	22	Internal Revenue Service's Twenty-Factor Test to Distinguish Between Employees and Independent Contractors.....	41	
F. Facility Appearance and Design.....	22	APPENDIX C.....	43	
G. Staff Attitudes.....	23	Pain Management and Attendant Symptoms.....	43	
H. Bedrooms and Bathrooms.....	23	AUTHOR BIOGRAPHIES.....	50	
I. Dining.....	23			
J. Activities.....	23			
K. Resident Care Services.....	24			

PREFACE

A Guide to Legal Issues in Life-Limiting Conditions provides an overview of the principal legal and practical issues that arise for individuals dealing with a life-limiting condition. Such individuals find themselves facing a host of complex decisions, often at a time when they are in crisis. In evaluating long term care options, many seniors and their families fall prey to the “chandelier effect” where they incorrectly conclude that a beautiful facility with attractive surroundings ensures they will receive high quality services. The questions in this *Guide* are designed to assist individuals accurately assess the type, frequency, and quality of services offered by health care providers as well as the related costs. As an aid to the planning process, this *Guide* is organized around the continuum of care, beginning with healthy individuals who are able to live at home to independent retirement communities, assisted living, long term care, and a possible return to the home with the aid of hospice services.

In addition to identifying the key decision areas along what might be considered the ‘customary’ chronic care continuum, the *Guide* stresses that individuals should plan for the future and make informed choices now to ensure that their wishes are known at a future time when their physical and/or mental functioning may be impaired. The need for this type of planning was brought home in 2004-2005 through news coverage of the complex legal, medical, and bioethical issues in the case of Terri Schiavo.



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AHLA also gratefully acknowledges the contribution of Ira R. Byock, M.D. in reviewing this *Guide* and authoring the Foreword. Finally, I wish to thank my mother, Patricia A. Belmont, for being an exemplary role model in meeting the challenges associated with having a life-limiting condition and for being my personal inspiration for the development of this *Guide*.

If you have suggestions for future publications, please contact Katherine Wone, Senior Legal Editor for Member Publications and Resources, at kwone@healthlawyers.org.

Elisabeth Belmont

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FOREWORD

The American Consciousness Regarding the End of Life

“I don’t want to think about it!”

This exclamation encapsulates our culture’s orientation toward dying and death. We act as though, if we just ignore these morbid (or should I say *mortal*) realities, they will go away. For most of life, death remains an abstract concept, lurking somewhere in the murky darkness beyond our minds’ eyes. By refusing to think or talk about it, we stay in the self-perpetuating dark. We remain fearful, consciously or subconsciously, about life’s eventual end, knowing little about what is likely, what we want, or what is possible.

As a long-term strategy, avoidance, of course, is doomed to fail, since death, ultimately, is unavoidable. The cultural and social taboos that keep us from preparing for the future make dying and death, when they come, all the harder.

In times of health, individuals’ aversion to thinking about death often takes the form of dark humor. “I want to sink that birdie on the 18th hole and, ‘ZAP!’ be struck by lightning.” One day while pleading my case in a minor moving violation before a judge in traffic court, he glanced at my paperwork and asked me what a “palliative care physician” did. When I explained that I care for people with advanced, life-limiting illness, he said, “Well, I have cancer, but I’ll need none of that.” When I gingerly asked him why not, he replied with a wry smile, “I’m not going to die. Direct assumption; I’m going straight to heaven.” I was not in a position to argue.

Not all such deflections are funny. Sitting at a kitchen table discussing a news story about President Reagan’s dementia, Christopher Reeve’s paralysis, or Terry Schavio’s persistent vegetative state, a father may flippantly remark, “If I end up like that, just shoot me,” without realizing how his words may ring in the ears of his spouse and children months or years later. If a stroke or car accident renders him suddenly unable to speak or eat—with recovery possible, at least partially, but uncertain—such memories will not prove helpful in making substitute judgments, but instead can sow seeds of doubt, confusion, and family conflict.

Despite what one might expect, it doesn’t always get easier to talk about these matters when someone is ill. Ironically, at least for some people, it becomes harder. Denial grows increasingly defiant as evidence of their mortality mounts. I regularly meet people in the hospital who have developed complications

of long-standing congestive heart failure, or emphysema or cancer. Many have never discussed advance directives with their physicians. No matter how sensitively I recommend that they consider doing so now, a common plaintive query is, “Am I *that* bad off?” as if making contingency plans for future incapacity and dying can make the unwanted come true. In this century of scientific achievement and in these centers of medical sophistication, superstition reigns.

The resistance is not restricted to clinical relationships or settings. When an ill family member or friend says, “I don’t know if I’m going to make it much longer,” our culturally ingrained tendency is to respond, “Don’t talk like that.” By doing so, we avoid what might have been an intimate, heartfelt discussion. Instead of recognizing the signal of her willingness to talk about dying, we protect ourselves (but only momentarily) from the pain of loss.

Social science research has pierced the shell of denial that surrounds illness, dying, and death. Surveys consistently find that people most fear being a burden to their family and others, and loss of personal control. Fear of pain usually runs a distant third.

These days, it is common for a patient to say they want to stay in the hospital to die, or go to a nursing home, or even preempt death with suicide to spare their family from the pain of their illness. I assure them that it’s too late. Their family already owns this pain. Although disease strikes one individual, it affects everyone who loves them. Dying alone or by one’s own hand is not likely to lessen a family’s pain. When illness strikes, we can care for those who love us by sharing the sadness and pain of illness and impending loss together. If we want to diminish our family’s burden in the future, we can thoughtfully prepare our practical matters and personal affairs earlier, when we have the physical energy and emotional resources to do so.

When my mother died suddenly and unexpectedly in November of 2003, my sister and I knew exactly where to find the papers—her will, titles, accounts, and certificates—we needed to manage her affairs. Over the months that followed, I silently thanked her a hundred times for taking such good care of us. Even in death, she was teaching me by example how to be a good parent to my daughters.

My perspective derives from practicing emergency medicine earlier in my career and continuing to work in palliative care. In emergency departments, after someone died suddenly of catastrophic illness or injury, I often struggled to find words and ways to comfort a family as they gasped, unprepared, nearly drowning in grief. In contrast, in home hospice or



hospital-based palliative care, I regularly work with patients and families who are tending to the practical and emotional work of life completion, and whose sadness is suffused with a sense of celebration for the gift of the lives and relationships, grief unencumbered by doubts of things left unsaid.

The denial of death as part of our human reality—to such an extreme as to avoid contemplating and rationally preparing for its inevitability—is psychologically and culturally immature. It is time for American culture to grow the rest of the way up. We are mortal. That means that we will inevitably die—and so will everyone we love. As unwanted and unhappy as these facts may be, I suggest we get over it, and get on with making the best of life in its fullness.

As hard as it is to contemplate one's own illness and dying, or the infirmity and deaths of people we love, preparation is essential. The hard truth is that 80% of us will be physically dependent on others during the last months, weeks, or days of life. That includes needing help for basic daily activities, including the biological needs of eating, personal hygiene, and elimination. Like it or not, when the day comes when we have lost the capacity to speak for ourselves, someone we know and trust will be asked to speak for us.

We can't alter the inherent vulnerability and frailty of being human; nevertheless, we can project our personal values and choices forward. By being proactive, not only can we protect our choices, but we can also diminish the burden of decision-making our friends and family feel.

Medical and legal professionals can assist the individuals who we serve in sorting through available options for medical treatments, living arrangements, and ongoing care. We can help them in weighing the advantages and disadvantages of each option, and in deciding what choices best fit their values and their (and their family's) situation. By doing so, such professionals serve to provide patients and families with the information about their rights and what is reasonable to expect in each setting, as well as to help them gain access to the facilities and services they need.

Advance directives have fallen from grace in academic circles of late. It's true that, despite decades of efforts to educate the professions and public, few individuals have them. It's also true that, even when advance directives have been completed, they often can't be found. Regrettably, even when they are in the medical record, they may be ignored. These problems cannot be denied. Yet, with all their challenges and imperfections, it is also true that in many situations across the country every day, advance directives are of inestimable value to patients, and even more so, to families. An advance directive that is well

considered and crafted can dissolve family conflicts before they arise. In so doing, not merely is conflict averted, but family members are free to attend to the inherently difficult tasks of caring and of grieving.

It's not sufficient for an individual's advance directives to merely comply with prevailing statutes; to be most useful, it must be crafted in a manner that is meaningful in contemporary clinical settings and situations. Advance directives are most useful when the choices encompassed are based on conversations within families.

Attorneys who approach end-of-life planning as a legal exercise in the drafting of documents miss the critical opportunity to model for their clients that it is safe to think about and talk about life's end. This is a service that befits the title of counselor. In modeling that these difficult topics are approachable, the attorney can transfer confidence to their clients and can encourage them to discuss their values and choices with their families.

A Legal Guide to Life-Limiting Conditions is a rich resource for practicing attorneys and their clients, containing pertinent facts and real-world guidance savvy that will make it an advocacy tool for patients and their families. It provides key information about patient's rights, health agencies, and programs, including assisted living, long term care, home health, palliative and hospice care, Medicare, and health insurance. It lists critical questions to ask in navigating the dizzying maze of details that surround the care of an aged grandparent, frail parent, or a seriously ill or injured loved one or close friend. The information can help ensure that an individual or the affected person they love receives the best care possible.

This *Guide* deserves a place on the desk of any attorney, physician, nurse case manager, or social worker who helps elderly or ill clients think about and plan for the future. It sits on mine.

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Grantham, N.H.

*Dr. Byock is the author of *Dying Well*, *The Four Things That Matter Most*, and *The Best Care Possible*. Dr. Byock's website, www.dyingwell.org, provides a wealth of information for individuals who face a life-limiting condition or who care for a loved one with a life-limiting condition.*

A GUIDE TO LEGAL ISSUES IN LIFE-LIMITING CONDITIONS

I. INTRODUCTION

As Virgil noted, “The greatest wealth is health.”¹ When we are healthy, we take for granted our ability to manage our lives and make decisions. It is, however, when we are healthy and least likely to think about end-of-life issues that we should plan for a future when our physical and/or mental functioning may be impaired in order to ensure that our wishes are followed.

It is therefore prudent to understand applicable federal and state laws and regulations that affect our own decision-making capacity or that of loved ones affected by life-limiting conditions. For the purposes of this guidebook, the term “life-limiting condition” is defined as a medical or surgical condition with significant functional impairment that is not likely (according to medical authorities) to be reversible by curative therapies and is anticipated in its ordinary course to progress towards death despite attempts at curative therapies or modulation, the time course of which may or may not be determinable through reasonable medical prognosis. Such conditions affect both the young and elderly. Families may

be ill-equipped to care for them in their homes and, thus, require assistance through home health or institutional care. It is important to remember that all individuals have unique circumstances, and the appropriate fit for the individual’s needs will be determined in part by those circumstances.

Individuals with life-limiting conditions face several complex decisions, often at a time when they are in crisis. This guidebook will provide you with an overview of key legal and practical issues that arise when caring for someone with a life-limiting condition. To help you plan, this guidebook is organized around the continuum of care, beginning with the healthy individual who can live at home, to independent retirement communities, assisted living, long term care (LTC), to an eventual return to the home with the aid of hospice services.

Because each individual’s situation is unique, this guide does not provide legal advice, but rather identifies the relevant issues for consideration. Please consult an attorney experienced in elder care issues and estate planning for specific issues.



1. Virgil. www.quote garden.com.



II. PLANNING FOR THE FUTURE

It is important to engage in appropriate estate planning in the event of death or disability, and to collect and organize important documents in one location known by a responsible spouse, life partner, relative, or friend. This will facilitate the handling of personal affairs by others who may be required to step in without advance knowledge and ensure that an individual's final wishes are carried out in accordance with his or her desires. In addition, individuals are encouraged to plan ahead and write a letter of instruction to designated family members and/or their personal representative or executor detailing their specific desires about the settlement of their estate and business affairs regarding items not covered in a will and trust. Such written instructions will minimize uncertainty, confusion, and possible oversights following an individual's death. It also is useful to prepare an index so that others will be certain they have all relevant documents in hand. The person responsible for placing the patient in a hospital or LTC facility will need access to some of these documents. Issues to address in a letter of instruction include the following:

1. Funeral and burial arrangements (*e.g.*, where, by whom, what kind, and at what cost);
2. Anatomical gifts (*e.g.*, identify the nature and location of any anatomical gift declarations made);
3. Memorials and contributions (*e.g.*, identify what organizations or institutions might be appropriate recipients of memorials or charitable donations made in memory of the affected individual);
4. Preparation of obituary and identification of which newspaper(s) it should be sent;
5. Notifications of friends, relatives, business associates, and colleagues in charitable or civic groups to be contacted upon the affected individual's death, noting any particular requests or messages to be given and listing their current addresses and phone numbers;
6. Location of any safe-deposit box and its key;
7. Location of the will, trust, and related estate planning documents (including any extraneous writings incorporated in an individual's will, as well as durable and financial power of attorney);
8. Medical and hospital insurance coverages (including, without limitation, LTC insurance and disability insurance) and location of the policies and related identification cards;
9. A list of physicians and their contact information, as well as current prescription and non-prescription medications and any medication allergies;
10. Social Security and Veterans Administration benefits (*i.e.*, identify current or potential benefits);
11. Life insurance (indicating where policies are located, and what steps should be taken to collect policy proceeds);
12. Location and explanation of title documents and other records relating to an individual's assets (*e.g.*, deeds, stocks, bonds, bank accounts and deposits, retirement plans, and vehicle titles);
13. Identify obligations involving periodic payments (*e.g.*, home mortgage, car loans, and other debts), including amount and to whom payable;
14. House or apartment insurance policies, alarm information, and list of individuals responsible for providing maintenance;
15. Identify the responsible attorney and current professional advisers (including accountant, financial advisor, stock broker, trust officer, and insurance agent);
16. Identify key employees and professional colleagues to keep business operating until sale, and any shareholder's agreement or buy-sell agreement;
17. Identify digital assets including digitally stored content either locally or on devices accessed via the Internet "in the cloud" (*e.g.*, images, photos, videos and text files) and online account(s) owned by an individual (*e.g.*, email accounts, social media profiles, and social networking profiles); and
18. List of passwords for electronic media and devices.

Individuals should review and update letters of instruction periodically to ensure they are complete and current. Additionally, individuals should discuss the contents of the letters of instruction with the persons to whom such letters are addressed to clarify or augment the instructions and answer any questions. Finally, it is advisable to give letters of instructions once written to the addressees so that they will be aware of any actions that need to be taken promptly after the individual's death as well as the location of all relevant personal papers and assets.

A. Advance Directives

There are various kinds of advance directives; some of the more commonly known examples include a living will and durable power of attorney (DPOA) for health care decision-making. Advance directives are governed by state law, which often differs in applicable requirements. A patient's decision-making capacity is decided by the individual's physician, which is related to functional aspects, while competency is determined by the judicial system based on legal considerations.

A living will states the wishes of the person creating the document and instructs family and health care providers on how to proceed if the person is unable to speak for herself. Generally, a living will is effective only if the person is terminally ill although this may vary with applicable state law and the terms of the document.

On the other hand, a DPOA for health care allows a person to appoint someone to make health care decisions for the designating individual when he or she is unable to make decisions personally. Usually, a DPOA for health care is effective only after a person has been deemed incapacitated; the criteria and method of that determination is controlled by state law. The terminology varies from state to state. In general, however, the person creating the DPOA is usually called the "principal." The person appointed to act on behalf of the principal is the "attorney-in-fact." The principal need not be terminally ill for a DPOA for health care to be in effect. The person can be in a coma or a persistent vegetative state (PVS)—a condition that Nancy Cruzan suffered and whose case was decided by the United States Supreme Court²—or under any other situation or conditions the principal designates. A similar case involving a PVS is that of Terri Schiavo, a young woman in Florida. Neither Ms. Cruzan nor Ms. Schiavo had an advance directive in place. As a result, their families have had to litigate the health care decisions of their loved ones for years.

A general power of attorney (POA) allows an individual to make business and financial decisions for another (the "principal") and can be effective immediately without the principal being declared incapacitated. A general POA is different from a health care DPOA as the former applies only to business and financial issues and will remain effective if the principal becomes incapacitated. A guardian is court-appointed and makes decisions regarding the care and custody of an individual (or ward). A conservator also is court-appointed and makes decisions specifically regarding the person's (or ward's) finances.

Individuals should consider the following issues relating to advance directives:

1. General Considerations
 - a. What is the difference between a patient being incompetent and incapacitated based on the law of the governing jurisdiction? Can this status change?
 - b. Is the proposed attorney-in-fact in good health and thereby likely to be available when the principal is incapacitated?
 - c. Does state law allow for successors or alternatives?
 - d. Under state law, is the proposed attorney-in-fact required to be a resident of the same state as the principal?
 - e. Is the proposed attorney-in-fact aware of the principal's wishes?
 - f. Does the proposed attorney-in-fact agree with the principal's wishes?
 - g. Will the proposed attorney-in-fact carry out the principal's wishes, even if the proposed attorney-in-fact does not share the principal's views?
 - h. Does the principal desire any of the following? If yes, under what circumstances and for how long (*e.g.*, immediately after a stroke, but to be discontinued if no improvement is seen after a certain period of time; if the principal has Alzheimer's disease, cancer, or a similar terminal condition)?
 - Cardiopulmonary resuscitation (CPR);
 - Ventilator;
 - Antibiotics;
 - Hospitalization; or
 - Hospitalization for correctable injuries, such as a broken bone.²
 - i. Does the principal want artificial nutrition and hydration? If so, under what conditions? Can the artificial nutrition and hydration be discontinued at a later date if there is no evidence of improvement or decline?
 - j. Does the principal have a thorough understanding of the medical issues that may be involved?
 - k. Has the principal considered that sometimes one's wishes change over time or as a result of having developed a particular condition?

2. *Cruzan v. Director, Missouri Department of Public Health*, 497 U.S. 261, 110 S.Ct. 2841, 111 L.Ed.2d 224 (1990).



- l. What is the role of the principal's physician in the decision-making process?
 - m. Do the terms of the DPOA for health care allow the attorney-in-fact to make decisions based not only on the principal's express instructions, but also on his or her knowledge of the principal's value system, taking into consideration how the principal would react if confronted with changed conditions, medical advances, or other unanticipated circumstances?
 - n. Should only one person be appointed as the principal's attorney-in-fact?
 - If more than one is appointed, what happens if they disagree on how to proceed?
 - What happens if one person is unavailable or unable to make the decision?
 - o. Will the advance directive be applicable if the principal moves to another state?
 - p. Will the attorney-in-fact be available to make decisions if the principal moves to another state? If not, is there an alternate choice?
 - q. Under what circumstances should an alternate take over?
 - r. What happens if the first choice resigns or is unable to make the decisions for the principal?
 - s. Under the law of the principal's state, when does a DPOA for health care take effect?
 - t. How many physicians must certify that the principal is incapacitated before the DPOA for health care takes effect? Does state law allow other professionals (*e.g.*, psychologists) to make this certification?
 - u. Who decides which doctors determine capacity?
 - v. How often should advance directives be reviewed to see if they still comport with the principal's wishes?
 - w. Should the attorney-in-fact control the principal's finances as well?
 - x. Should the attorney-in-fact be the executor of the principal's estate? Is there a potential conflict of interest?
 - y. Should the attorney-in-fact be able to control who visits the principal? For example, assume the principal's daughter is the attorney-in-fact regarding health care decisions. Assume further the principal has a good relationship with a stepson, but the daughter does not. Can the daughter, acting as health care decision maker, keep the stepson from visiting the principal? Can the daughter keep the stepson in question from taking the principal out of the health care facility for a short leave of absence (*e.g.*, home for Thanksgiving dinner)? Can the stepson receive information about the principal's state of health without the daughter's permission?
 - z. Does the authority of an attorney-in-fact continue after the principal's death? If so, under what circumstances (*e.g.*, principal as organ donor; principal representation in the event of an autopsy)?
 - aa. Does the attorney-in-fact have to be a family member or can she be an unrelated person who shares the principal's beliefs?
 - bb. What is the medical opinion of the patient's attending physician with respect to the patient's capacity?
 - cc. Does the patient, family, principal, and attorney-in-fact understand the patient's medical condition?
2. DPOA for Health Care vs. Guardian/Conservator
 - a. When should the arrangement of guardianship or conservatorship be used instead of a DPOA for health care?
 - b. When is one more appropriate than the other?
 - c. Does the appropriate jurisdiction have a surrogate decision maker statute that allows someone to make health care decisions for a person who does not have an advance directive? If so, is a guardianship necessary?
 - d. Can a guardian move the ward out of state?
 - e. Is a guardianship still valid in another state?
 - f. Is a conservatorship still valid in another state?
 - g. Can a guardian agree to a do-not-resuscitate (DNR) order?
 - h. Can a conservator agree to a DNR?
 - i. What might happen if the guardian refuses to serve in this role or chooses not to continue to serve?
 - j. Who should file for guardianship?
 - k. When is it appropriate to seek a guardianship or conservatorship?
 - l. What is required under the applicable state law to obtain a guardianship and conservatorship over another person?

- m. Who has the primary authority when both a guardian or conservator and a DPOA for health care have been established?
 - n. How can a guardianship or conservatorship be terminated? What is the state law's procedure if the guardian/conservator appears to act in a manner inconsistent with the person's best interest or prior expressed views?
 - o. Has an experienced estate attorney been consulted?
 - p. What are the anticipated legal fees and other costs to establish a guardianship or conservatorship?
3. DPOA for Health Care vs. General DPOA
- a. What is the difference between a general DPOA and a DPOA for health care? Are both necessary?
 - b. Is there a way to limit the scope of the general DPOA or a DPOA for health care?
 - c. Does the designation of a DPOA for health care need to be recorded with any state agency? If so, are witnesses required? What limitations exist on who can be a witness? Must the principal's signature be notarized to be valid? (Note: In some states, for example, some individuals are prohibited from serving as witnesses [*e.g.*, close family members, persons likely to inherit from a principal's estate, health care providers, and insurance company personnel].)
 - d. What is the effect of a DPOA for health care that does not meet all state law requirements but nevertheless contains instructions for care and names an attorney-in-fact?
 - e. What is required to revoke a DPOA for health care?
 - f. Can a DPOA for health care be revoked if the principal is incapacitated or incompetent? If so, how?
 - g. What is the procedure if the attorney-in-fact violates the principal's best interests?
 - h. What is the procedure if it appears that the principal, although not fully competent to make medical decisions, seems to have changed his or her mind about specific instructions or seems to disagree with a proposed medical plan?
 - i. What items must be included in the general DPOA or the DPOA for health care to render those items effective? (Note: For example, some states require a DPOA for health care to specifically include the removal of, or decision not to institute, artificial nutrition and hydration or a decision to withhold or withdraw certain treatments if that decision would or could result in the person's death. In that case, if the document establishing the DPOA for health care is silent on these issues, then the attorney-in-fact has no legal authority to request removal of a feeding tube even after it is clear the principal is in a PVS with no reasonable hope of recovery.)
 - j. Can the attorney-in-fact pursuant to a DPOA for health care, agree to a DNR order?
 - k. Can the attorney-in-fact, pursuant to a general DPOA, agree to a DNR order?
 - l. Should a principal establish both a DPOA for health care and a living will? Can those be included in the same document? (Note: It is prudent to provide general instructions and examples of the principal's wishes in a document, but to allow the attorney-in-fact sufficient discretion to make decisions based on the principal's known value system in the context of changed circumstances and advances in medical science.)
 - m. Does the DPOA contain appropriate language to allow authorized individuals to receive protected health information consistent with applicable state and federal laws and regulations relating to the privacy and confidentiality of medical records and personal health information? (Note: Individuals may wish to make the DPOA effective immediately upon execution because of the Health Insurance Portability and Accountability Act³ (HIPAA) if the applicable state laws do not require incapacity before the DPOA is effective. If the agent's power only becomes effective upon incapacity, the principal's physician may not agree to speak with the agent because the power has not yet become effective and the agent would not be able to speak with the physician to obtain an evaluation of the principal. The DPOA clearly can state that the agent cannot override the principal's wishes as long as the principal has decisional capacity.)
 - n. Under state law, can the attorney-in-fact, pursuant to a general DPOA, have access to the principal's medical records?
 - o. Should the list of authorized individuals who can receive protected health information in the DPOA include:
 - An agent designated in a DPOA for the purpose of determining the principal's capacity as defined in the power of attorney or by governing law;

3. 42 U.S.C. §§ 1320d-1329d-8; 45 C.F.R. Parts 160 and 164 as amended.



- The trustee, or a designated successor trustee, of any trust of which the principal is a beneficiary or for the purpose of determining the principal's capacity as defined in the trust;
 - Any owner of a business of which the principal also is an owner for the purpose of determining the principal's capacity as defined in the partnership or operating agreement;
 - The principal's lawyer for the purposes of determining the principal's capacity to make *inter vivos* gifts, to execute estate planning documents, and whether and to what extent a guardianship or other protective proceeding is necessary or desirable; and/or
 - A guardian *ad litem*, if one is appointed, for the purpose of determining whether and to what extent a guardianship or other protective proceedings for the principal is necessary or desirable.
4. Surrogate Decision Makers
- a. Is the designation of surrogate decision makers available in the principal's state?
 - b. Who is likely to comprise the class of persons permitted to make health care decisions for the individual?
 - c. Are those persons likely to know the individual's wishes for care at the end-of-life or in life-limiting circumstances?
5. Financial Considerations
- a. When is the appropriate time to seek sound financial planning?
 - b. Should an elder care lawyer or an experienced estate lawyer be consulted?
 - c. What other legal services are available for the elderly if finances are an issue?
 - d. What medical expenses will Medicare and supplemental health insurance cover?
 - e. Is there a way to set up an estate to minimize inheritance taxes after a diagnosis of a terminal illness has been made, or after the principal has been declared incompetent?
 - f. Do any transfers on death provisions for personal property or real estate exist in the principal's state?
 - g. If a long term care facility is required, what happens when an individual's private resources are exhausted and no Medicaid bed is available or the facility is not licensed for Medicaid beds? What are the consequences if the principal is forced to move?

- Under state law, can a LTC facility designate a "spend down" bed?
 - Are the facility's beds both Medicare- and Medicaid-certified?
- h. How does HIPAA affect the ability of health care providers to discuss medical information with third parties?

B. Long Term Care Insurance

LTC insurance can help protect individuals from the catastrophic costs of long term care. It may also allow them to retain control of their assets and maintain their own independence and dignity. There are no "standard" LTC insurance benefits. Various types of policies provide certain coverage for care offered by home care agencies, senior centers, adult daycare centers, traditional nursing homes, and retirement communities that provide a continuum of care. Consumers should carefully analyze their reasons for purchasing LTC policies and their ability to pay for them for the balance of their lives, given that many such policies are cancelled by policyholders on fixed incomes as a result of annual premium increases that exceed their incomes.

1. What coverage is available?
 - a. Is such coverage constructed as a fixed dollar amount each day (or month) for which services are received?
 - b. Is coverage provided as a percentage of the cost of services of a specified amount to cover the actual charges for care?
 - c. Is coverage included as a benefit in certain individual life insurance policies?
 - d. Does coverage include shared benefit plans that also cover spouses or domestic partners?
 - e. Does the coverage include inflation protection, allowing the policy's benefit to increase to keep pace with the rising cost of care offered (*e.g.* daily benefit increases by a fixed percentage)?
 - f. What is the premium for the desired coverage? Are the premiums for a fixed period or do the payments continue until the individual qualifies for the benefits?
2. What benefits are offered?
 - a. What level of licensed care is provided (*e.g.*, skilled nursing care, licensed rehabilitation therapists, custodial care or non-licensed services, and/or homemaking services)?
 - b. Where are services provided (*e.g.*, in-home; skilled or intermediate-care facilities; assisted living facilities)?

- c. Does the policy use the same terminology as the licensure status? For example, if the policy pays for an assisted living facility and the individual's state does not have such a category but does have another similar licensed category, will that licensed facility be covered?
 - Are services that are provided by businesses which provide custodial care covered?
 - Are services that are delivered in the home covered? If so, does the coverage extend to services rendered by a family member?
3. Are any of the following *not* covered:
 - a. Mental disease and nervous disorders (including Alzheimer's disease);
 - b. Addictions to drugs and alcohol;
 - c. Injuries and illnesses caused by war;
 - d. Treatment for injuries and illnesses paid by the government;
 - e. Services provided by family members in the home;
 - f. Injuries that are self-inflicted (*e.g.*, suicide attempts, injuries from dangerous activities such as skydiving or scuba diving);
 - g. Injuries occurring outside the United States; and/or
 - h. Injuries occurring at work that are covered by worker's compensation.
 4. What are the limits on benefits?
 - a. What is the cap, if any, on the daily rate/monthly rate paid to LTC facilities?
 - b. What is the limit, if any, on the daily rate for home care or on the number of hours at a specific rate per hour?
 5. When do the benefits begin?
 - a. What is the elimination period (*i.e.*, the number of care days for which an individual is required to pay) prior to the payment of benefits under the policy?
 - b. Who determines whether the individual is entitled to benefits (*e.g.*, the individual's primary care physician, the insurance carrier, or a physician required by the insurance carrier)?
 - c. Does this determination involve consideration of activity-specific criteria, such as a condition wherein the individual is unable to perform three or more activities of daily living (ADL) (*e.g.*, bathing, dressing, toileting, transfers to and out of a chair or bed, continence)? (Note: ADL criteria are not the same from one insurance carrier to another.)



- d. Is there a mental-functioning standard such that coverage is afforded even if the individual is physically able to perform the activities specified in the policy?
- e. Is there a requirement for a prior hospital admission?
6. Are any of the following required to file a claim for policy benefits:
 - a. Written notice within a specified number of days of disability;
 - b. Periodic verification of a continuing disability; or
 - c. Completion of a claim form by a specified physician and certain medical records.
7. What limitations exist on policy renewal?
 - a. Is the policy guaranteed as renewable?
 - b. What cancellation criteria exist, if any?
 - c. What payment renewal options exist (*e.g.*, monthly, quarterly, annually)?
 - d. Are renewal discounts available for spouses or domestic partners of covered individuals, or for the covered individual's maintenance of her own good health?
 - e. Are there limitations based on residency within/outside the United States?



8. Does the individual's employer, or a professional association to which the individual belongs, offer LTC insurance? If yes, is such insurance offered:
 - a. At a discounted rate as a benefit;
 - b. As a guaranteed minimum benefit regardless of pre-existing conditions; and/or
 - c. For a family member and, if so, under what conditions?
9. Has the individual explored with a qualified tax professional whether the annual LTC insurance premium qualifies for a federal or state income tax deduction?

C. Family and Medical Leave Act

The Family and Medical Leave Act of 1993 (FMLA)⁴ requires employers with fifty or more employees to allow eligible employees up to twelve weeks of unpaid leave in a twelve-month period⁵ for one or more of the following qualifying events:

1. Childbirth and care of a newborn;
2. Adoption or foster care of a child;
3. A serious health care condition that makes the employee unable to perform the functions of her job; or
4. A serious health care condition of an employee's child, parent, spouse, or domestic partner that requires the employee's care.

A "serious health care condition" under the FMLA is defined as an illness, injury, impairment, or physical or mental condition that involves inpatient care or continuing treatment by a health care provider.⁶ Some states have analogous provisions, and some jurisdictions have provisions that are more generous than the federal law.

1. Has the employee reviewed her employer's FMLA policy?
2. Does the employee's condition/situation meet the criteria of the specific policy and the defined health condition?
3. Is it desirable for the employee to take the leave on an intermittent basis (e.g., leave taken in separate blocks of time due to a single injury or illness [rather than for one continuous period of time], and may include leave periods

from an hour or more to several weeks), or on a reduced-work-schedule basis (i.e., a work schedule that reduces the usual number of hours per work week or hours per work day) to care for the child, parent, spouse, or domestic partner who requires the employee's care? Alternatively, is a temporary transfer to another available position an option?

4. Does the medical certification from the ill individual's health care provider include the following?
 - a. The date on which the health condition began;
 - b. The probable duration of the health condition;
 - c. The appropriate medical facts within the provider's knowledge regarding the health condition;
 - d. A statement that the employee is needed to care for the ill individual (if applicable);
 - e. An estimate of the amount of time that the employee is needed to care for the ill individual (if applicable);
 - f. A statement that the employee's leave is necessary to care for the ill individual or assist in her recovery (if applicable);
 - g. The expected duration of the leave; and
 - h. The schedule of the intermittent or reduced-work schedule.

D. Elder Care Benefits

Because some of the more routine tasks involved in caring for individuals with life-limiting conditions are not covered under the FMLA, an increasing number of employers have realized that employees who care for parents, relatives, or other loved ones with life-limiting conditions struggle with practical and emotional issues that can affect their work performance. This is true particularly because many primary caregivers also work outside the home. As the population ages, more employees will fall into this group. Some employers are therefore expanding their employee benefits to include offerings that range from simple referral services and flexible work schedules to workshops and more personalized assistance.

4. 29 U.S.C. Section 2601 et seq. See also 29 C.F.R. Part 825.

5. The FMLA was amended by the National Defense Authorization Act for Fiscal Year 2008 and the National Defense Authorization Act for Fiscal Year 2010 to provide two important leave entitlements that benefit military families: (i) Qualifying Exigency Leave under which eligible employees who are the spouse, son, daughter, or parent of a military member may take up to 12 weeks of FMLA leave during any 12-month period to address the most common issues that arise when a military member is deployed to a foreign country, such as attending military sponsored functions, making appropriate financial and legal arrangements, and arranging for alternative childcare. This provision applies to the families of members of both the active duty and reserve components of the Armed Forces; and (ii) Military Caregiver Leave under which eligible employees who are the spouse, son, daughter, parent or next of kin of a covered service member may take up to 26 weeks of FMLA leave during a single 12-month period to care for the service member who is undergoing medical treatment, recuperation, or therapy, is otherwise in outpatient status, or is otherwise on the temporary disability retired list, for a serious injury or illness incurred or aggravated in the line of duty on active duty. This provision applies to the families of members of both the active duty and reserve components of the Armed Forces

6. See 29 C.F.R. Section 825.114

Does the individual's employer offer any of the following elder care benefits?

1. Counseling on elder care issues provided through either the employer's Employee Assistance Program or outside contractor;
2. Referrals to elder care resources in the community or in the city where the elderly individual resides;
3. Seminars or "brown-bag lunches" for employees to discuss elder care issues;
4. Access to and group rates for LTC insurance for employees and/or their relatives;
5. Back-up caretakers if an elderly relative's caretaker does not show up for work; or
6. Flexible work schedules to accommodate the employee's elder care responsibilities.

III. INDEPENDENT LIVING AT HOME OR IN A RETIREMENT COMMUNITY

It may be necessary to assist an individual in maintaining an independent and active lifestyle. There are several options for obtaining staffing for home health care. One is to obtain all home-health personnel from an agency. Such services may include nursing, physical therapy, occupational therapy, and other professional needs in addition to assistance from nurse's aides, chore workers, and other similar non-professional personnel. Another option may be for the principal and family to employ all necessary nursing personnel and non-professional workers directly. (Under this model, other professionals [e.g., physical and occupational therapists and other workers who do not require supervision by a nurse] would be provided through a home-health agency, even when most of the staff is directly employed.) A third choice might be to obtain certain professional personnel from an agency, especially registered nurses and therapists, and to employ the home health aides and chore workers directly. With this option, the non-professional personnel who perform any nursing functions would ideally be subject to the delegation and direction of the registered nurses supplied by the agency.

Advantages and disadvantages attend each of these options. When agencies are available, they may provide the most expeditious and trouble-free way to obtain staffing, but problems can arise. The following section discusses some considerations.

A. General Considerations

Several issues affect the decision to explore any particular type of staffing and the levels of staffing required:

1. What are the patient's medical needs?
2. Is there a physician order?
3. Are professional nursing services (*i.e.*, either registered nurses [RNs] or licensed professional nurses [LPNs]) required?
4. What other types of professional services may be required (*e.g.*, physical or occupational therapy, pharmacy, nutrition)?
5. Are non-professional staff (*e.g.*, home health aides and chore workers) required?
6. Are both professional nursing services and non-professional staffing required?
7. Will non-professional staff be limited to providing only custodial care (*e.g.*, bathing, dressing, and other ADL)?
8. Will non-professional staff perform some nursing functions? If so, what level of professional supervision is required?
9. Are there agencies that would be willing to provide nurses to supervise the client's employed non-professional staff or do the agencies have their nurses supervise only their own non-professional staff?
10. Is the plan consistent with the responsible physician's opinion as to the patient's needs?
11. What other functions need to be performed? Are there off-site functions (*e.g.*, patient shopping, taking the patient to physician appointments or on outings)? How will transportation be provided (*e.g.*, via public transportation, the client's vehicle, or the worker's vehicle)? Will an agency be willing to allow its staff to do these functions or must such workers be directly employed?
12. Will the staff member's duties include any functions for the family, such as shopping, cooking, light housekeeping, laundry, or other similar functions? Will an agency allow the assigned staff member perform these functions or must such workers be directly employed?
13. What is the payment plan for the services?
 - a. Is there any available reimbursement through insurance or governmental programs?



- b. Does a third-party payer pay for any or all of these services through health insurance, a health maintenance organization (HMO), a preferred-provider organization (PPO), Medicare, Medicaid, or other similar programs? (Note: Medicaid pays for in-home personal care services in many states. Generally, the personal care attendant cannot be a member of the immediate family.) Do these programs pay for professional services only or will they also pay for home health aides and chore persons?
 - c. Does the patient have LTC insurance? For what levels of staffing and services will it pay?
 - d. Does the reimbursement program pay for a wide range of professional services? If so, does it require that all of these services (e.g., nursing, physical therapy, occupational therapy, nutrition, pharmacy) be provided from a single agency/supplier? If there is also reimbursement for home health aides, must they come from the same supplier?
 - e. If there is no reimbursement or reimbursement is only for professional services, are the agency's rates affordable for the patient and family? If not, are there agencies that have variations in their staffing models geared to client affordability?
14. What are the expectations for patient/family private time? Is there quiet patient/family time without unnecessary worker intrusion? Is it anticipated that staff members will think they have become "part of the family?" How can the family ensure their wishes are followed on that issue? What should they do if their expectations are not met?
15. Does the layout of the home allow privacy for family members other than the patient? Are lavatories shared? Are lavatories situated within a bedroom suite? Will staff respect family needs for rest, except in emergencies?
16. What are the provider's expectations in the event the patient has guests? Will the staff member respect the patient's need for privacy with her guests? How should it be handled if the staff member does not?
17. What are the expectations for staff lunches and breaks? Does the worker bring lunch and snacks for herself? Is the staff member welcome to eat family food? What items (if any) are off-limits?
18. If the patient has food and fluid restrictions, is the staff member permitted to eat and drink in front of the patient? What should be done if the staff member does not demonstrate respect for this issue?

B. Agencies

Many individuals contract with agencies to provide companions or personal care assistants (PCAs). It is important to obtain references from these agencies and a written agreement. Issues to discuss with agencies prior to contracting for PCAs include:

1. How long has the agency been in business?
2. Is the agency licensed by the state?
3. Is the agency certified by Medicare or the state Medicaid program?
4. Is the agency accredited by any organization?
5. Are survey reports available? If so, will the agency share the reports?
6. Does the accrediting agency have a website?
7. Are quality reports available on the website?
8. Will the agency provide references from persons who have used its services?
9. How does the agency select and train its employees?
10. Has the agency performed a criminal background check on their employees, including a check on the state employee disqualification list, or other list maintained by the state, of persons found to have abused a child or elderly person?
11. Are the agency's employees bonded?
12. How is quality measured during employment and afterward?
13. What are the agency's sources of employees?
14. Does the agency furnish written materials explaining all costs and payment-plan options?
15. Does the agency provide supervisors who oversee the quality of care that patients receive? If so, how often do the supervisors visit the patients? If disputes arise between the nurses and aides, what is the process for resolving those disputes?
16. Do the agency's employees take time to educate the patient's family about the patient's care and needs?
17. What is the agency's turnover rate? (Note: In general, when the average length of employment is long, the satisfaction level of the agency and its employees with each other is likely to be higher, and the satisfaction level of clients is likely to follow.) How do the turnover rates of other agencies under consideration compare to each other?
18. How does the agency staff for professional nursing services? Does the agency provide RNs or LPNs?

19. Has the agency considered the level of staffing that is (or might be) needed for this assignment?
20. Does the agency provide alternate coverage if a scheduled employee fails to report to work?
21. How long has the assigned employee been with the agency?
22. Has the assigned agency employee worked with individuals with similar health conditions?
23. Have any complaints been made to the agency against the assigned employee?
24. If the assigned employee does not work out for any reason, can the client request a replacement?
25. What is the process if problems arise with a worker? Does the process differ if the issues are about patient care? What changes if issues with honesty occur?
26. What specific duties will the assigned employee perform? Do special state-law requirements or limitations apply when such employees perform certain duties, such as:
 - a. Care of pets;
 - b. Accompanying the ill individual to medical and dental appointments;
 - c. Housekeeping services;
 - d. Personal care services (including dressing and bathing);
 - e. Administration of medications (*e.g.*, by mouth, gastric tube, rectal suppository and/or intravenously);
 - f. Grocery or other shopping;
 - g. Other services;
 - h. Wound care; and/or
 - i. Nail trimming.
27. Does the agency have an evaluation process? Will the client have an opportunity to participate? Will the client receive copies of the evaluation?
28. What is the agency's complaint process? Will the agency share with its clients past complaints about employees it intends to supply or has supplied? If the employee is disciplined by the agency over a matter relating to the employee's assignment to the client, is the client informed? What is the process if the employee is disciplined over matters unrelated to the client?
29. How will the agency respond to complaints of theft, neglect or other concerns?
30. Does the assigned employee maintain notes regarding the services provided and, if so, does the agency comply with the HIPAA Privacy Standards and Security Standards?
31. Can the assigned employee communicate directly with health care providers without the family member's permission in the event of an emergency or under other defined conditions?
32. Does the agency provide coverage twenty-four hours per day, seven days per week?
33. Who decides the number of hours for which service will be provided?
34. Is the assigned employee responsible for providing her own food and beverages?
35. Is the assigned employee responsible for handling cash and maintaining receipts?
36. What other expenses are charged by the agency (*e.g.*, mileage, admission fees to events, and/or client evaluation fees)?
37. Are the hourly rates different for weekends, holidays, and nights? How much notice does the agency provide in the event of fee increases?
38. Does the agency provide reliable "after-hours" telephone coverage service?
39. Can the individual communicate with the assigned employees independent of the agency (*e.g.*, home telephone and cell numbers; home addresses)?
40. What does applicable state law say about administration of certain medications or procedures at home? Is the assigned employee credentialed and have sufficient experience to administer such medications or perform such procedures?
41. If the agency has considered using LPNs, has the agency considered whether all the necessary functions are in the LPN's scope of practice? Are there state law restrictions on what LPNs can do? (Note: In some states, LPNs cannot start an intravenous line; in some states, they cannot add drugs to an intravenous line; in some states, they are limited to acting only under RN supervision.). Does the agency have a plan for related staffing and supervision?
42. What information is available about the financial stability of the agency?
 - a. Is the agency insured? What type of coverage and policy limits does it have? Does it include professional liability, commercial general liability, and/or workers' compensation?
 - b. Does the agency pay all federal and state employment taxes?
 - c. What benefits do workers receive? Does the agency pay all benefits?



- d. Has the agency ever been involved in litigation? If so, did it involve (i) quality or financial issues with a patient or family; (ii) a dispute with employees; (iii) regulatory issues; (iv) quality-of-care issues; (v) financial issues; (vi) a dispute with a vendor; or (vii) nonpayment by the agency of its obligations? Does the presence of any of these features constitute a reason for a credit check or checking with state tax authorities?

C. Independent Contractors

Some PCAs who do not work for agencies are available for hire as independent contractors. In addition to the foregoing issues, principals and their families should consider the following when considering the use of independent contractors.

1. Is a written agreement in place with the PCA?
 2. Is the PCA responsible for paying her own health, disability, retirement, and/or other benefits?
 3. Is the PCA responsible for Social Security taxes, Medicare, withholding taxes, and unemployment taxes arising out of the agreement or the services performed?
 4. Is the PCA responsible for medical coverage for any injury that she may incur while providing services pursuant to the agreement?
 5. Is the PCA responsible for maintaining professional liability insurance for all services rendered during the term of the agreement, as well as ensuring that the form and amount of such coverage is acceptable to the client? Is the PCA required to provide the client with a Certificate of Insurance evidencing such coverage upon request? Is the PCA required to provide the client with not less than thirty days' written notice prior to the cancellation or expiration of such insurance?
 6. How much notice is given if a PCA cannot cover a scheduled shift?
 7. Under what circumstances can a PCA be an independent contractor rather than an employee? What issues arise if the individual is considered as an employee? (Note: The IRS has a test known as the "twenty-factor" test. See Appendix B)
 8. Do the workers expect benefits? Is there paid vacation? Can the employer arrange for health insurance, or does the worker have another source?
- ### D. Direct Employment of Personal Care Assistants
1. How are PCAs recruited? Are references requested and checked? Is a background check performed? Does this include a credit check as well as a criminal background check? If the PCA will be driving on the job, has the individual's driving record been checked?
 2. Is there an employment agreement? What is the source of the agreement? Has the agreement been reviewed by an attorney? Does it provide for termination of an employee at will (*i.e.*, whenever the employer decides to terminate, without the need to state a reason)? Does it terminate whenever there is no further need for the services? Is prior notice required? Will the employer be required to pay over a period of time when services are not needed (*e.g.*, when the patient is hospitalized or upon the patient's death)?
 3. Is there a written job description that was agreed to in advance? Does it cover all functions, including any functions for persons other than the principal? Does it include off-site functions? If so, does it address transportation? If someone's private automobile will be used, what automobile insurance issues need to be addressed? If the client's automobile will be used, must the insurance company be notified? If the PCA's automobile is being used, does the worker have insurance or will that be the client's responsibility? Is there an exclusion in the PCA's insurance policy for using the automobile on the job? Must the PCA's insurance carrier be informed?
 4. Can the PCA lawfully perform all tasks? Are there tasks that only nurses or physicians can perform? If so, what is the plan for professional supervision?
 5. Does the PCA have any medical condition(s) and/or take prescription medication(s) that would affect the PCA's ability to perform the required tasks?
 6. To whom does the PCA report (*e.g.*, the patient/client, a family member, an RN)? If the reporting is to the family member, what happens if the patient gives contrary instructions? What happens if differences arise between an RN and the patient/client or family member?
 7. Will there be only verbal reporting, or are there also written reports? Will there be daily notes? What will they include? Is there a need to include in such reporting any changes in medication administration, vital signs, significant events, communication between shifts, and/or communication with physicians and other care providers? Will this reporting process change if a professional nurse supervises the PCA?
 8. Are multiple shifts required? How will personnel working different shifts communicate with each other? Is there any particular person who coordinates or schedules all shifts? If so, what is the relationship between that person and the other workers? How will disputes be resolved?



9. What is the plan for problem resolution? Will there be evaluations? How frequently will they be performed? Are they in writing? Is there an opportunity for the PCA to raise issues? How will these be resolved?

IV. LONG TERM CARE OPTIONS

If at-home care is ruled out as an option, other types of LTC services are available to meet the needs of the elderly and disabled. Many providers have developed a continuum of LTC services and housing options. The primary LTC options available to individuals include adult daycare, assisted living, and skilled nursing facilities. Some providers have developed locations, called continuum-of care facilities, to combine all three of these primary LTC services.

Other LTC services provided independently or in conjunction with LTC services (discussed herein) may include hospice, home care, and affordable senior housing. Applicable state law may dictate what types of care a nursing home, assisted living, or basic residential care facility may offer to residents.

The decision to place a loved one in a LTC facility is always a difficult one, involving complex emotions and anxieties. Individuals and their families alike need to understand their options when considering LTC placement for a loved one.

A. Independent Senior Housing Units With or Without Ancillary Services

Independent senior housing units are becoming more prevalent. Generally, independent senior housing units provide social support, meals, laundry service, housekeeping services, activities, and exercise in an environment limited to seniors. Most offer or allow additional health care services by a home health agency. Home health agencies can assist in medication management and activities of daily living such as bathing and dressing. Relevant inquiries include:

1. Does the state require a license for such activities?
2. Are there any health-related restrictions to living in the independent senior housing units?
3. Is there a licensed health care or nursing facility adjacent to or on the same campus as the independent senior housing units?
4. Do the independent senior housing units:
 - a. Allow pets? If so, is there a weight limit or species limit (e.g., cats or dogs only, no birds, snakes or rabbits)?
 - b. Include assistance with preparing meals and/or other ADL?
 - c. Permit smoking?
 - d. Have a 24-hour call system? If so, what services are offered?

B. Adult Daycare

Adult daycare centers provide health, social-support, and recreational services to impaired adults for longer than four hours in a given day. Participants do not stay in the center overnight, and continue to live in their homes.

1. Are adult daycare services appropriate?
 - a. Is the individual capable of living at home?
 - b. Is the family capable of continuing care for the individual when not at adult daycare?
 - c. Does the individual need assistance with transportation?
 - d. Is the individual in need of medical, social, and dietary services when the family is occasionally or regularly unavailable?
 - e. Is a physician's order required?
 - f. Must the individual function with minimal assistance?
2. Does the adult daycare facility provide the following services?
 - a. Nutritional and social work services;
 - b. Physical, occupational, and speech-therapy services;



- c. Personal care services;
- d. Transportation;
- e. Therapeutic activities;
- f. Hair care;
- g. Escorted trips to medical appointments;
- h. Extended hours of care before and after the normal program hours;
- i. Training in the delivery of emergency medical care (e.g., CPR); and
- j. Respite care.

C. Assisted Living

There is great confusion in the marketplace about assisted living facilities. The regulation and requirements with respect to assisted living depend on state law. In some states, housing units may call themselves “assisted living facilities” without being licensed and may provide only limited services; in this situation, other services must be provided by outside contractors, the principal, or the principal’s family. In other states, assisted living facilities are licensed and subject to closer government oversight.

Consumers need to be aware of the exact type of facility they are entering. Residents of assisted living facilities usually live in their own room or apartment within a building, yet have some or all of their meals as a group. Assisted living primarily is appropriate for persons who may be unable to live by themselves, yet do not need twenty-four-hour care. Assisted living facilities are regulated inconsistently. The following issues should be considered when evaluating the option of an assisted living facility.

1. Is the individual’s condition appropriate for an assisted living facility?
 - a. Does the individual need help with certain ADL?
 - b. Is the individual capable of living alone and willing to eat meals with others?
 - c. Does the individual have few medical service needs, primarily limited to dispensing medications?
 - d. Does the individual desire social and recreational activities that otherwise would not be enjoyed?
2. Does the assisted living residence provide or coordinate:
 - a. Twenty-four-hour supervision;
 - b. Two to three meals per day;
 - c. Snacks in a central dining room;
 - d. A range of services that promote resident quality of life and independence, including personal care services (e.g., help with eating, bathing, dressing, toileting);
 - e. Minimal health care services (usually limited to assistance with medications);
 - f. Social services;
 - g. Supervision of persons with cognitive disabilities;
 - h. Social and religious activities;
 - i. Exercise and educational activities;
 - j. Arrangements for transportation;
 - k. Laundry and linen service; and
 - l. Housekeeping and maintenance?
3. Is the facility licensed? If not, what services does it provide?
 - a. Does the assisted living facility have contracts with outside providers for services it does not provide?
 - b. Is there a mechanism to supervise the services provided by an outside provider?
4. What are the discharge criteria?
5. Are there discharge appeal rights?
6. What is the facility’s fee structure?
7. What is the facility’s policy on overnight guests?
8. Are personal pets allowed?
9. Is Internet access available?
10. Are community computers available for access by residents?
11. Is a negotiated risk agreement, which allocates responsibility and liability between the resident and assisted living facility, available to accommodate a resident’s preferences if she does not wish to comply with the health care options recommended by the assisted living facility? Can the resident relocate? Does applicable state law place any restrictions or limits on the use of a negotiated risk agreement?
12. Does state law allow an individual on hospice to remain in an assisted living facility? If so, is the assisted living facility sufficiently staffed to care for the person’s medical needs?

D. Skilled Nursing Facilities

Nursing facilities provide 24-hour skilled care and related services for residents who require medical or nursing care. The question of whether an individual requires the services of a skilled nursing facility usually relates to the individual’s ability to function, especially his or her ability to perform

ADL. When faced with a decision about admission to a skilled nursing facility, it is prudent to consider the following issues.

1. Does the individual need assistance with ADL?
2. Does the individual use assistance with other activities or services, such as:
 - a. Preparing meals;
 - b. Shopping;
 - c. Housework and laundry;
 - d. Making or traveling to appointments;
 - e. Paying bills or other financial matters; and/or
 - f. Simple maintenance and repair of household items?
3. Does the individual need assistance with the provision of care, including:
 - a. Dispensing properly and remembering to take medications;
 - b. Diabetes monitoring;
 - c. Using nose or eye drops;
 - d. Oxygen needs; or
 - e. Caring for colostomy or bladder catheters?
4. Does the nursing home under consideration provide:
 - a. Medically necessary services;
 - b. Dietary services (*e.g.*, dietary supplements, medically prescribed diets);
 - c. Tube feeding;
 - d. Oral feeding;
 - e. Nursing services (*i.e.*, by at least one RN, an LPN, licensed practical nurse, certified nurse aides, certified nurse aides, certified medication aides/technicians);
 - f. Therapy services (including physical, occupational, speech, respiratory, and restorative therapies);
 - g. Safety and treatment equipment (*e.g.*, partial or full bed rails, standard walkers/wheelchairs, IV administration stands, suction apparatuses, oxygen equipment, and pressure relieving/reducing mattresses for chairs and beds);
 - h. Personal laundry services;
 - i. Routine personal hygiene services;
 - j. Housekeeping services;
 - k. Access to a beauty shop or other grooming care;
 - l. Transportation for doctor's appointments or therapy;

- m. Activities (both within and outside the facility);
- n. Social services; and
- o. Security mechanisms (*e.g.*, patient monitoring systems and door alarms)?

V. LONG TERM CARE FACILITY SELECTION

A. General Considerations

LTC facilities are highly regulated by the federal and state governments, with federal oversight authority residing with the Centers for Medicare & Medicaid Services (CMS). LTC facilities serve more than just the elderly. Many of them care for otherwise healthy individuals who need to recover from a serious injury or illness and/or for younger individuals with chronic disabilities.

Placement in a LTC facility can be stressful for both the individual needing care and her family. It is advisable for such families to seek agreement within the family unit by involving the individual and family members in the facility selection process. This will not only help relieve immediate concerns, but also ease the transition into the chosen facility.

This section will explain what individuals and their families can expect once the decision is made to seek care from a skilled or intermediate-care facility. The process of choosing a LTC facility may seem overwhelming at first. It may help to remember that although LTC facilities share a common set of goals and purposes regarding resident care, every facility (and type of facility) has certain areas of expertise, offers certain special services, and specializes in serving certain clientele. In other words, specific factors (*e.g.*, payment method, location, and availability of special care units) will make one LTC facility better-suited to a particular individual than another. The following are issues to consider when choosing a LTC facility:

1. Who will pay for the LTC services?
 - a. Are there sufficient resources for private pay, including insurance?
 - b. If there are insufficient resources, does the individual qualify for the state Medicaid program?
 - c. Does the individual qualify for Medicare? (Note: Medicare is available for limited time periods and the resident must meet certain conditions to qualify for payment of skilled nursing facility care.)
2. Does the state Medicaid program pay for assisted living care?



3. Does the chosen facility accept payment by Medicare and/or Medicaid?
4. Will a Medicare or Medicaid bed be available for the individual in the chosen facility after private funds are depleted?
5. Does the chosen facility expect an individual to purchase an interest in the facility or sign over assets to the facility (a process sometimes referred to as a Life-Care Contract)?
 - a. Are there special laws regulating this type of entity?
 - b. Is the entity financially stable?
 - c. If a deposit has been made and the entity declares bankruptcy, does the deposit belong to the resident or entity?
 - d. If the property is sold, are there any assurances that the new owner will maintain the same types of services and amenities?
 - e. Has an attorney reviewed the contract before entering into the agreement? (Note: This is always a good idea when investing a substantial amount of money.)
6. Is the location convenient for the individual's friends and family?
7. Does the location (*i.e.*, urban, suburban, or rural) reflect the individual's lifestyle?
8. Does the facility offer special services to better treat certain disabilities (*e.g.*, secured Alzheimer's or dementia-related units, specialized rehabilitation services, or sub-acute care services)?

B. Obtaining Referrals

The first step in the selection process is to seek referrals. Has the individual or family contacted the following sources to obtain valuable information about the chosen facility?

1. LTC professionals;
2. Hospital discharge planners and social workers;
3. Facility physician and friends;
4. State ombudsman program;
5. Senior community centers; and/or
6. Clergy (if applicable).

C. Facility Visits

The best way (and arguably the only meaningful way) to determine the appropriate match of LTC services and the individual's needs is to visit the facility or facilities under consideration. The following issues should be considered when an individual and her family are choosing a LTC facility.

1. Can choices be narrowed by phone calls and questions?
2. Will the individual and her family visit three or more facilities?
3. Are tours offered to prospective residents and families?
4. Are prospective residents and families encouraged to watch or participate in activities?
5. Are prospective residents and families allowed to visit at all hours (and encouraged to visit more than once) to observe care and activities throughout the day and evening?
6. Are prospective residents and families allowed to visit during meals to taste the food and observe the residents in a social setting?
7. Have the prospective resident and family made scheduled and unscheduled visits of the facility to observe care and interaction between residents and staff?
8. Does the facility have resident- and family-council meetings? If so, can the prospective resident and family attend to learn how other residents and families perceive the care and services?

The individual (and her family) should ensure that all of their questions have been answered fully. They should feel comfortable with the facility and its staff before deciding on that individual's new home. The following are suggested inquiries that can help individuals and their families conduct effective and successful facility visits.

D. Licensing and Accreditation

1. Does the facility hold a current license from the state for its type of facility?
2. Does the administrator hold a current license from the state?
3. What are the results of the facility's most recent survey (*e.g.*, state and/or federal inspections)? Are these reports available?
4. Is the facility accredited by any organization, such as the Joint Commission?
5. Is the facility a member of any state or national professional or trade associations for that type of facility? (Note: a facility that is not licensed and is required to be by the state should be eliminated from consideration.)
6. Does the facility have in place appropriate emergency planning, response, and recovery procedures?⁷

7. For information on *Emergency Preparedness, Response & Recovery Checklist: Beyond the Emergency Management Plan*, please visit www.healthlawyers.org/checklist.

E. Location

1. Is the individual and her family happy with the location?
2. Will family and friends be able to visit frequently?
3. Will the individual's personal physician make visits to the facility if the resident's condition requires such visits?
4. If the individual's personal physician does not visit the facility on a regular basis, is the facility close enough to allow for needed medical appointments?
5. Is the facility located in a reasonably secure neighborhood, and/or does the facility provide reasonable security measures?

F. Facility Appearance and Design

1. Does the facility have a "welcome" feel?
2. Does the facility meet the requirements for its particular license category (*e.g.*, skilled nursing facility, assisted living)?
3. Does the entire facility satisfy the resident's personal cleanliness and other standards?
4. Does the facility appear organized and well maintained?
5. Are the grounds neat and well-kept?
6. Is sufficient parking available to and accessible for visitors? Is secured parking available?
7. Is the view pleasant?
8. Is there outdoor furniture for the residents to use?
9. Is the facility free of unpleasant odors?
10. Are there areas where residents can enjoy being outside? Are they encouraged to do so?
11. Have certain rooms been designated for physical examinations or therapy?
12. Is there a room for private visits with family and friends?
13. Are hallways and rooms free from hazardous objects?
14. Are there security mechanisms (*e.g.*, patient monitoring systems, door alarms)?
15. May residents use their own furniture and/or bedding?

G. Staff Attitudes

1. Is the facility's general atmosphere warm and pleasant?
2. Has the facility embraced a culture change that reflects a more home-like environment? If so, are staffing assignments consistent? Does staff eat with residents? Do residents assist with laundry and other tasks? Does the facility have a chef to assist with meal planning?

3. Do staff members show interest in and affection for individual residents?
4. Are staff members courteous and respectful?
5. Do staff members know residents by name and address them by their preferred names? Do staff members take time to interact with them personally?
6. Do staff members and the facility's administrator take time to answer all questions, hear complaints, and discuss problems?
7. Do staff members respond quickly to resident calls for assistance?
8. Are visiting hours convenient for residents and visitors?
9. Does the staff encourage family visits?

H. Bedrooms and Bathrooms

1. Does every bedroom have a window?
2. Are the rooms private or do residents share rooms?
3. Does each room or bed have enough privacy for the principal's personal standards?
4. Is fresh drinking water available at the bedside in each resident's room?
5. Does every resident have a comfortable chair in the room?
6. Are the lights sufficient for reading?
7. Do residents have their own clothes closet and drawers for personal items?
8. Are there personal items throughout the room and on the walls?
9. Is the furniture spaced so that a wheelchair can maneuver easily?
10. Is each bed easily accessible?
11. Are the bathrooms convenient to the bedrooms?
12. Are bathrooms easy for wheelchair residents to use?
13. Does each bathroom have a nurse call button or bell?
14. Are handgrips on or near the toilets?
15. In shower areas, do showers and tubs have non-slip surfaces and handgrips?

I. Dining

1. Is the dining room attractive and inviting?
2. Are tablecloths and linens used?
3. Are the tables and chairs comfortable and safe?
4. Is it easy to move around, even for those in wheelchairs?



5. Is the food tasty and attractively served?
6. Does it appear that residents enjoy the food that is served?
7. Is the atmosphere conducive to dining? Is the dining room too noisy or too hectic?
8. Are the meals served buffet style? If not, does the menu feature a pleasant variety from meal to meal?
9. Are residents given enough time to eat?
10. Are meals served at convenient times? Is there any flexibility for residents to select alternative meal times?
11. Do meal times accommodate sleeping habits?
12. Do residents receive help eating if they need it?
13. Is food delivered to the rooms of residents unable to eat in the dining room?
14. Are alternative foods available if requested?
15. Are snacks available twenty-four hours a day, seven days a week?
16. Are special dietary needs accommodated?
17. Is there a nutritional evaluation of the residents? Is this nutritional evaluation ongoing as a resident's physical status and nutritional requirements change? Does the nutritional service coordinator regularly communicate and consult with the resident's physicians so that the resident's dietary plan is consistent with her medical care plan?

J. Activities

1. Is adequate room provided for residents' activities?
2. Are activities planned?
3. Are all residents able to get involved in some activity?
4. Is equipment available to use for activities (*e.g.*, games, craft supplies, books, videos)?
5. Can the facility accommodate a resident's unique hobbies (*e.g.*, painting at odd hours, gardening, or woodworking)?
6. Does it appear that residents use the equipment on a regular basis?
7. Is the resident's activity preferences observed?
8. Are outside trips planned for residents who are able to enjoy them?
9. Does the facility provide computer access for internet-based calls and e-mails? Is WiFi available?
10. Does the facility serve or allow alcohol for "happy hours" or other social events?
11. Do volunteers work with residents?

12. Are animals allowed in the facility for pet therapy?
13. Is exercise included in the planned activities?

K. Resident Care Services

1. Does the facility have an arrangement with a nearby hospital for transfer if necessary?
2. Is emergency transportation readily available?
3. Is a physical therapy program that is directed by a qualified therapist available to residents?
4. Is therapy available to meet a resident's particular needs?
5. Is occupational and/or speech therapy available?
6. Is a social service worker available to assist residents and family?
7. Is an RN available for nursing staff?
8. Are barbers and beauticians available for residents?
9. Do staff members encourage residents to maintain a neat appearance? Does staff help in this endeavor if needed?
10. Is there a gift shop or store on the facility premises?
11. What is the facility's policy on the use of side rails?
12. What is the facility's policy on the use of restraints?
13. What is the facility's policy on the use of psychotropic medications?
14. What is the facility's smoking policy?
15. Are there arrangements with local churches and synagogues for regular visits by clergy to the facility?
16. Can the facility dictate to the resident's family the type of PCAs they use? Is approval of certain agencies required?
17. Does the facility partner with any other health care entities, such as an accountable care organization (ACO)?

L. Residents' Rights

1. Does the facility have a written description of the residents' rights and responsibilities?
2. Is the description readily available for residents and families to review?
3. Are staff members trained to protect dignity and privacy and abide by residents' rights?
4. Does the facility have a resident council or family council?
5. Have arrangements been made for residents to worship as they please?
6. Have arrangements been made to accommodate residents who celebrate religious holidays?

7. Are arrangements made for religious leaders to visit the facility?
8. Does the facility encourage residents to vote?

M. Costs

1. Are most services covered in the basic daily rate? If not, is a list available of specific services not covered in the basic rate?
2. Does the facility accept Medicaid payments?
3. What is the facility's policy on returning advance payments?
4. What happens when the resident's payment source changes (e.g., from Medicare to Medicaid or from private pay to Medicaid)?

N. Family Involvement

1. Are family and friends prepared to ease the resident's transition to a facility by remaining with the resident for several hours on admission day, as well as the days immediately following?
2. Are family and friends ready to visit the resident frequently and ensure the resident's friends also visit regularly?
3. Are family and friends willing to provide the resident with the same amount of visitation and affection in the facility as they would if the resident was at home?

O. Nursing Home Compare

1. Has the resident or family reviewed the facility at Nursing Home Compare (www.medicare.gov/nursinghomecompare), a federal government website that compiles detailed information about every Medicare and Medicaid-certified skilled nursing facility in the country? (Note: The quality indicators in Nursing Home Compare should be a starting point for questions. Skilled nursing facilities may score differently because they take specialized residents that others in the area do not. For example, a skilled nursing facility may have a high number of residents with pressure ulcers because it specializes in the care and treatment of them, not because it provides poor care.)
2. How does the facility's staffing compare to others in the area? (Note: Nursing homes specializing in a certain type of care may have more of a certain type of staff. For example, nursing homes specializing in the care of residents on ventilators may have respiratory therapists on staff whereas other facilities that do not have residents on ventilators will not.)

VI. WHAT TO EXPECT UPON ADMISSION TO A HEALTH CARE FACILITY

Once the resident and her family choose a facility that provides the services they need and with which they feel comfortable, the next step will be to undergo a process where the individual receiving care is "admitted" to the facility. The admission process varies based on a number of factors, including those listed in this section.

A. Level of Care Required

1. Does the individual need only assisted living services? (Note: Assisted living facilities are not governed by any federal regulations on admissions and resident care, so all of their requirements [if any] will derive from state laws and regulations.)
2. Does the individual need nursing home care? (Note: State as well as federal laws and regulations govern nursing homes, and certain parts of their admissions processes are spelled out in those regulations. Nursing homes also are likely to complete more-detailed medical assessments of residents upon admission than other types of facilities.)
3. Is the anticipated level of care consistent with the recommendations of the individual's physician?

B. Payment

1. If Medicaid is paying for the resident's care, has all additional paperwork been completed to ensure that the resident qualifies to have Medicaid pay for her care?
2. If the resident is paying privately, what other types of contracts will she need to sign?

C. Admission Policies and Applicable Laws

Depending on the state, laws for what a LTC facility has to do at admission may vary. Some states require that certain guides to state laws are provided, so checking with the appropriate state health department may be worthwhile. The types of contracts and forms the resident and/or family must sign may vary. Also, every facility likely will have certain types of forms that are unique for their residents.

D. Admissions Agreements

Although admissions processes will vary for each facility, some basic parts are going to be the same. Generally, the admissions process involves completing certain forms, including an admissions agreement. This admissions agreement should state clearly the obligations of the LTC



facility. It also should list the resident's responsibilities, obligations, and required behaviors. If a family member or other individual serves as co-signatory to the agreement, that document should convey that person's responsibilities as well. Most importantly, the admissions agreement should delineate what services or items are included for the amount that the resident, her family, Medicaid, or insurance is paying.

1. Do the admissions agreement and admissions forms include the following?
 - a. Admissions Record;
 - b. Financial Assessment;
 - c. Choices of Professional Services;
 - d. HIPAA Privacy/Confidentiality Notification and Privacy Practices;
 - e. Consent to Release Records or Information;
 - f. Management of Resident Funds;
 - g. Financial Agreement;
 - h. Information about advance directives and/or sample advance directive forms;
 - i. Social History/Resident Preferences;
 - j. Nutritional Interview;
 - k. Activities Interview;
 - l. Clothing and Personal Property Inventory;
 - m. Discharge Record/Readmission Record;
 - n. Description of Resident Rights and Responsibilities; and
 - o. Description of the Facility Rules and Policies.
2. Special Considerations
 - a. Are there any additional charges for care? (Note: Because the levels of care in different facilities may vary, part of the financial agreement [or other disclosures made by the facility] should identify any additional costs and services not included in the basic or flat rate. LTC services vary widely in terms of what services are provided by different types of facilities [and even different facilities within the same classification]. Therefore, the resident and/or her family should ensure that they understand what will and will not be covered as part of the monthly [or other] rate charged by the facility.)
 - b. What services are provided by the assisted living facility? (Note: Admission agreements for assisted living facilities should detail what services are available at the facility, including services required by the applicable regulations. As stated, the agreement should draw a distinction between services and amenities that are included in the monthly fee and those that are provided for an extra charge. The facility should describe any optional services in an addendum to the contract, featuring current pricing information and a statement as to whether that pricing is subject to change with or without notice.)
 - c. What services are excluded in the agreement? (Note: Some services may be specifically excluded from coverage because they are beyond the ability or desire of the facility to provide them. Similar to those services included in the agreement, it is also important that the agreement specify what, if any, of those services cannot be provided. For example, skilled nursing care may be identified explicitly as a service that is not included and/or provided. Agreements may also specifically exclude such items as medications, services of physicians, nurses and other licensed staff, or hearing aids and eyeglasses.)
 - d. Will there be additional charges if more care is needed? (Note: It is important for the principal and her family to understand that if a resident's condition worsens or deteriorates, more services may be required, an event that may affect what the facility charges for the care the resident receives. It also is important to understand what is included in the cost of care in a nursing home [though, in most cases, nursing home care will not increase based on the level of care the resident needs]. Some nursing homes do charge a higher premium if the resident needs a specialized unit, such as a secured dementia unit.)
 - e. Does the agreement protect the confidentiality of an individual's personal and health information? (Note: Under HIPAA, every health care provider must take certain steps to ensure that every resident's personal and health information is kept confidential and is not disclosed [except under certain circumstances, e.g., for treatment and payment]. Before agreeing to care at a facility, a principal should insist that the facility's staff explain their confidentiality practices and provide a copy the facility's *Notice of Information Practices*. The principal or her family should ask any questions they have, and discuss these practices with the facility by raising any objections to the use of the individual's information.)
 - f. Does the agreement contain an arbitration agreement or a negotiated risk agreement? (Note: Increasingly, facilities providing LTC are seeking agreement from a prospective resident and her family before admittance about the liability that the facility will have if



the resident or their family is unhappy with the facility or the care that is provided. If this process is understood by both sides, the agreement can benefit both parties. Often, these are called arbitration agreements. Arbitration agreements generally state that both the facility and the resident agree to settle any dispute outside of the legal system. “Negotiated risk agreements” are similar in that the facility attempts to explain before admittance those services/responsibilities for which it intends to be responsible, as well as those for which it intends not to be responsible. In utilizing either of these agreements, the facility should explain any of these provisions fully, as well as whether the facility is requiring the arrangement to be signed before they will care for the individual. An individual (or family member) that has questions about such agreements should address their concerns with the facility, or have an attorney review the document, prior to signing.)

- g. Does the agreement contain information about how it may be terminated (either by the facility or the resident)? Does it include a discussion of resident rights in the event of termination? Does it impose penalties on the resident if the resident chooses to leave the facility?

VII. PALLIATIVE AND HOSPICE CARE

Hospice is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting condition no longer responds to curative treatments. If a patient has been diagnosed with a terminal illness with a life expectancy of six months or less, a patient may want to consider hospice as an alternative. (Note: Medicare will only pay for hospice services if one or more physicians have certified that the patient has a life expectancy of six months or less if the individual’s medical condition runs its usual course.) Hospice is a philosophy of care designed to provide comfort care as well as spiritual and emotional support for patients in the final phase of a terminal illness. Hospice focuses on enhancing the quality of life, rather than prolonging the length of life. Hospice neither prolongs nor hastens death. It should be emphasized, however, that when patients elect hospice and palliative care, they may give up their right to seek curative treatment for the terminal illness that is not for symptom management and pain control, depending upon the particular payer. Treatment may still be provided for medical conditions unrelated to the individual’s terminal illness. In addition, a patient may decide to revoke his hospice election to pursue curative treatment. Those issues should be explored thoroughly before any such election is made.

Palliative care and hospice both involve a team-oriented approach to medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s unique needs and wishes. Both disciplines provide support to the patient’s loved ones as well. Palliative-care and hospice organizations typically provide a myriad of educational resources available to individuals who face a life-limiting condition or who care for a loved one with a life-limiting condition.⁸

A. Physician Orders for Life-Sustaining Treatment (POLST)

Individuals who have been diagnosed with a life-limiting condition or who may have a life expectancy of less than one year and is interested in defining his wishes for end-of-life care may wish to consider discussing physician orders for life-sustaining treatment (POLST) with their health care providers. A POLST form is a set of medical orders based on a patient’s preferences for care (e.g., cardiopulmonary

8. See The Center to Advance Palliative Care at www.capc.org and the National Hospice and Palliative Care Organization at www.nhpc.org.



resuscitation; level of medical intervention including hospitalization, antibiotic therapy, and artificial hydration and nutrition) and is signed by the patient's health care provider; these orders are intended to follow a patient across care transitions and to be applicable in all care settings.

Although a POLST form is characterized as a physician order, only physicians credentialed and privileged by a particular hospital can write orders for a patient admitted to that facility or treated in the facility's emergency department. Long term care facilities typically do not have such limitations which is the reason that a POLST form is valuable in that setting. An advance directive and a POLST form should be integrated in order to resolve any conflicts between the two documents to ensure that the values and care preferences expressed by the patient are consistent. Additionally, transitions of care across state lines raise the issue of variable state requirements with respect to the execution of a POLST form (e.g., whether the patient needs to sign the form).

In considering the use of a POLST form, individuals should ascertain the following:

1. Does the post-acute care setting have a mechanism for translating the medical orders from a POLST form into inpatient orders when the individual is admitted to an acute care hospital when a transfer is necessary?
2. Does the post-acute care setting have standardized order sets consistent with the POLST form?
3. Does the acute care setting communicate the POLST form to post-acute providers to ensure continuity of care and the implementation of the individual's wishes?

B. Palliative Care

Palliative care is defined as treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals, rather than affect the underlying disease. An individual's needs must continue to be assessed, and all treatment options explored and evaluated in the context of the individual's values and symptoms. The individual's choices and decisions regarding care are paramount and must be followed.⁹ Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in

their illness or disease process. No specific therapy is excluded from consideration.

In selecting a palliative care program that best meet the individual's unique needs and situation, the following issues should be considered:

1. Admission Criteria
 - a. When is a patient eligible for palliative care services (e.g., at the initial diagnosis of a life-limiting condition, twelve month prognosis, or other time)?
 - b. What treatments, if any, must the patient discontinue, and which ones may she continue?
 - c. If a patient's diagnosis changes, will ongoing contact with the palliative care team continue? What do the patient's discharge plans include?
2. Setting
 - a. Where are the palliative care services provided (e.g., home, dedicated palliative care inpatient unit at a hospital, medical office, residential care setting, nursing facility, hospice, or other independent organization)?
 - b. How will the continuity of care be maintained if a patient's location changes?
3. Staffing
 - a. What disciplines are involved in the patient's palliative care team (e.g., physician, nurse, social worker, home health aide, chaplain) and what services can they provide?
 - b. Is the staff shared with a hospice, hospital, or other facility?
 - c. What type of medical and nursing leadership is provided?
 - d. What is the role of the patient's attending physician once palliative care begins?
 - e. Does the palliative care program utilize volunteers? If so, what services do volunteers offer? Does the program provide transportation and assistance with ADL? What screening process is used with volunteers, and how are they trained?
4. Family Involvement and Support
 - a. How will the family be included in the patient's plan of care?
 - b. How does the palliative care team recognize domestic partners or friends who fulfill the role of family?

9. See the National Hospice and Palliative Care Organization's *Standards of Practice for Hospice Programs*, www.nhpc.org.

- c. How are the patient and/or family caregivers given the information and training needed to meet the patient's care needs?
5. Comfort and Pain Management
 - a. How does the palliative care team or staff communicate and work with the patient's attending physician on pain-control issues?
 - b. What is the process to address pain- and symptom-control emergencies, both during regular business hours and after-hours?
 - c. How does the palliative care team address the spiritual and emotional needs of the patient and family?
 - d. What additional palliative care services, if any, are offered?
 6. Contracts with Other Facilities and Providers
 - a. Are palliative care services delivered to patients in the available settings provided by employees, independent contractors, or agency personnel? If such services are rendered by independent contractors or agency personnel, what mechanisms exist to ensure the quality of care?
 - b. Does the palliative care organization have contracts with hospitals; nursing homes; assisted living facilities; durable medical equipment suppliers; or physical, speech, or occupational therapists to meet the patient's anticipated needs?
- C. Hospice Care**
1. Hospice Team Membership—When considering a particular hospice service, determine whether the health care team includes the following members:
 - a. A medical director;
 - b. An attending physician;
 - c. A registered nurse or licensed practical nurse;
 - Does the nurse make regularly scheduled visits to the patient providing pain management and symptom control techniques?
 - Does the nurse provide the complete spectrum of skilled nursing care?
 - Is the nurse available twenty-four hours a day, seven days a week?
 - d. A certified nursing assistant;
 - e. A social worker;
 - Does the social worker provide assistance with practical and financial concerns as well as emotional support, counseling, and bereavement follow-up?
 - Does the social worker evaluate the need for volunteers and other support services for the family?
 - Does the social worker facilitate communication between the family and community agencies?
 2. Hospice Benefit Coverage—When evaluating a hospice provider, does the benefit coverage include:
 - a. Physician services;
 - b. Nursing services (intermittent with twenty-four hours on call and more frequent services during crisis care);
 - c. Pain medication;
 - d. Home health aide and homemaker services;
 - e. Medical supplies and appliances related to the terminal illness;
 - f. Short-term acute inpatient care (in an approved hospital, nursing home or hospice center);
 - g. Physical therapy, occupational therapy and speech language pathology services;
 - h. Medical social services;
 - i. Spiritual and other counseling;
 - j. Continuous care during periods of crisis;
 - k. Volunteer services (companionship and support); and/or
 - l. Bereavement services.
 3. Insurance Coverage for Hospice Benefits
 - a. Is insurance coverage available if the hospice care is covered by Medicare/Medicaid?
 - b. Does private health insurance coverage require pre-authorization before hospice services are covered?
 4. Eligibility for Hospice Benefits
 - a. Is the patient eligible for Medicare Hospital Insurance (Part A)?



- b. Are the patient's attending physician and the hospice medical director willing to certify that the patient is terminally ill with six months or less to live if the disease process runs its expected course?
 - c. Is the patient or surrogate decision maker willing to choose comfort care over curative treatment by electing the hospice benefit instead of standard Medicare benefit?
 - d. Is hospice care being provided by a Medicare approved hospice?
5. Duration of Hospice Benefits
- a. Is payment coverage different under private insurance than Medicare?
 - b. Under Medicare are hospice benefits time limited?
 - If so, can the hospice benefit be elected for successive time periods (e.g., if a Medicare beneficiary elects to receive hospice care for two ninety-day periods, can those periods be followed by other time periods)?
 - Can Medicare benefit periods be used consecutively or at intervals?
 - Under Medicare hospice benefits, when does the patient have to be certified as terminally ill?
 - Under Medicare hospice benefits, how often must the patient be certified as terminally ill?
 - Under Medicare hospice benefits, how often must there be a face-to-face evaluation by the physician or a physician extender?
6. Change of Providers During the Course of Hospice Care
- a. With Medicare payment?
 - b. With private insurance coverage?
7. Change or Cancellation of Hospice Benefits
- a. Can a patient cancel hospice and return to a curative mode?
 - b. Can the patient later re-elect the hospice benefit in the next benefit period?
8. Medicare Part B Benefits
- a. If a Medicare Part A hospice patient also has Medicare Part B, can the patient use all appropriate Medicare Part B benefits for the treatment of health problems unrelated to the terminal illness?
 - b. Is the patient responsible for Medicare's deductible and coinsurance amounts for those services?
9. Selection of a Hospice Care Provider
- a. Is the hospice agency accredited by a nationally recognized independent accrediting body, such as the Joint Commission or the Community Health Accreditation Program (CHAP)?
 - b. Is the hospice agency considered a "non profit hospice"?
 - c. Is the hospice agency a local agency or is it owned by a national company?
 - d. Does this hospice have particular religious affiliations in the community?
 - e. Is the hospice program Medicare certified? If so, did it meet federal minimum requirements for patient care and management during the last survey?
 - f. Is the hospice agency licensed by the state?
 - g. Does the hospice agency have written statements, brochures or handbooks outlining services, eligibility criteria, costs, and payment procedures, employee job descriptions?
 - h. Does the hospice agency have evidence of professional liability insurance? How many years has the hospice agency been serving the community?
 - i. Can the agency produce any references from other health professionals in the community?
 - j. If uncertain whether a patient qualifies for hospice, or whether the patient wants hospice, is the hospice agency willing to make an assessment and discuss these issues?
 - k. Does the hospice attempt to condition admission to a patient having a DNR code status? (Note: There are restrictions under federal law on whether a hospice can require a DNR.)
 - l. Does the patient's attending physician recommend a particular hospice?
 - m. Does the hospice agency create an individualized plan of care for each new patient?
 - Is the plan of care developed with input from the patient and family?
 - Is the patient's plan of care updated as the patient's needs change?
 - Are sample care plans available for review?
 - n. Does the hospice require a designated family member to serve as primary caregiver as a condition of admission?

- How much responsibility is expected of the family caregiver?
- What assistance can the hospice offer in coordinating and supplementing the family's efforts or filling in around job schedules, travel plans, or other responsibilities?
- If the patient lives alone, what alternatives does hospice suggest?
- o. Does a nurse, social worker, or therapist conduct a preliminary evaluation of services needed in the patient's home?
- Is the evaluation conducted in the home or via telephone?
- Does the evaluation cover what the patient can do for him or herself?
- Does the evaluation include consultation with the patient's attending physician and/or other professionals already providing for the patient's health care needs?
- Are other family members consulted?
- Is safety of children or other vulnerable adults residing in the home taken into consideration in terms of providing a secure lock box for storage of the patient's medications?
- p. How many references does the agency have on file for its employees?
- Does the hospice agency train, supervise and monitor its caregivers?
- How often does a supervisor come to the patient's home to review the care being given to the patient?
- Are caregivers licensed and bonded?
- Are background checks and licensure verifications conducted on all employees?
- Are all professional staff trained in CPR when CPR is indicated for the patient and the patient has not signed a DNR order or other form rejecting CPR?
- q. Who can the patient or family call with questions and concerns?
- r. How does the hospice agency handle payment and billing?
- What resources does the hospice agency provide to help for financial assistance if it is needed?
- Are standard payment plan options available?
- s. Does the agency have a twenty-four-hour telephone number the patient or family can call to ask questions?
- How does hospice staff respond to the first call?
- Does telephone staff convey an attitude of caring, patience, and competence from first contact, even if they need to return the patient's call?
- Does the staff speak in plain understandable language about the patient's needs?
- What is the procedure for receiving and resolving complaints?
- t. What is the scope of services offered by the hospice agency?
- How quickly can hospice initiate services?
- What are the geographic service boundaries?
- Does the hospice offer specialized services such as rehabilitation therapists, pharmacists, dietitians, family counselors, pastoral care and bereavement services?
- How quickly can drugs be delivered from the agency's contracted pharmacy to the patient once ordered by the attending physician?
- How much time is spent training the family caregiver on medication administration and other aspects of effective pain management?
- Does the hospice provide medical equipment or other items that might enhance the patient's quality of life?
- u. What are the hospice agency's policies regarding inpatient care?
- Does this hospice agency have more than one contracted location for inpatient care? If so, where?
- What are the requirements for an inpatient admission?
- How long can patients stay in the hospital?
- What happens if the patient no longer needs inpatient care, but cannot return home?
- Can the patient or family choose the inpatient unit or residential facility?
- What kind of follow up is provided by hospice during an inpatient stay?
- With what nursing homes does this hospice have a contract?
- Does the hospice provide as much nursing, social work, and aide care for each patient in the nursing home as it does in the home setting?
- v. Does the agency explain patient's rights and responsibilities at admission?
- w. Does the hospice have a designated individual to call in the event of patient concerns or a crisis?



VIII. PACE

The Program of All-Inclusive Care for the Elderly (PACE) is a program that serves seniors with chronic-care needs and their families within the community, whenever possible. Eligible individuals must meet the following criteria: (i) age fifty-five years or older; (ii) certified by their state to need nursing home care; (iii) able to live safely in the community at the time of enrollment; (iv) and live in a PACE service area. Financing for PACE is capped, which allows providers to deliver all services participants need rather than limit the services to only those provided under the Medicare and Medicaid fee-for-service programs.

A PACE program provides a range of integrated preventative, acute care and long-term care services to manage the often complex medical, functional and social needs of the frail elderly. PACE was created as a means to provide clients, family, caregivers and health care practitioners with the flexibility to meet an individual's health care needs while continuing to live safely in the community. The purpose of a PACE program is to provide pre-paid, capitated, comprehensive health care services that are designed to enhance the quality of life and autonomy for frail, older adults; maximize the dignity of and respect for older adults; and enable frail, older adults to live in their homes and in the community as long as medically and socially feasible to preserve and support the older adult's family unit.

The PACE service area is defined by the ZIP code served by the PACE program. As of 2012, there were 88 PACE programs operational in 29 states. The number of PACE programs is not limited by CMS. The state Medicaid programs control whether PACE programs are created in their states. An organization that wishes to create a PACE program must approach the state Medicaid agency and participate in an approval process; even then, it is the state that submits the PACE application. Therefore the state controls not only whether a PACE program is founded, but also whether the state wants to expand into it.

Once created, each PACE program has a specific service area. The PACE website¹⁰ is the best place to see if a PACE program is available in a given area. Although all PACE participants must be certified for nursing-home care, the majority of PACE participants continue to stay or reside in their home. If a PACE enrollee does need nursing home care, the PACE program pays for and coordinates the patient's care. PACE is like health insurance: If a person qualifies for Medicaid, the Medicaid program pays for the monthly PACE program; Medicare will pay the balance. Individuals not qualified for Medicaid will pay the monthly premium in the amount Medicaid traditionally would pay.

A. Available Services Offered Through PACE

Does the applicable PACE program offer the following?

1. Adult daycare;
2. Medical care provided by a PACE physician familiar with the history, needs, and preferences of each participant;
3. Home health care and personal care;
4. All necessary prescription drugs;
5. Social services;
6. Medical specialists (*e.g.*, audiology, dentistry, optometry, podiatry, and/or speech therapy);
7. Respite care; and/or
8. Hospital and nursing-home care when necessary.

B. PACE Participation Requirements

As indicated, PACE participation has straightforward restrictions, but offers the entire continuum of care to seniors with chronic care needs. Does the individual's state PACE program have the following eligibility requirements?

1. Individual must be fifty-five years of age or older;
2. Certified by the state to need nursing home care; and
3. Live in an area served by a PACE program.

C. PACE Organization Requirements

Does the individual's state PACE program have the following characteristics?

1. Operates as a not-for-profit, for-profit private or public entity that is primarily engaged in providing PACE services (Note: For-profit entities operating PACE organizations do so under demonstration authority.);
2. Has a governing body that includes participant representation;
3. Provides the complete service package regardless of frequency or duration of services;
4. Has a physical site and staff to provide primary care, social services, restorative therapies, personal care and supportive services, nutritional counseling, recreational therapy and meals;
5. Has a defined service area;
6. Employs safeguards against conflict of interest;
7. Demonstrates fiscal soundness;
8. Has a formal Participant Bill of Rights;
9. Has a process to address grievances and appeals; and

10. www.npaonline.org

10. Does not discriminate against any participant in the delivery of required PACE services based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation or source of payment indicated.

IX. MEDICAID WAIVER PROGRAM

Medicaid waiver is a program funded jointly by the federal government and the applicable state. In it, a principal who qualifies for skilled nursing care can obtain the services in the home, or in a setting other than a skilled nursing facility. While the PACE program applies only to seniors, Medicaid waivers can apply to a number of individuals in all age groups. Such waivers also apply for services provided under the Children's Health Insurance Program (CHIP) and for individuals who are developmentally disabled. State programs must be approved by the federal government to participate. If the state is approved, then Medicaid funding may be available for care in a setting other than a skilled nursing facility.

1. What is a Medicaid waiver?
2. Who qualifies for Medicaid waiver?
3. Does the applicable state participate in the Medicaid waiver program?
4. In which Medicaid waiver program does the state participate and what type of waiver is applicable?
 - a. Section 1115 Research & Demonstration Projects (Note: States can apply for program flexibility to test new or existing approaches to financing and delivering Medicaid and CHIP.);
 - b. Section 1915(b) Managed Care Waivers (Note: States can apply for waivers to provide services through managed care delivery systems or otherwise limit people's choice of providers.);
 - c. Section 1915(c) Home and Community-Based Services Waivers (Note: States can apply for waivers to provide long-term care services in home and community settings rather than institutional settings.); or
 - d. Concurrent Section 1915(b) and 1915(c) Waivers (Note: States can apply to simultaneously implement two types of waivers to provide a continuum of services to the elderly and people with disabilities, as long as all federal requirements for both programs are met.).
5. Is in-home care or other care available in the applicable jurisdiction under a Medicaid waiver?



6. Are the following services covered under the waiver?
 - a. Room and board;
 - b. Medications;
 - c. Therapy;
 - d. Personal Care;
 - e. Housekeeping; and
 - f. Ancillary services such (e.g., podiatry, dental care).
7. Is durable medical equipment (e.g., hospital bed, manual/ electric wheelchair, mechanical lifts) covered?
8. Does the state use a managed care delivery system rather than a fee-for-service system?
9. How long is the waiting period for the individual to be eligible to participate in the state's Medicaid waiver program?
10. Are there care limitations that would prevent admission into the state's Medicaid waiver program?
11. Since Medicaid waiver eligibility does not transfer from state to state, what happens if the individual desires to relocate to another state?
12. If the individual plans to relocate to a new state and is already participating in a Medicaid waiver program, how long is the waiver waiting period in the new state?
13. Does the state's Medicaid waiver program cover autism?
14. What services are available using Medicaid waiver dollars?
 - a. Behavioral support;
 - b. Community access;
 - c. Community guide;
 - d. Community living support;
 - e. Community residential alternatives such as assistance with ADL;



- f. Dental services;
 - g. Environmental accessibility adaptation to modify a home to make it more accessible (e.g., ramps, grab bars);
 - h. Financial support;
 - i. Professional therapeutic services;
 - j. Respite care;
 - k. Specialized medical equipment and supplies;
 - l. Support coordination;
 - m. Transportation; and
 - n. Vehicle adaptation.
15. What home and community-based services are available for Medicaid beneficiaries?
- a. 1915 (c) Home and Community-Based Waivers;
 - b. 1915(i) State Plan Home and Community-Based Services;
 - c. 1915(j) Self-Directed Personal Assistance Services Under State Plan; and
 - d. 1915(k) Community First Choice. 

APPENDIX A

SELECTED HEALTH CARE GLOSSARY

Accountable Care Organization (ACO)—A group of coordinated health care providers that care for all or some of the health care needs of a defined population. This business model generally focuses on moving away from fee-for-service by creating payment and delivery reforms that tie provider reimbursements to quality metrics, reductions in the total cost of care and patient satisfaction.

Accelerated Death Benefits—Some life insurance companies offer life insurance policies with a special feature that allows payment of the death benefit when the insured person is still alive. Such payment usually is limited to situations in which the individual is terminally ill. The benefits are available to cover the costs of long-term care services.

Activities of Daily Living (ADL)—Physical functions that an independent person performs each day, including bathing, dressing, eating, toileting, walking or wheeling, and transferring into and out of bed or a chair.

Acute—A sudden and severe condition.

Adaptive/Assistive Equipment—An appliance or gadget which assists the user in the operation of self-care, work or leisure activities.

Adult Daycare Center—A community-based program offering structured activities and meals. Some health services may be offered for an additional fee. Transportation may be provided. Most programs operate during the week and can be attended full or part-time.

Adult Day Health Care—Provision of care and services in a residential health care facility or approved extension site, on an outpatient basis, under the medical direction of a physician. Services are in accord with a comprehensive assessment of care needs and individualized health care plan.

Advance Directives—A written statement of an individual's preferences and directions regarding health care. Advance directives protect a person's rights even if he or she becomes mentally or physically unable to choose or communicate his or her wishes.

Aging-in-Place—A term used to describe the circumstance that elderly residents who have lived in their homes or apartments for several years often require more supportive services than when they were initially moved-in. Physiologically, a combination of changes brought on by normal aging and chronic underlying illnesses resulting in increased frailty. Aging-in-place generally describes a movement to moving services to an individual where they live, rather than moving the individual to the services.

Alzheimer's Disease—A progressive and irreversible organic disease, typically occurring in the elderly and characterized by degeneration of the brain cells, leading to dementia, of which Alzheimer's is the single most common cause. Progresses from forgetfulness to severe memory loss and disorientation, lack of concentration, loss of ability to calculate numbers and finally to increased severity of all symptoms and significant personality changes.

Ambulate—To walk.

Area Agencies on Aging (AAA)—Local government agencies which provide or contract for services for older persons within their area.

Assessment—Determination of a resident's care needs, based on a formal, structured evaluation of the resident's physical and psychological condition and ability to perform activities of daily living.

Assisted Living—Senior housing that provides individual apartments, which may or may not have a kitchenette. Facilities typically offer twenty-four-hour on-site staff, congregate dining, and activity programs. Limited nursing services may be provided for an additional fee.

Audiologist/Audiology—Health care professionals specializing in the measurement of hearing and the correction of hearing impairment or hearing loss.

Bed Sores—See Pressure Ulcers

Bedfast—To be bedridden.

Board and Care Homes—These are group living arrangements that are designed to meet the needs of people who cannot live independently, but do not require nursing facility services. These facilities offer a wider range of services than independent living options. Most provide help with some of the activities of daily living. In some cases, private long-term care insurance and medical assistance programs will help pay for this type of living.



Caregiver–Any individual who takes care of an elderly person or someone with physical or mental limitations.

Case Management–A system in which one individual helps the insured person and his or her family determine and coordinate necessary health care services and the best setting for those services.

Case Mix–A formulative method used in some states to determine patients’ needs for health care resources within a nursing facility. The assessment is based in part on the resident’s functional ability to perform ADL, as well as the medical and psychiatric diagnosis. It also refers to the classification of a patient’s impairments that a facility or service provider uses to determine the daily rate charged for the resident’s care based on his or her condition and the care received at the time of the assessment.

Centers for Medicare & Medicaid Services (CMS)–Formerly the Health Care Financing Administration, CMS is an element of the Department of Health and Human Services, which finances and administers the Medicare and Medicaid programs. Among other responsibilities, CMS establishes standards for the operation of nursing facilities that receive funds under the Medicare or Medicaid programs.

Certificate of Medical Necessity–A document completed and signed by a physician to certify a patient’s need for certain types of durable medical equipment (i.e. wheelchairs, walkers, etc.).

Certified Home Health Care–An entity that provides, as a minimum, the following services which are of a preventative, therapeutic, health guidance and/or supportive nature to persons at home: nursing services; home health aide services; medical supplies, equipment and appliances suitable for use in the home; and at least one additional service such as the provision of physical therapy, occupational therapy, speech/language pathology, respiratory therapy, nutritional services and social work services.

Certified Nursing Assistant (CNA)–The CNA provides personal care to residents or patients, such as bathing, dressing, changing linens, transporting and other essential activities. CNAs are trained, tested, certified and work under the supervision of an RN or LPN.

Cognition–The process of knowing; of being aware of thoughts. The ability to reason and understand.

Cognitive Impairment–A diminished mental capacity, such as difficulty with short-term memory.

Co-morbidities–Multiple disease processes.

Companion Care–Non-medical services that are provided in the patient’s home. Examples include, but are not limited to helping the senior with everyday activities, making meals, grooming, ensuring safety, etc. No medical care is provided.

Congestive Heart Failure (CHF)–A common type of heart disease characterized by inadequate pumping action of the heart.

Conservator–Person appointed by the court to act as the legal representative of a person who is mentally or physically incapable of managing his or her affairs.

Continuing Care Retirement Communities (CCRCs)–Housing communities that provide different levels of care based on the needs of their residents - from independent living apartments to skilled nursing in an affiliated nursing facility. Residents move from one setting to another based on their needs, but continue to remain a part of their CCRC’s community. Typically CCRCs require a payment (called an endowment) prior to admission, then charge monthly fees above that.

Custodial Care–Board, room and other personal assistance services (including assistance with activities of daily living, taking medicine and similar personal needs) that may not include a skilled nursing care component.

CVA–Refers to a cerebrovascular accident or stroke in which an area of the brain is damaged due to a sudden interruption of blood supply.

Decubitus–See Pressure Ulcers.

Dementia–Progressive mental disorder that affects memory, judgment and cognitive powers. One type of dementia is Alzheimer’s disease.

Developmental Disability (DD)–Refers to a serious and chronic disability, which is attributable to a mental or physical impairment or combination of mental and physical impairments. Those affected have limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity of independent living, economic self-sufficiency. Those who have a developmental disability often require long-term treatment and care planning.

Diagnostic Related Groups (DRGs)–DRGs are used to determine the amount that Medicare reimburses hospitals for in-patient services. The hospital is reimbursed a fixed amount based on the DRG code for the patient.

Discharge Planner—A social worker or nurse who assists patients and their families with health care arrangements following a stay in a health care institution.

Distinct Parts—Separate units in a nursing facility where beds are available only for people whose care is paid for by a specific payment source, such as Medicare.

Durable Medical Equipment (DME)—Durable medical equipment, as defined by Medicare, is equipment which can (i) withstand repeated use; (ii) is primarily and customarily used to serve a medical purpose; (iii) generally not useful to a person in the absence of an illness or injury; and (iv) is appropriate for use in the home (e.g. wheelchairs, hospital beds, walkers).

Durable Power of Attorney for Health Care (DPAHC)—A legal document in which a competent person gives another person (called an attorney-in-fact) the power to make health care decisions for him or her if unable to make those decisions. A DPAHC can include guidelines for the attorney-in-fact to follow in making decisions on behalf of the incompetent person.

Dual Eligible(s)—Someone who is qualified for both Medicaid and Medicare.

Eden Alternative—Concept for skilled nursing facilities that embraces children, nature and animals to be part of facility life.

Emergency Response Systems—Electronic monitors on a person or in a home that provide automatic response to medical or other emergencies.

End Stage Renal Disease (ESRD)—Medical condition in which a person's kidneys no longer function, requiring the individual to receive dialysis or a kidney transplant to sustain his or her life.

Exclusion—Any condition or expense for which a policy will not pay.

Fee for Service—Method of charging whereby a physician or other practitioner bills for each encounter or service rendered. This is the usual method of billing by the majority of physicians.

Fee Schedule—A listing of accepted charges or established allowances for specified medical, dental, or other procedures or services. It usually represents either a physician's or third party's standard or maximum charges for the listed procedures.

Fiscal Intermediary (FI)—Private health insurance company under contract with the Centers for Medicare & Medicaid Services (CMS) to handle claims processing for Medicare Part A.

Geriatrics—The branch of medicine that focuses on providing health care for the elderly and the treatment of diseases associated with the aging process.

Grace Period—Thirty days after the premium is due before the long-term care insurance policy lapses.

Grandfather—A legal term that means all existing conditions that were present at the time of a law, legal agreement, or ordinance do not have to be changed since they were there when the conditions were legal.

Guardianship—An extreme measure that severely restricts the legal rights of a person based on a court's finding of legal incompetence. Another individual is assigned the responsibility of handling the person's legal affairs.

Healthcare Directive—A written legal document which allows a person to appoint another person (agent) to make health care decisions should he or she become unable to make or communicate decisions.

Healthcare Power of Attorney—The appointment of a health care agent to make decisions when the principal becomes unable to make or communicate decisions.

Health Maintenance Organization (HMO)—An organization that, for a prepaid fee, provides a comprehensive range of health maintenance and treatment services (including hospitalization, preventive care, diagnosis, and nursing).

Home Health Agency (HHA)—An agency that provides medical services in a home setting. Services may be provided by a nurse; occupational, speech or physical therapist; social worker, or home health aide.

Hospice—Hospice/palliative care is provided to enhance the life of the dying person. Often provided in the home by health professionals, today there are many nursing facilities and acute care settings that also offer hospice services. Hospice care, typically offered in the last six months of life, emphasizes comfort measures and counseling to provide social, spiritual and physical support to the dying patient and his or her family.

Indemnity Benefit—A flat payment made directly to the policyholder, rather than to the provider for services rendered.



Inflation Protection—One of several mechanisms that can be built into insurance policies to provide for some increase over time of the daily benefit to account for inflation. Addition of this feature to a policy can be important depending on your situation, but it also raises the price of the policy.

Intermediate Care Facility/Mentally Retarded (ICF/MR)—A licensed facility with the primary purpose of providing health or rehabilitative services for people with mental retardation or people with developmental disabilities.

Inpatient—A patient who has been admitted at least overnight to a hospital or other health facility (which is, therefore, responsible for the patient's room and board) for the purpose of receiving a diagnosis, treatment, or other health services.

Instrumental Activities of Daily Living (IADL)—An index which measures a client's ability and degree of independence in cognitive and social functioning, such as shopping, cooking, doing housework, managing money, and using the telephone.

IV/Infusion Therapies—The way that liquid solutions or liquid medications are administered directly into the blood stream through an intravenous catheter inserted in a vein in the body. Infusion therapies can include total parenteral nutrition, antibiotics or other drugs, blood, and chemotherapy.

Living Will—A legal document in which a competent person directs in advance that artificial life-prolonging treatment not be used if he or she has or develops a terminal and irreversible condition and becomes incompetent to make health care decisions.

Long Term Care (LTC)—The broad spectrum of medical and support services provided to persons who have lost some or all capacity to function on their own due to a chronic illness or condition, and who are expected to need such services over a prolonged period of time. Long-term care can consist of care in the home by family members who are assisted with voluntary or employed help, adult day health care, or care in assisted living or skilled nursing facilities.

Long Term Care Insurance—A policy designed to help alleviate some of the costs associated with long-term care. Benefits are often paid in the form of a fixed dollar amount (per day or per visit) for covered expenses and may exclude or limit certain conditions from coverage.

MDS (Minimum Data Set)—A core set of screening and assessment elements, including common definitions and coding categories that form the foundation of the comprehensive assessment for all patients of long-term care facilities certified to participate in Medicare and Medicaid.

The items standardize communication about patient problems and conditions within facilities, between facilities and outside agencies.

Medicaid—The federally supported, state operated public assistance program that pays for health care services to people with a low income, including elderly or disabled persons who qualify. Medicaid pays for long-term nursing facility care, some limited home health services, and may pay for some assisted living services, depending on the state.

Medicaid-Certified Bed—A nursing facility bed in a building or part of a building which has been determined to meet federal standards for serving Medicaid recipients.

Medical Records Director/Coordinator—Plans and directs the activities and personnel of the department. Coordinates the management of resident medical records and the clerical needs of the nursing department.

Medically Necessary—Medical necessity must be established (via diagnostic and/or other information presented on the claim under consideration) before the carrier or insurer will make payment.

Medicare—The federal program providing primarily skilled medical care and medical insurance for people aged 65 and older, some disabled persons and those with end-stage renal disease.

Medicare Part A—Hospital insurance that helps pay for inpatient hospital care, limited skilled nursing care, hospice care, and some home health care. Most people get Medicare Part A automatically when they turn 65.

Medicare Part B—Medical insurance that helps pay for doctors' services, outpatient hospital care, and some other medical services that Part A does not cover (like some home health care). Part B helps pay for these covered services and supplies when they are medically necessary. A monthly premium must be paid to receive Part B.

Medicare Supplemental Insurance—This is private insurance (often called Medigap) that pays Medicare's deductibles and co-insurances, and may cover services not covered by Medicare. Most Medigap plans will help pay for skilled nursing care, but only when that care is covered by Medicare.

Medigap Insurance—A term commonly used to describe Medicare supplemental insurance policies available from various companies. Medigap is private insurance that may be purchased by Medicare-eligible individuals to help pay the deductibles and co-payments required under Medicare. Medigap policies generally do not pay for services not covered by Medicare.

Nursing Facility (NF)–Nursing facilities are licensed to provide custodial care, rehabilitative care, such as physical, occupational or speech therapy or specialized care for Alzheimer’s patients. Additionally, nursing facilities offer residents planned social, recreational and spiritual activities. NFs are usually certified for participation in the Medicaid program. If the facility also participates in Medicare, it is generally termed a “skilled” nursing facility.

Nursing Home–A facility that provides an organized professional staff and inpatient beds and that provides continuous nursing and other health–related, psychosocial, and personal services to patients who are not in an acute phase of illness, but who primarily require continued care on an inpatient basis. Generally, nursing home residents have physical or mental problems that keep them from living on their own and they usually require daily assistance.

Nurse, Licensed Practical (LPN)–A graduate of a state–approved practical nursing education program, who has passed a state examination and been licensed to provide nursing and personal care under the supervision of a registered nurse or physician. An LPN administers medications and treatments and acts as a charge nurse in nursing facilities.

Nurse, Registered (RN)–Nurses who have graduated from a formal program of nursing education (two–year associate degree, three–year hospital diploma, or four–year baccalaureate) and passed a state–administered exam. RNs have completed more formal training than licensed practical nurses and have a wider scope of responsibility including all aspects of nursing care.

Nurse Practitioner–A nurse who has one or more years of advanced training and has passed a special exam. A nurse practitioner often works with a doctor and can do some of the same things a doctor does.

Occupational Therapist–Occupational therapists evaluate, treat, and consult with individuals whose abilities to cope with the tasks of everyday living are threatened or impaired by physical illness or injury, psychosocial disability, or developmental deficits. Occupational therapists work in hospitals, rehabilitation agencies, long term care facilities, and other health care organizations.

Ombudsman–An advocate (supporter) who works to solve problems between residents and nursing homes, as well as assisted living facilities. Also called “Long–Term Care Ombudsman.”

Outline of Coverage–A description of policy benefits, exclusions and provisions that makes it easier to understand a particular long–term care insurance policy and compare it with others.

Outpatient–A patient who receives care at a hospital or other health facility without being admitted to the facility for an overnight stay. Outpatient care also refers to care given in organized programs, such as outpatient clinics.

Patient Assessment–Also called resident assessment. A standardized tool that enables nursing homes to determine a patient’s abilities, what assistance the patient needs and ways to help the patient improve or regain abilities. Patient assessment forms are completed using information gathered from medical records, discussions with the patient and family members, and direct observation.

Period of Confinement–The time during which an individual receives care for a covered illness. The period ends when the individual has been discharged from care for a specified period of time, usually six months.

Private Pay Patients–Patients who pay for their own care or whose care is paid for by their family or another private third party, such as an insurance company. The term is used to distinguish patients from those whose care is paid for by governmental programs (Medicaid, Medicare, and Veterans Administration).

Program of All–Inclusive Care for the Elderly (PACE)–PACE programs serve individuals with long term care needs by providing access to the entire continuum of health care services, including preventive, primary, acute and long term care. A basic tenet of the PACE philosophy is that it is better for both the senior with long term care needs and the health care system to focus on keeping the individual living as independently as possible in the community for as long as possible.

Personal Care–Nonskilled, personal care, such as help with activities of daily living like bathing, dressing, eating, getting in and out of bed or chair, moving around, and using the bathroom. It may also include care that most people do themselves, like using eye drops. The Medicare home health benefit does pay for personal care services.

Physical Therapy–Services provided by specially trained and licensed physical therapists in order to relieve pain, restore maximum function, and prevent disability or injury.



Power of Attorney—A legal document allowing one person to act in a legal matter on another's behalf pursuant to financial or real-estate transactions.

Pre-Admission Screening—An assessment of a person's functional, social, medical, and nursing needs, to determine if the person should be admitted to nursing facility or other community-based care services available to eligible Medicaid recipients. Screenings are conducted by trained preadmission screening teams.

Preexisting Conditions—Medical conditions that existed, were diagnosed, or were under treatment before an insurance policy was taken out. Long term care insurance policies may limit the benefits payable for such conditions.

Pressure Ulcers—A breakdown of the skin, to which bed-ridden persons are especially susceptible. Also referred to as pressure sores or decubitus ulcers.

Prospective Payment System (PPS)—A method of reimbursement in which Medicare payment is made based on a predetermined, fixed amount. The payment amount for a particular service is derived based on the classification system of that service. Certain providers, including hospitals, skilled nursing facilities, and home health agencies are paid by Medicare under PPS.

Provider—Someone who provides medical services or supplies, such as a physician, hospital, x-ray company, home health agency, nursing home or pharmacy.

Psychotropic Drugs—Antidepressants, anti-anxiety drugs, and anti-psychotic drugs used for delusions, extreme agitation, hallucinations, or paranoia. They are often referred to as mind or behavior altering drugs.

Qualified Medicare Beneficiaries (QMB)—A federally required program where states must pay the Medicare deductibles, co-payments as well as Part B premiums for Medicare beneficiaries who qualify based on income and resources.

Quality Assurance Director—Coordinates quality assurance programs and policies for the facility, and typically is a licensed nurse.

Range of Motion (ROM)—The movement of a joint to the extent possible without causing pain.

Reasonable and Necessary Care—The amount and type of health services generally accepted by the health community as being required for the treatment of a specific disease or illness.

Resident—A person living in a long term care facility. Since nursing facilities are licensed health care facilities, residents are often also referred to as patients.

Resident Assistant (RA)—RAs generally work in assisted living residences and provide direct personal care services to residents, but they are not certified CNAs. Depending on the state, this position is also available in some nursing facilities.

Resident Care Plan—A written plan of care for nursing facility residents, developed by an interdisciplinary team which specifies measurable objectives and timetables for services to be provided to meet a resident's medical, nursing, mental and psychosocial needs.

Residential Care Facility—Group living arrangements that are designed to meet the needs of people who cannot live independently, but do not require nursing facility services. These homes offer a wider range of services than independent living options. Most provide help with some of the activities of daily living. In some cases, private long-term care insurance and medical assistance programs will help pay for this type of service.

Respiratory Therapy—Assists patients with breathing difficulties to reduce fatigue and increase tolerance in performing daily activities.

Respite Care—Scheduled short-term nursing facility care provided on a temporary basis to an individual who needs this level of care but who is normally cared for in the community. The goal of scheduled short-term care is to provide relief for the caregivers while providing nursing facility care for the individual. Short-term stay beds used for respite care must be distinct from general nursing facility beds.

Restorative Assistant (RA)—A person generally working in a nursing home whose primary function is to provide range-of-motion to residents.

Senior Housing—Independent living units, generally apartments. Any supportive services, if needed, are through contract arrangement between tenant and service provider.

Senile Dementia—Dated term for organic dementia associated with old age. Now referred to as dementia and/or Alzheimer's disease.

Side Rail—Rails on a hospital-type bed that are meant to protect a patient or to facilitate movement.

Skilled Nursing Care—Nursing and rehabilitative care that can be performed only by, or under the supervision of, licensed and skilled medical personnel.

Skilled Nursing Facility (SNF)–Provides twenty–four–hour nursing care for chronically ill or short–term rehabilitative residents of all ages. SNFs are usually certified for participation in the Medicare program.

Speech Therapy–This type of service helps individuals overcome communication conditions such as aphasia, swallowing difficulties and voice disorders. Medicare may cover some of the costs of speech therapy after client meets certain requirements.

Sub–Acute Care–A level of care designed for the individual who has had an acute event as a result of an illness, and is in need of skilled nursing or rehabilitation but does not need the intensive diagnostic or invasive procedures of a hospital.

Sub–Acute Care Facilities–Specialized units often in a distinct part of a nursing facility. Provide intensive rehabilitation, complex wound care, and post–surgical recovery for persons of all ages who no longer need the level of care found in a hospital.

Subsidized Senior Housing–A program that accepts Federal and State money to subsidize housing for older people with low to moderate incomes.

Supplemental Security Income (SSI)–A federal program that pays monthly checks to people in need who are sixty–five years or older or who are blind or otherwise disabled. The purpose of the program is to provide sufficient resources so

that any one who is sixty–five or older, blind, or otherwise disabled, can have a basic monthly income. Eligibility is based on income and assets.

Tax Qualified–The tax deductibility of long term care insurance premiums depending upon meeting the federal government’s threshold of personal adjusted gross income.

Total Parenteral Nutrition (TPN)–TPN is typically administered through a large vein in the body because of its high concentration of ingredients. Individuals who are unable to eat or who do not receive enough calories, essential vitamins, and minerals from eating can receive enough nutrients from TPN to maintain their weight. This type of nutrition requires a doctor’s order.

Ventilator–A ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

Sources:

Centers for Medicare & Medicaid Services at www.cms.hhs.gov
American Health Care Association at www.ahcancal.org
Leading Age at www.leadingage.org



APPENDIX B

INTERNAL REVENUE SERVICE'S TWENTY-FACTOR TEST TO DISTINGUISH BETWEEN EMPLOYEES AND INDEPENDENT CONTRACTORS

I. EMPLOYEES VS. INDEPENDENT CONTRACTORS

The issues relating to whether a worker is an employee or an independent contractor depend heavily on the individual facts of a given situation. Generally, if a worker arrives for shifts pre-designated by the employer and provides services under the employer's direction, and is paid an hourly wage, then the worker is an employee. If a worker comes at the worker's discretion to perform a function, and is paid a fee per the

function rather than on an hourly basis, then the worker may be treated as an independent contractor. Professional personnel may be independent contractors if they: (i) set their own schedules; (ii) provide their own equipment; (iii) perform a professional service; (iv) work with multiple clients; and (v) pay their own taxes (FICA) and benefits. Federal and state penalties can apply if the wrong choice is made.

The IRS twenty-factor test is complex; rarely does any situation fit clearly within all the factors. Patients and families who consider hiring workers directly and treating them as independent contractors are well advised to consult an attorney.

The following chart delineates the twenty factors used by the IRS to distinguish between employees and independent contractors.

	Issue	Employee	Independent Contractor
1	Instructions	Required to comply with employer's instructions as to how to do the job.	Follows own instructions.
2	Training	Required to be trained by employer on how to do the job.	Does not require training from employer.
3	Integration	Services are fully integrated into employer's business, which is significantly dependent upon them.	Services are not integrated into employer's business.
4	Personal	Required to perform services personally.	Not required to perform services personally.
5	Assistants	Assistants are hired, supervised and paid by employer.	Generally hires own assistants, required only to attain a particular result.
6	Continuity	A continuing economic relationship which may include work at recurring but irregular intervals.	No assumption of continuing relationship.
7	Hours of Work	Required to perform work within set hours of work specified by employer.	Free to establish own hours of work.
8	Time Required	Usually devoted full-time to employer's business, may be restricted from performing work for others.	May work at any time and for whom he chooses.
9	Work Location	Performs work on employer's premises. (Importance dependent on nature of work and requirements, if any, of employer)	Work may be performed anywhere, often at worker's office or location.
10	Sequence of Work	Follows order or sequence of work set by employer.	Free to accomplish work in any sequence.
11	Reports	Generally makes regular or periodic, either oral or written, to employer.	Not necessarily required to submit regular reports.
12	Payment	Is generally paid by time, i.e. hour, week or month.	Is generally paid by result, i.e. completion of project or straight commission.
13	Expenses	Is generally reimbursed for business-related expenses, implying right of regulation and direction by employer.	Generally, covers own expenses and expenses may be included in total payment.
14	Tools & Materials	Tools and materials needed for job are provided by employer.	Uses his own tools and materials to accomplish work.
15	Facility Investment	Generally has no investment in facilities required to accomplish work, indicating dependence on employer's facilities.	Has an investment in facilities, such as an office rented from third party.
16	Profit or Loss	Cannot realize a profit or loss on his services.	Has an exposure to economic gain or loss on accomplishment of work.
17	Simultaneous Work	Performs work under a single financial arrangement.	Performs work simultaneously for multiple, unrelated persons or entities.
18	General Public	Does not make services available to general public.	Makes services available to general public on regular basis.
19	Discharge	Employer can fire and thereby control nature and pace of work through threat of firing.	Cannot be discharged so long as the result is satisfactory.
20	Termination	Can quit at any time without liability.	Can terminate only with risk of breach of contract liability.

II. ADDITIONAL ISSUES IF INDIVIDUAL IS CONSIDERED AN EMPLOYEE

- A.** The worker must be paid at least minimum wage and paid overtime.
- B.** State and federal unemployment taxes (FUTA) will apply.
- C.** Employers must pay a FICA tax under the Federal Insurance Contributions Act and either deduct the employee's share or pay it directly. At the employer's election, these employees may be treated as household employees; the taxes are paid as part of the employer's quarterly tax payments, and the final report is made on Schedule H at year's end when the employer files IRS Form 1040. It is important to note that state laws may vary, and may require monthly or quarterly deposits of tax.
- D.** The employer is not required to withhold employee income taxes (other than FICA, as discussed), but may do so if the employee requests. Schedules are available from the IRS and state tax agencies for associated withholding and payment.
- E.** There may be mandatory state taxes, such as unemployment compensation (either in the form of a tax or mandatory insurance). There also may be workers' compensation tax or insurance requirements. The state may or may not use the same schedules as IRS for reporting and payment.



APPENDIX C

MANAGEMENT OF PAIN AND ATTENDANT SYMPTOMS¹¹

I. GENERAL CONSIDERATIONS PAIN

Pain, an unpleasant sensory and emotional experience associated with actual or potential tissue damage, is the third largest global public health problem.¹² New evidence suggests that more than 100 million Americans live with pain.¹³

Literature suggests that more than 50% of people greater than 60 years old have chronic pain (*i.e.*, non-malignant and persistent pain lasting more than 3 months). In the United States, greater than 11 million individuals are diagnosed

with cancer annually and, by 2020, global cancer rates are estimated to increase by 50%.¹⁴ Furthermore, 80% of people with cancer experience pain, and more than 40% have end-of-life pain (*i.e.*, pain in the last 6 months of life).¹⁵ All types of pain including breakthrough pain (*i.e.*, pain flares interrupting well-controlled baseline pain), cancer related chronic pain and end-of-life pain negatively affect health and well-being.¹⁶ By 2030, the number of Americans with cancer is expected to grow to 18 million, or 2.3 million new cases each year. Both cancer and pain are global public health problems that exact a significant psychological, familial, and societal toll while costing more than \$560 billion and more than \$227 billion annually in direct and indirect health costs.¹⁷ Since there will be greater than 110 million people over 50 years old in the U.S. by 2030,¹⁸ pain will have an increasingly important effect on society's collective health.

11. The Task Force is grateful for the assistance of Jeanne G. Lewandowski, M.D., in reviewing drafts of this Appendix and making recommendations. Dr. Lewandowski is a Detroit, MI, area pediatrician who provides palliative care to dying children, and is board-certified in pediatrics and palliative care medicine.
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Pain is a feared and neglected public health problem and a silent epidemic with significant and potentially devastating socio-economic and health ramifications.¹⁹ In the United States, pain is the most frequent cause of disability (more than 700 million lost workdays) and the leading cause of physician visits in the United States costing \$560-635 billion health care costs annually.²⁰ Despite its toll, one of the most difficult tasks facing patients living with pain is to obtain access to quality pain care and effective management of their pain and attendant symptoms. This may be particularly difficult for an individual with a life-limiting condition who has chronic pain (i.e., persistent pain lasting more than 3 months).

There are many different therapeutic modalities such as psychological counseling, physical therapy, massage, medications (i.e., opioid, non-opioid, adjuvants), complementary and alternative techniques, and nerve blocks available to relieve pain. These techniques, however, are not always deployed and unfortunately seldom are used effectively in conjunction with each other. Medical professionals agree that: (i) it is possible to provide significant relief for most painful conditions and most unpleasant symptoms; (ii) patients deserve good pain management; and (iii) the best practice is to believe the patient's reports of pain. Studies demonstrate that it is unhealthy for patients to be in pain, and that appropriate pain relief both prolongs life and contributes to improvements in quality of life. Thus, health care providers need to appropriately assess pain complaints and recommend appropriate pain-relief regimens that are effective to optimize pain care.

Literature supports wide variability in pain assessment and treatment based upon patient and health care provider sociodemographic characteristics such as age, race, ethnicity, gender, class and insurance status contributing to differences and disparities in the quality of pain care. In addition, the literature suggests that although pain is one of the most frequent reason a patient consults his physician, all health care professionals receive minimal education regarding how to appropriately assess and treat pain complaints.

A. Patients And Their Families Often Have Significant Questions and Concerns Regarding Pain and Symptom Management.

1. Is the individual in pain? Can the patient's pain be relieved?
2. Do physicians believe the patient's reports of pain?
3. Are there benefits to optimizing pain management? Are there side effects of pain management such as loss of mental or physical function, constipation, or a risk of tolerance, dependence, or addiction?
4. Is it a sign of strong character to be stoic in the face of pain, and avoid pain medication? Is pain a sign that an individual's disease has become worse? Will complaints of pain prevent health care professionals from treating other medical problems?
5. Are there cultural or religious issues related to pain and pain medication?
6. Is it a cause for concern if, over time, a patient requires different dosages of medication or different types of medication? If so, is this a sign of addiction, or a sign that the patient is developing tolerance or dependence and requires an adjustment in pain medication (especially opioid analgesics) to maintain a consistent level of relief of pain?
7. Is it a cause for concern if an individual patient requires higher dosages than other patients with the same type of condition?

B. Similarly, Health Care Professionals Often Have Serious Concerns

When Addressing Pain-related Issues of Their Patients.

1. What is the nature of the condition that is causing the pain?
2. What types of pain medication, dosages, frequencies or other measures are appropriate in the patient's situation?
3. Is the patient's pattern of medication usage consistent with a need for pain relief?

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- C. It is very important for the patient and family to have** a clear understanding of the responsible health care professional's views, because differences in professional views exist on which medications or categories of medications are the most effective, and which have the greatest potential for risk. Families and patients should be educated to the potential benefits and risks of all therapeutic modalities used to manage pain as well as the need for multiple therapeutic modalities to be used in combination to manage pain complaints.
- D. Medications should be selected based on the patient's** condition, age, type of pain, overall medication regimen, other co-morbidities and known allergies or intolerances. Patients and families should be educated that opioids are only one component of therapy and many other medications are available to manage pain.
- E. Generally, it is recognized that, with respect to many** types of pain medications (*e.g.*, many in the opioid family), there is no upper limit of dosage, nor any minimum frequency, for administering the medication. Other medications used to manage pain such as anticonvulsants may require such limitations. The goal of pain-relief specialists is to use the lowest dose medication to achieve relief of pain symptoms and alleviate suffering with the least risk and unwanted side effects for the individual patient.
- F. Patients and families need to be informed about the** patient's pain-management needs, the medications available, and what the potential is for effective and optimal pain control in the patient's particular case. When the pain-management regimen is not effective, patients and families should keep the following in mind:
1. The attending or responsible physicians or health care professional should be informed if the medication or other pain-management regimen is not effective.
 2. There is no reason necessarily to think it is normal to be in pain, regardless of the patient's particular condition or disease process. Pain assessment, however, remains the gold standard of quality pain care.
 3. Side effects and any new concerns should be reported, including:
 - a. Nausea, vomiting, loss of functionality, excessive sleepiness or non-responsiveness (which may be signs that the pain regimen requires adjustment); and
 - b. Constipation (an expected side effect of some pain regimens, which may be alleviated by other measures [*e.g.*, stool softeners or changes in diet]).
- G. If pain and other unpleasant symptoms are not adequately controlled,** patients and their loved ones should ask the following questions:
1. What is the classification of the pain?
 - a. Acute pain, such as pain immediately after surgery or an injury?
 - b. Chronic cancer pain?
 - c. Chronic non-cancer pain, which may develop from other conditions or from poorly controlled acute pain?
 2. What is the type of pain?
 - a. Aching or throbbing (*i.e.*, somatic pain)?
 - b. Burning, shooting, or electric (*i.e.*, neuropathic pain)?
 - c. Other unpleasant symptoms (*e.g.*, numbness or tingling)?
 3. What medications are available for the classification and type of pain?
 4. What medications have been prescribed? What others could be tried?
 5. What forms (*i.e.*, tablets, capsules, liquids, patches), dosages and frequencies have been tried? What others are available?
 6. What risks or side effects might occur with a different form or different dosage or frequency? Do these risks or side effects vary with the dosages or the length of time of use?
 7. Are there combinations of drugs that could be effective when used together? Are consultations needed from other health care professionals (*e.g.*, pharmacy, physical therapy, social work)?
 8. May the following modalities that could be used alone, in combination with each other, or along with medication be tried:
 - a. Heat or cold;
 - b. Physical therapy and exercise;
 - c. Massage;
 - d. Machines known as transcutaneous electrical nerve stimulation (TENS) to promote blood flow to an area which, in turn, brings warmth, and therefore reduces pain;
 - e. Psychological counseling; or
 - f. Hypnosis, mindfulness, or distraction?

9. Is the patient's health care professional team knowledgeable about palliative care, which is a concept of care that attends to overall patient comfort? (Note: This care should be provided within the context of the patient's overall needs for care, and in all types of settings, ranging from medical care for acute conditions to hospice care for a patient with limited life expectancy.)

H. Sometimes the patient's third-party payer or administrator (e.g., insurance companies, HMOs, PPOs, and certain Medicare or Medicaid programs) have rules that affect prescribing, or they may have an approved medication list called a formulary. In those cases, patients and families should ask the following questions:

1. Are there effective substitute medications within the formulary?
2. If not, is there a process for prior approval, waiver or appeals to expand the formulary? Is there a patient representative or other resource to assist with related special problems?
3. In addition, are there special requirements for approval of referrals to pain specialists?
4. Is the patient eligible for a prescription assistance plan?

I. Sometimes patients may question whether they are receiving adequate pain management because of the following physician concerns:

1. The health care professional may be concerned that the patient's usage patterns or behavior suggest misuse or drug diversion;
2. Some health care professionals may have concerns about regulatory scrutiny simply on a potential basis that the physician prescribes certain dosages or frequencies of particular medications; or
3. Patients and health care professionals must address their own biases in order to ensure optimal pain care.

J. When pain is not well controlled, patients and their families should consider the following:

1. Is there concern that the patient may be misusing the drugs?
2. Is there concern that the patient may be diverting or selling drugs? Is there a concern about a prior or ongoing substance abuse disorder? Is there a concern about regulatory scrutiny?
3. Is there concern when the patient receives pain medication from multiple health care providers? Is this a sign that the patient is seeking drugs for non-medicinal

purposes, or is it a sign (as research shows is more commonly the case) that the patient's pain is not well controlled?

4. Would any of these concerns be alleviated by consultation with a pain specialist?
5. Would it be helpful for the patient and health care provider to enter into a written agreement (sometimes called a pain contract)? These contracts are recommended by some regulatory authorities in circumstances when a patient has unusual medication needs for the patient's condition, the pain is chronic and the need for medication is anticipated to exist for a long time, or the patient has previously had or currently has some other type of addiction. Typically, these behavioral contracts include one or more of the following provisions:
 - a. The patient will obtain pain medication only from one health care provider, or from multiple specialists who collaborate or otherwise keep each other informed on this point;
 - b. The patient will fill prescriptions only at one pharmacy;
 - c. The patient will store prescriptions securely (especially around children), and will take precautions against theft when other people are in the area where drugs are kept;
 - d. The patient will not habitually claim having lost medications or misplaced prescriptions; and
 - e. The patient will comply with all components of therapy such as physical therapy and psychological counseling, if prescribed as well as testing (including urine drug screening).

K. Patients and families need to balance their pain-medication needs with any and all related concerns raised by physicians and pharmacists. It is a crime to prescribe, distribute, or use certain pain medications for other than legitimate medicinal purposes. Physicians, pharmacists and regulators on state and federal levels have concerns when patients receive pain prescriptions on a regular basis from multiple health care providers, or fill multiple prescriptions at different pharmacies. Although these concerns are not unfounded (with respect to the potential for drug abuse, misuse, and/or diversion), significant research findings reflect that the majority of patients who seek pain medication from multiple health care providers do so because their pain is not well controlled. This illustrates the importance of optimizing physician/patient communication to ensure the best possible outcomes for pain care.



II. CONSIDERATIONS BASED UPON TREATMENT LOCATION

A. Hospitals and Other Acute Care Sites

Whenever a patient is in a hospital or other acute care health care facility, the patient should be reassessed periodically for pain issues. This is required by regulators, including health-facility licensing authorities and accreditation agencies.

1. Assessment should begin at admission. There are many pain scales that can be used. These include asking the patient to score pain from 0 to 10, with 0 being “no pain” and 10 being “the worst pain that the patient could imagine.” Another scale uses a pictorial range from “smiley faces” to “sad faces” to “frowns” and “crying faces.” Other scales require medical professionals to measure pain on behalf of infants and others who cannot communicate, with ratings for grimacing, moaning, and so on.
2. A patient should be reassessed at regular intervals after administration of pain medication to measure the effectiveness of the treatment regimen.
3. A patient should also be assessed before and after any treatments that could potentially cause pain, upon any changes in condition and at discharge.
4. In hospitals and other sites where procedures are performed, physicians usually are available to prescribe pain medication and to receive reports of nursing assessments of pain. In that setting, pain is usually well controlled. In rare situations, the patient may not receive adequate pain management, or there may be inconsistent administration of medications used for pain. When that happens, patients or their families should bring the situation to the attention of the medical team, so that the patient can receive adequate pain relief, and to ensure that the reasons for poor pain control can be addressed. These reasons can range from failure to prescribe the type, dosage, or frequency of medication required by the particular patient; use of artificially long durations between administration of medications; disagreements by some members of the team with the dosage and frequency prescribed; and, rarely, diversion of some or all of the medication by a member of the health care team.

B. Nursing Homes and Other LTC Facilities

Many of the same issues described in this Appendix apply in skilled nursing facilities and other types of LTC facilities; however, the following issues are unique to long term care settings.

1. Achieving the right medication regimen may be particularly difficult in skilled nursing facilities, because

physicians are not present on a daily basis and staff and staffing levels may vary. Additionally, in some states, nurses do not have the option to adjust dosages of medications based on patient needs in skilled nursing facilities. The loved ones of patients in a skilled nursing facility who have questions about the pain regimen should not hesitate to ask how they may be put in contact with the responsible physician in order to achieve an acceptable and appropriate level of relief.

2. The need for and effects of pain medications (based on type, dosage and frequency) may change over time.
3. Many patients in these facilities may be unable to advocate for their own needs.

C. Hospice Care

Achieving pain relief frequently is a hallmark of quality hospice care, whether in residential facilities or at home under a hospice regimen. It is not unusual for patients and families to express surprise when the patient is admitted to hospice care that the patient’s pain can be so well controlled, often without affecting a patient’s ability to interact with family and friends.

D. Home Use, Assisted Living, and Adult Foster Care

When patients are prescribed pain medications for use in the home or in other non-hospital settings, pharmacists may question the need for prescriptions, or not wish to fill them, if they do not personally know either the patient or the physician. It is important to establish a good relationship with a single pharmacy to fill prescriptions for controlled substances. Generally, when problems occur, it is because the pharmacy is caught by surprise and may not have the medication in stock, or does not know the patient or physician. (Some pharmacies limit their medication stocks to anticipated needs in order to minimize the risk of theft.) These problems can be minimized when the patient and/or family encourage collaboration between the physician and the pharmacy, and keep the pharmacy informed of the general refill schedule and when there are changes in medications. Rarely, patients will feel they are under scrutiny at a pharmacy even when their pain medication prescriptions are appropriate. If this happens, the patient should try to find a different pharmacy. If this problem persists, state pharmacy regulators should be consulted. When patients are to be prescribed medications for home use or in other non-hospital settings, the following issues should be addressed:

1. Are medications kept in a secure place where others cannot access them?
2. In addition to the patient, who has access to pain medications?

- a. Family members?
- b. Other residents?
- c. Home health care workers or other household staff?
 - Are they employees of the patient, self-employed or provided by agencies?
 - Are backgrounds and references carefully checked?
 - Is there a history of drug use or abuse?
 - Is there a history reflecting financial distress?
3. Are medication stocks regularly counted, and discrepancies accounted for by the patient or another reliable person?
4. Are there special prescription rules that need to be followed for prescriptions for home use?
 - a. Are there special forms that physicians may forget to use (e.g., some states require special prescription forms for certain controlled substances)?
 - b. Are there limitations on how many drugs can be prescribed on the same form? (Note: Federal regulations require a separate form for certain controlled substances.)
 - c. Are there limitations on refilling prescriptions for certain types of medications (e.g., certain controlled substances cannot be refilled, and require a new prescription)?
5. Does the patient have difficulty getting prescriptions filled?

III. PATIENT EDUCATIONAL TOOLS

When pain is not controlled, it is appropriate for patients and families to consult with professionals and to access educational tools. There are several recognized professional resources. Websites and print materials do not replace professional expertise; nevertheless, it may be comforting for patients to know that such resources exist. They may help the patient and family understand the patient's needs or may lead to other sources of help if problems arise. Such resources include the following:

A. Professional Resources

1. *Pain management specialists* are physicians who specialize in assisting patients whose painful conditions are difficult to treat or that resist treatment. A treating physician frequently will make a referral or ask a pain management specialist to consult on a case. If the physician does not do so, the patient or family may request the treating physician to make a referral, or the patient and family may make their own direct arrangements. Patients should be aware that some third-party payers (e.g., an insurance company, HMO, Medicare, or Medicaid) may require prior approval or require physician referrals. These physicians are often board certified in this emerging specialty. They are often associated with university and hospital practices.
2. *Palliative care specialists* are physicians whose care emphasizes patient comfort and maximum acceptability of uncomfortable situations which cannot be alleviated, so long as this treatment remains within the context of the patient's overall medical condition and needs for medical care. They also are often associated with university and hospital practices as well as hospices.
3. *Pharmacists* may be able to provide the greatest amount of assistance when involved in a collaborative relationship with the patient, as well as with the physicians who prescribe any medications for the patient. They are particularly knowledgeable about the indications, uses, effectiveness, side effects, risks and consequences of medications, as well as about interactions of pain medications with each other and with other medications in the patient's overall regimen. Because most patients have multiple prescribing physicians, it is important (to the extent possible) to use a single pharmacy or pharmacy chain, so that newly prescribed drugs can be evaluated in the context of the overall medication regimen, and potential drug interactions can be identified. Many pharmacies now have warning systems that attempt to help physicians and patients anticipate or avoid problems.
4. *The American Pain Society* offers significant educational information on its website²¹ for the benefit of patients and their families. In addition, it provides protocols and guidelines for use by physicians, based on the classification of the pain (e.g., acute, chronic-cancer or non-cancer) and the appropriate types of drugs. These protocols follow a "ladder" approach developed by the World Health Organization (WHO). This "ladder" approach to treating pain begins with non-opioid analgesics, and moves progressively to combinations of opioids and non-opioids, and ultimately to opioids (e.g., morphine), until a type of medication and dosage is found that best controls the pain without incurring unwanted risks or side effects. In using this approach, health care providers prescribe within classifications by adjusting dosages through a process called "titration." With titration, dosages and frequency are gradually

21. See www.ampainsoc.org;



changed based on their effectiveness consistent with the patient's tolerance, the risk factors related to each drug and the avoidance of unwanted side effects for each particular patient. If a particular type or classification is ineffective, then the physician may prescribe different types of drugs, or use them in combinations demonstrated to be effective. It is generally recognized that no single dosage of most medications fits all people with the same painful condition and that, for many drugs, there should not be artificial or upper limits on dosage or frequency, nor should there be minimum intervals in frequency of administration. It is generally recognized that, over time, patients may develop what is called "tolerance" to pain medication, and will require changes in dosage or frequency (or different types of medications) to maintain pain relief. Tolerance should not be confused with addiction.

B Federal and State Laws Regarding Controlled Substances

These laws generally categorize analgesics on schedules that range from the federal Food and Drug Administration (FDA) Schedule V to Schedule II, with those on Schedule II generally being of the greatest strength or potency. (Schedule I consists primarily of substances with no medicinal use.) There are differences of professional view about whether the Schedule II drugs have greater risks than drugs on other schedules, but the emerging view is that Schedule II drugs are not necessarily more risky, and some Schedule II drugs may have fewer side effects than some drugs on other schedules. Some analgesics and adjuvant pain therapies are not on the schedules (*e.g.*, nonsteroid anti-inflammatory drugs, anticonvulsants, antidepressants or acetaminophen), and some are available over-the-counter without a prescription. It should not necessarily be assumed that over-the-counter drugs are necessarily less risky or have fewer side effects than controlled substances. Nevertheless, over-the-counter medications should not be used in combination with controlled substances without physician advice. The patient should examine warnings on packages and package inserts, as some over-the-counter medications are contraindicated for patients with certain conditions (*e.g.*, some medications affect eye pressure or blood pressure). Except when acting on physician advice, patients should follow strictly the label warnings of over-the-counter drugs as to dosages, frequency of use and contraindications.

In order to minimize adverse drug interactions, patients who are under a physician's care for pain issues should keep the physician informed if the patient uses other drugs, including over-the-counter medications

C. Federal and State Authorities

Each state has regulatory agencies that govern pharmacies and pharmacists, as well as other agencies that govern health care facilities and physicians (*e.g.*, state medical boards). These agencies often have websites with patient information, and provide instructions about how patients and the public can express concern. The FDA has authority to approve medications. The federal Drug Enforcement Administration (DEA) enforces the laws as to use of drugs for non-medical purposes and drug diversion. The federal laws and the laws of the several states strive to create a balance between prevention of drug diversion and access by patients to the pain medication they need. Both goals are equally important, and neither should interfere with the other.

D. Federation of State Medical Boards

The Federation of State Medical Boards has recommended guidelines for use by the medical boards of each state that address issues related to pain, *Model Policy for the Use of Controlled Substances for the Treatment of Pain*. These guidelines reflect the emerging view that patient pain should be controlled to the extent medically available, and also include recommendations for patients with comorbid substance use disorder. The Model Policy covers measures that can be used when a physician has concerns that a patient may be misusing drugs, or may be selling them to others. Such measures include limiting the amount of doses prescribed at any one time to what is deemed necessary for a short period, as well as entering into pain contracts between the physician and the patient.

E. Educational Information for Consumers

Patients and their families who are dealing with pain management issues may find the following resources of interest:

1. American Pain Foundation: www.painfoundation.org
2. National Pain Foundation: www.nationalpainfoundation.org

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