

**When It Is Time**

**For Children to Make Decisions for Their Parents**

Supporting Your Parents with Competence and Compassion

A Workbook

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by Eileen Gold

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Supporting Your Parents with Competence and Compassion

A Workbook\*

\*Intended to be used as a teaching guide in conjunction with seminar information presented by Eileen Gold

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**FORWARD**

Professionally, I coach families who have an older adult whom they wish to help. The family is most often in crisis or at least in significant concern. Something has triggered this concern. Typically, the aging parent has changed noticeably: physically, emotionally, intellectually, behaviorally. Something is wrong. And suddenly grown children become alarmed.

They wonder:

"What can I do? What are Dad's assets? How do I decide how to allocate them?"

"What should I be doing: legally, medically, financially, spiritually, socially, emotionally?"

"How will my parent respond if I start taking charge of his life?"

"Do I even have authority to take control?"

"What will my siblings think if I get so involved?"

"Do I have the time and energy necessary to insure Mom's health, wealth and safety?"

"What resources are available to help me help my parent?"

I walk people through the practical (legal, financial, business, medical, behavioral, plan of care, placement, etc.); the ethical; the psychological; and the spiritual dimensions of eldercare management.

A family consultation typically takes three hours. After about two, people's eyes begin to glaze over. They become deeply aware of the magnitude of the job confronting them. That awareness brings with it an emotional tidal wave of ancient feelings/memories and future fears.

I am quick to reassure family members that they are able to do what needs to be done. I further promise them I will help.

**NOTES**

I will be there every step of the way to brainstorm, to consider available options, to offer a resource, to provide emotional support, and to do any of the tasks they cannot or care not to do.

I promise you the same.

I have 30 years professional experience. I have also walked this same journey with my own parents. The problems and pragmatics of human service are never tested so deeply as when they are applied to one's self.

The path you are about to walk is bifurcated. On one track you will find a lot of work and little reward. On the other, you might begin to experience the rewards of supporting someone through the last chapter of his life. You might approach unconditional love. From both tracks you will grow.

Thank you to my clients for sharing with me the intimacy of struggling with the right thing to do, even when it was hard, even when it seemed impossible, even when their parent seemed impossible, even when they have felt they were not up to the challenge. Thank you for sharing so much of yourself and finding joy in the journey.

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**INTRODUCTION**

It might be startling to many that I would begin a "how to" workbook by telling you that a family member is the least qualified person to provide direct support and care for a loved one. I have been the child of aging parents in need of help and the professional assisting other children's parents. Without question, I have had much more success playing the latter role. Like most of you, through experience, I came to acknowledge the following compelling considerations:

**First:**

The well-intentioned relative is going through his or her own sense of loss and grief. The relationship with the parent is fundamentally changed. This change in form translates into a small death. You want to care for Mom. But you must minister to your own feelings and needs.

**Second:**

The change in relationship has caused a disruption in the family dynamic. Power and control are no longer as they once were.

**Third:**

It's stressful. The change, the feelings, the neediness, the time demands are draining.

**Fourth:**

The rest of the people in your life need you and you need them.

**Fifth:**

It disrupts the normal pattern of family behavior.

**Sixth:**

This disruption creates resentment.

**Seventh:**

Resentment results in guilt.

**Eighth:**

Your loving intentions turn into traumas/dramas.

**Ninth:**

It's exhausting.

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Tenth:

Most family members lack the skills to adequately care for the loved one.

### **Supporting Your Parent with Dignity**

It is important, if you are to support your parent well, that you create a context in which to place all the activities in which you will engage. It is important that this context include your sanity and your parent's well being.

Dignity is important to preserve while caring for an aging individual. Allowing Mother to retain her role as mother because you keep your role as child, may be the greatest gift you have to give. If possible, help preserve the family structure she has always known. Contributing to her security in this way may be far more valuable than attending to her personal hygiene. Anyone can provide mother with personal hygiene assistance; only you can be her daughter. Moreover, to many people it is humiliating to have a relative perform "personal tasks". While Mother was changing your diaper she never anticipated you changing hers. She bathed you; she might experience discomfort in having you bathe her. Dad fed you; his pride might suffer to have you feed him. Mother delivered you into this world naked and might be embarrassed to have you view her in a similar way.

As adults we are used to paying professionals to perform certain tasks. Most of us have paid lawyers to file papers, accountants to prepare taxes, mechanics to fix cars. We don't experience a loss of our personhood with these relationships. In a similar way, hiring a professional to take care of the business of caring for Mom and Dad's bodies and finances is a way of preserving their self-esteem. Professional care managers do an excellent job of coordinating in home services, interfacing with the medical community, knowing community resources, managing personal business, paying bills, being an advocate and a good friend. They relieve children of these responsibilities and allow them to be family. Mom and Dad might feel more comfortable sharing their feelings about disease, death, dying, and finances with a professional than with you.



**NOTES**

*Most parents best-kept secret from their children is the amount of money they receive in their Social Security check each month!*

**The Professionals**

There are many professionals in the community that can assist you in assisting your parents. It is of paramount importance that you select the right professional. The following guidelines might be helpful to you in this often-confusing task.

**Choosing the Right Professionals**

What to look for:

1. Individuals who specialize in the needs of older adults (there are now specialties in both law and medicine: elderlaw attorneys; geriatricians)
2. Commitment to facilitating a quality life for your relative
3. Integrity
4. Knowledge of community resources; successful patterns of networking and collaborating with other professionals
5. Familiarity with issues impacting the lives of older adults and their families
6. An emotional connection
7. Relevant professional experience
8. Willingness to communicate openly and regularly with family members
9. Professionalism:
  - confidentiality
  - clarity regarding services, fees, etc.
  - good communication skills (written and oral)
10. Sense of humor, good coping strategies/balance
11. Civic involvements
12. Recommendations from community organizations such as: Alzheimer's Association, Senior Outreach Services, Jewish, Lutheran, Catholic Family Services, adult day programs, etc.

**The First Professionals to Contact:****Geriatricians**

A geriatrician is a medical doctor who has completed advanced training in the area of the aging adult. Just as you would choose a pediatrician to care for your child because of his expertise, it is wise to choose a geriatrician to be the team leader of your parents' medical care.

**Geriatric Care Managers**

Parents and children often have a difficult time discussing matters related to death, dying and money. It is not unusual that these topics create a barrier in communication. This is definitely the time for professional assistance. A good care manager will have ease in approaching and delving into these issues with family members. She will also be aware of good long-term care planners, elderlaw attorneys, financial planners, as well as community resources such as: medical professionals, in home support services, adult day care. She is a **key player** in your and your parents' support system. Rather than cost Mom, Dad and the estate money, she typically conserves it.

To find a referral to care managers call local resources such as the Alzheimer's Association, family services groups, county programs or The National Association of Geriatric Care Managers.

**An Elderlaw Attorney**

I'm not an attorney. The information contained in this workbook is not intended to be advice. It offers an opinion, based on 30 plus years of experience. It is a place for you to start.

A recognized specialty (like entertainment, patent, divorce, business) of the law is "elderlaw". Individuals with this emphasis are typically aware of the most current Social Security, Medicare, Medicaid, gifting, and other regulations that significantly impact the security and welfare of older adults. Therefore, they are a wonderful source of not only legal information but also asset management.

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Elderlaw attorneys are good at teasing out issues of competency. (Competency is a legal term that means that a person has sound mental faculties to make decisions such as handling finances, making new wills, changing beneficiaries, etc.) They are skilled at establishing healthy boundaries between family members and guarding against undue influences on the aging parent. Many have involvements in the community to help protect older adults against elder abuse. They make sound judgments regarding independence and the needs for more extraordinary measures such as "conservatorship". They are most respectful of privacy issues and yet are sensitive to working within the family dynamic. Elderlaw attorneys are familiar with the various stages of mental and physical decline of older adults; therefore, they speak in ways that communicate. Based on both their legal and social skills, I highly recommend them to you.

Look for them in the Yellow Pages, through your local BAR Association, or the National Association of Elderlaw Attorneys. Determine their attitude toward older people. Ask about credentials and relevant experience. Compare their fees to other elderlaw attorneys. (In my experience, cheaper has not always been better; conversely, more expensive is not always better...fees should be fair. If a professional charges more than the norm in your area, ask why. Perhaps they are faster, more experienced, more successful, better at what they do. Perhaps not!).

**PART 1*****A. NAVIGATING THE BUREAUCRATIC MAZE: legal, financial, insurance and more*****Understanding the Language**

When you start caring for your parents, you will be engaging in estate planning. The terminology and legal tools available for you to handle the work follow. Good planning reduces future troubles. The early days of your work are busy with structuring. Be assured that the time and effort spent will reduce costs, preserve assets and reduce stress.

**Estate Planning**

Estate planning is a general term that includes a wide variety of subjects. It should reflect the current and long term needs of your parents. It should also reflect their values, wishes, desires and preferences. It will be highly influenced by their financial assets. Planning helps support your parents with dignity.

***Warning:*** *issues of money are highly charged. Even in the most harmonious of families, I have seen money issues create tremendous strain.*

These are my biases. ***First*** and foremost, the money should go for the care of the parent. As long as there are sufficient funds, Dad should be supported in every way that adds to the quality of his life. Matters of inheritance are irrelevant. With that being said, I recognize the value many older people place on "leaving their children something". I have always honored that choice, ***secondarily***. Conflicts between family members can be significantly reduced by a well thought out estate plan executed by sensitive competent professionals. Early planning provides opportunities for asset protection. Updating the plan periodically allows for adjustments due to changes in laws or family circumstances.

**Durable Powers of Attorney**

There are different kinds of "POAs". A POA is a legal mechanism agreed to by your parent during a period of time

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that he is considered legally competent. (Competency to make the decision will be determined by the attorney. A judge, if questioned by any interested party, can resolve questions of competency.) While competent, a person can terminate at any time a POA. Durable power of attorney transfers decision-making power to a designated person. Depending on the state in which you live separate POAs may be required for "health care", "finances", and "real estate".

**POA: Finances**

This power allows you to write checks, work with financial institutions and general accounts on your parents' behalf. It gives you the authority to file taxes, enter into contracts and perform all business transactions that are outside of a trust. Some states require an additional power to execute real estate transactions.

**POA: Health Care**

It is not necessary to employ the services of an attorney to complete this document. However, there are benefits. A well-drafted POA could eliminate the necessity for more costly, judicially determined limitations on your parent at a future time. (An adjudication of incompetence in order to make beneficial decisions is sometimes necessary but oftentimes extreme). An elderlaw attorney will help your parent identify life saving, life enhancing, life prolonging procedures and ask, under what circumstances if any, would they would want these medical interventions. Most people are clear whether or not they want to be maintained on artificial life supports. It might be more difficult for you, as your parents' agent, to decide whether to approve the use of respirators, feeding tubes, etc. Knowing your parents' wishes prior to a need makes the decision making easier. However, engaging in a discussion with your parent about these various medical interventions might be emotionally difficult for you. Elderlaw attorneys are knowledgeable about procedures, ramifications and implications. They feel at ease discussing them. For both emotional as well as practical reasons, consider having a professional draft all your legal documents.

**Living Will**

These documents are basically letters to the medical community stating the conditions under which an individual no longer wants to be kept alive. As America becomes an increasingly litigious society, living wills becoming increasingly meaningless. Considering the possible financial and emotional implications of these wishes, it is prudent to insure the individual's desires through a POA for Health Care.

**Advanced Directives**

Many long-term care facilities require advanced directives as part of the admission procedure. (A well-drafted POA for health care should include each consideration stipulated in the advanced directive.) These are letters of instruction regarding health care issues. They serve as a communication between the elder and his agent. They may include information to a physician regarding your parents' wish to use or not use extraordinary means to maintain life. The instructions might tell the agent how the elder wants to receive treatment when various options are available (e.g. in home, small group home, skilled nursing, etc.) Additional thoughts for inclusion could address hospice care, and palliative (pain control only) vs. curative treatments.

**Trust(s)**

A trust is legally constructed container for personal assets. It is akin to a corporation. Into the corporation go property, savings accounts, stocks, etc. Like a business, by virtue of its legal status, the trust enjoys prescribed tax benefits. A trust is also a way to control the distribution of money before and after death.

A living trust is a means of gifting property from one living person to another while avoiding probate. It ensures that in the event of incapacity this property is protected and will be used in accordance with the grantor's wishes. A revocable living trust gives the grantor the right to change the terms of the trust as well as dissolving it.

A testamentary trust is assurance that designated individuals (beneficiaries) will receive property upon the death of the

**NOTES**

grantor/testator. When the testator dies, the trust becomes irrevocable i.e. no changes can be made to it.

A trustee is a person designated by the testator to insure that all his wishes are executed, as he would have them. He assumes responsibility for managing the trust. He executes provisions of the trust, pays taxes, debts and expenses.

A co-trustee means that more than one person has the power to execute the trust. Often a husband and wife share the responsibilities. However, more than 2 can be named. Discuss with your attorney the advantages and disadvantages of the adult child who has been chosen to become successor trustee being named co-trustee.

A successor trustee is a person named to assume the job of trustee upon the death or resignation of the original trustee. An individual may resign for any reason. Compromised health or mental status are two good reasons for a person to resign the position. If that individual is resistant, two letters from physicians attesting to incapacity are sufficient for the successor trustee to assume responsibility. This can be avoided if the successor trustee is also co-trustee with the power to act independently.

A conservatorship is an adjudication of incompetence. It is a legal mechanism for assuming control over a person and/or his estate after he has become incapacitated. It is a costly procedure...emotionally and financially. It requires court hearings, investigations and reports. It can almost always be avoided by good advanced planning.

A will is a document that describes how an individual wants his property distributed upon his death. It does not carry with it the "legalities" of a trust. However, it may include a trust.

An executor is the individual named to insure that the provisions for distribution of property stated in a will are executed. The trustee and executor may or may not be the same person.

**Letter of Instruction**

A letter of instruction is a guide for closing out financial and personal affairs of an individual subsequent to his death. The letter is not a legal document. It is a thoughtful addition to the will or trust. Possible inclusions might be people to notify of the death, desires respective to funeral arrangements, disposal of property, phone numbers, account numbers and the like.

Trusts, wills, and POAs are tools used to protect Mom, Dad, and their assets. It is common that the eldest child or the child that lives in the closest proximity to Mom and Dad is designated to assume responsibility.

***Become informed:*** *if you are the one with the responsibility, talk with the professionals. If assets allow, hire a care manager; retain the services of an elderlaw attorney; investigate the opportunities to purchase long-term care insurance; consult with reputable authorities in the locale of Mom and Dad to determine the availability and advisability of different health insurance options. The investment in time and money up front can save significant sums of dollars and frustrations in the future.*



**NOTES****B. MANAGING ASSETS: Assuming Responsibility****Getting started:**

Go through drawers, files, and safe deposit boxes. Look for bank accounts, checking accounts, stocks, bonds, insurance policies, warranties, guarantees, medical policies, annuities, mutual funds, money market funds, wills, trusts, businesses, tax returns and the like. Look for bills...paid and unpaid.

**Create 3 Tables.**

**Table 1:** list income sources: monthly and annual  
For example:

Monthly Income Source	Monthly Amount
Social Security	\$ 1,800
Pension (New York State Retirement)	425
Pension (Teacher's Fund)	325
Annuity	125
Repayment of Personal Loan	75
Other Specify	
<b>Total Monthly Income</b>	<b>\$ 2,750</b>

Annual Income Source	Annual Amount
Stock Dividends (approx.)	\$ 5,500
Bond Dividends	300
Interest on Money Market Account	1,470
State Reimbursement to Oil Rights	300
<b>Total Annual Income</b>	<b>\$ 7,570</b>

Total Monthly Income

\$ 2,750

+ Annual Income ÷ 12 (Amortized Annual Income)

\$ 631

=Total Monthly Revenues

**\$ 3,381**

**NOTES**

**Table 2:** list expense sources: monthly and annually  
For example:

Monthly Expense Source	Monthly Amount
Rent (Mortgage)	\$ 1,200
Food	400
Utilities	135
Household Maintenance	65
Medical	525
Insurance	150
Clothing	40
Entertainment/Travel	250
Clubs/Associations	60
Donations	70
Other	
<b>Total Monthly Expenses</b>	<b>\$ 3,445</b>

Annual Expense Source	Annual Amount
State Tax	\$ 235
Federal Tax	6735
Property Tax/Local Taxes	2300
Yearly Gifting (up to \$10,000 per person, per year)	20,000
Major Purchases	3,300
<b>Total Annual Expenses</b>	<b>\$ 32,570</b>

Total Monthly Expenses

\$ 3,445

+ Annual Expenses ÷ 12 (Amortized Annual Expenses)

\$ 2,715

=Total Monthly Expenses

**\$ 6,160**

Difference Between True Monthly Income and True Monthly Expenses

Monthly + Amortized Monthly Income

\$ 3,381

Monthly + Amortized Monthly Expenses

\$ 6,160

Difference

**\$ < 2,779**

**Table 3:** list all assets  
For example:

<b>Asset</b>	<b>Current Value</b>
<i>Home</i>	\$ 275,000
<i>(Mortgage)</i>	<100,000
Home Asset Value	175,000
Stocks	625,000
Money Market	75,000
Annuity	235,000
Personal Loans	80,000
CD	300,000
<b>Total Assets</b>	<b>\$ 1,640,000</b>

Children are often astonished to find out the net worth of their parents. Most people in their 80's have vivid memories of the "Depression". They lived and invested modestly. They think of money differently from baby boomers. And baby boomers think of money differently than Generation X. Personal values determine how one views, saves, invests and spends money. Help identify your parents' values and wishes for their assets. As their agent it is your job to be prudent (versus aggressive) in managing. Your first obligation is to insure that your parents' needs, wants, desires, and joys are fulfilled. That means that they have a right to contribute to charity and pick up the bill. They have a right to gift money (the IRS allows up to \$10,000 per person per calendar year with no tax consequences to the giver or the recipient...a good way to reduce taxable assets that would be subject to probate tax at a later time...check with reputable professionals). Remember to consider how Dad would have decided to manage his assets when it comes your turn to manage Dad's money.

If the expenses are greater than the income, as in the example above, you will be called to liquidate assets. (Your authority to do so comes from either a POA for financial matters, or co/successor trusteeship of the trust or a conservatorship. Assets in a trust must be managed by a trustee, assets outside the trust, such as a checking account, can be managed with a POA. If you become a conservator, accounts must be set up in the name of the conservatorship).

And you have many options.

What should you do? Sell stocks or bonds? Withdraw from CD's or money market accounts? Sell the house and move mom and dad into an assisted living facility and reduce expenses?

There are no easy answers. If mom and dad were well advised they would have written a letter of instruction that could be your guide. Typically, they have not.

***Become informed:*** contact your parents' financial planner, stockbroker, attorney, CPA. Try to get clarity on your parents' wishes as well as their assets. Determine a course of action based on long-term need, projected profitability of assets and family values. A secondary concern is sheltering liquid assets from future tax liability. Create a strategy that supports your parents well for the rest of their lives.

### **Insurance**

Most people in their 80's have some types of insurance. Reviewing the policies with a trusted financial planner is another part of estate planning.

### **Medical Insurance**

Health care for seniors is a national concern. Statistically speaking, more is spent caring for an individual in the last two years of his life, than the total of all the rest of his life.

***Become informed:*** contact the experts. HiCap is a program run by volunteers to inform seniors in layman's language of the benefits of various forms of insurance. They are knowledgeable and up to date. You may find them by calling your local Area Agency on Aging or Grey Law.

### **Medicare**

Medicare is a federal insurance program that covers a percentage of the medical and hospital costs for seniors. It has two parts. Part A: hospitalization Part B: other medical expenses. Part A is available to those over the age of 65, irrespective of income. Part B requires a monthly premium

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that for most people is automatically deducted from their Social Security check. Currently Medicare does not provide a prescription benefit. One applies for Medicare at a local Social Security office.

**Medigap**

Medigap is a generic name for supplemental insurance. These policies bridge the "gap" between what Medicare pays and what the elder must pay. There are many sources for these policies with varying premiums. Investigate and make an informed choice.

HMOs (Health Maintenance Organizations), PPOs (Preferred Provider Organizations), IPAs (Independent Practice Associations) are prepaid plans that contain medical costs by emphasizing prevention. The Medicare benefit is assigned to the health plan and in return the plan takes over the senior adults medical services.

***Caution:*** *medical services are determined, in varying degrees, not only on the health needs but also on the health coverage of the recipient.*

**Long-Term Care**

Long-term care insurance will pay the cost of caring for a person either in their own home, skilled nursing or residential care facility. These costs are not covered benefits of Medicare (or managed care). The insurance must be purchased pre need. That means that once some one has a need for in home support services, he is no longer eligible to purchase a policy. Additionally, an individual may be disqualified for pre-existing conditions. The younger and healthier the person, the less costly the premiums.

Long-term care insurance may be an excellent asset management vehicle. Look into various policies. Not all are equal. Beware of over insuring. Consider other assets when determining need. Look for policies that make no distinction between levels of care: skilled, custodial or intermediate. Consider policies that can be upgraded, are renewable and contain an inflation rider. Avoid policies that exclude

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dementia. Make sure that the coverage is allowed in the state in which you reside. Investigate the company and agent. Look for ones that are both licensed and in good standing. Find an agent who is ethical and understands your overall financial plan for your parents. Stay in touch. As the age wave moves forward, more of these products will be offered.

**Homeowners, Personal Property, Liability, Fire/Earthquake, and Automobile**

Check to see that your parents' policies are paid and in force. Often, older adults forget to pay some bills. Lapse in policies could be very costly to an estate. In the event you are to hire in home support help, you should call your Insurance agent. Policies should cover employees who maybe working in the home or driving the automobile.

**Pre Need Burial/Funeral Arrangements**

Pre need burial/funeral arrangements are becoming increasingly popular. They offer a senior the opportunity to plan his own funeral. Advanced funeral planning saves family members the stress of making good decisions during a period of time when they may well be in shock and mourning. The costs of the plot, casket, cremation, sanctuary, can all be funded through various mechanisms. Individual trusts (Totten), state regulated trusts, insurance policies and annuities are available. Each has advantages and disadvantages. The Federal Trade Commission developed regulations that require funeral directors to disclose in writing all the services, facilities and equipment that are included in the policies.

**Note:** *most of the information offered in this section is geared toward middle and upper income levels. Please see below for information regarding asset management and the Medicaid benefit.*

**NOTES****Managing Limited Assets**

Caring for two parents is very challenging. If one is in need of skilled nursing, the associated costs which are not covered by Medicare programs, will average around \$3300/month. If the couple have limited resources it might be the case that all the couples' assets go to pay for the long-term care facility, leaving the well spouse penniless. The State of California, being a community property state, has made some provision to protect couples in this situation. It is important to know that if a person goes into a skilled nursing facility as a private pay patient, once his resources have run out and he is receiving the MediCal benefit he **cannot** be existed from the placement. Also, MediCal allows individuals to have a burial trust and will consider it exempt in calculating eligibility for Medical. Of extreme interest is a program called the Impoverishment Act. The following is taken from the Public Interest on Long-Term Care Fact Sheet. It applies to California. If you live in a community property state, you may have the equivalent provision attached to Medicaid programs.

*Spousal Impoverishment Provision:*

*Couples looking at SNF (Skilled Nursing Facility) placement for a spouse need to be aware of the special laws allowing the spouse remaining at home to keep a certain amount of income and resources when the other spouse enters the SNF. This is intended to prevent impoverishment of the at-home spouse.*

*Income: For the year 2000, the at-home spouse may keep all of the couples' income up to \$2103 per month. This is called the community spouse's "monthly needs allowance". The amount may be increased by the at home spouse by court order or administrative hearing. The amount is adjusted annually by a cost of living increase.*

*If the at-home spouse receives income about the \$2103 limit in his/her name only, he/she can keep it all) "name on the instrument rule"); however, she/she will not be allowed to keep any of the nursing facility spouse's income. Income received by the nursing facility spouse will go to his/her share of costs of care. The spouse in the SNF is allowed to keep \$35 monthly for personal needs (haircuts, toiletries, etc.)*

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Resources: As of January 1, 1000, the at-home spouse can keep up to \$84,120 in resources (cash, property, other assets), and the institutionalized spouse may keep up to \$2000. (These amount changes each year based on the Consumer Price Index). This resource limit does not include the family home, one car, or several other exempt assets. Note that both separate and community property are combined and counted at the time of application to MediCal in ascertaining whether or not the non-exempt resources meet the eligibility requirements. Once the resource limit has been reached (by the institutionalized spouse), all ownership interest should be transferred to the at-home spouse. The institutionalized spouse's \$2000 resource limit should be kept separated and accounted for separately.

Transfer of Assets: Institutionalized MediCal recipients or applicants who transfer non-exempt assets (especially cash and income property) for less than fair market value during a 36 month "look back" period may be subject to a period of ineligibility for MediCal. (If the spouses have an IVT, the look back period is 60 months). The period of ineligibility begins on the date the transfer was made. The look back period begins upon the date of application or the date of institutionalization (for one already receiving MediCal).

Estate Claims and Liens: Liens are imposed on living MediCal beneficiaries' estates to property until the beneficiary or surviving spouse dies. Estate claims are claims made against the estate of the deceased MediCal beneficiary.

Federal law allows California to define "estate" to include any real and personal property that the MediCal beneficiary had any legal title or interest in at the time of death. The definition may include assets held in joint tenancy, tenancy in common, life estate, living trusts, etc. No recovery may be made until after the death of the surviving spouse and only if there is no minor, blind or disabled child.

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**Document Locator**

Create a file of important papers and information. If you do not have a copy of the document itself, make a note of where it can be located. The time it takes for this organization could save thousands of dollars over time.

Things to look for: (drawn from "The Complete Elder Care Planner" by Joy Silverman)

1. Personal Bank Accounts (include bank name, phone number, type of account and number)
  2. Personal Loans (include name, bank, number, and type)
  3. Automatic Deductions (include type, bank, phone number, account number)
  4. Business Bank Accounts (same information as for personal)
  5. Business Loans (same information as for personal)
  6. Foreign Bank Accounts (same information as for domestic)
  7. Company Pension Plans (include account of, company, telephone number, and account number)
  8. Retirement Accounts (include name, bank, telephone number, account number, type of account)
  9. Safe deposit box (box holder, bank, telephone number, box number, key location)
  10. Personal Safe (combination, key location)
  11. Business Safe (same as personal)
  12. Savings Certificates (depositor, bank, telephone number, certificate number)
  13. Savings Bonds (bond of, series number, type, location)
  14. Stocks and Bonds (stock of/bond of, broker, telephone number, stock name and number, location)
  15. Mutual Funds (funds of, broker, telephone number, fund name and number, location)
  16. Money Market Accounts (account of, broker, telephone number, location)
  17. Will (will of, attorney, telephone number, location)
  18. Trust (established by, date, attorney, telephone number, location)
  19. Living Will (will of, date, attorney, phone number, location)
  20. Power of Attorney (given to, telephone number, attorney, telephone number)
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**NOTES**

21. Durable Power of Attorney for Health Care (same as for POA)
  22. Letters of Instruction (written by, location)
  23. Funeral Arrangements (arranged by, funeral home, director, phone number)
  24. Donor Arrangements (donated by, donor bank, telephone number, location)
  25. Social Security/Medicare (name, numbers)
  26. Veteran Information (name, number)
  27. Income Tax (taxpayer, tax preparer, telephone number)
  28. Passport (name, number, location)
  29. Driver's License (driver, number, state issued, location)
  30. Charge cards and other charge accounts (cardholder, account name and number, card location)
  31. Health and Dental Insurance (insured, insurance agent, telephone number, policy name and number, location)
  32. Insurance (life, disability, homeowners, auto, real estate, homeowners, personal property, fire and earthquake, business (insured, insurance agent, telephone number, policy name and number, document location)
  33. Ownership: Vehicles (cars, boats, RVs, Trailers, Motorcycles) (owner, make/model, serial number, dealer, telephone number, location of title)
  34. Ownership: Real Estate (home, vacation home, investment home) (owner, co-owner, telephone number, bank/mortgage company, property location, document location)
  35. Ownership: Business (owner, co-owner, telephone number, business name and location, document location)
  36. Ownership: Land/Cemetery (in the name of, bank/mortgage company, telephone number, property location, document location)
  37. Subscriptions
  38. Memberships
  39. Items in Storage (in name of, item description, storage name and location, telephone number)
  40. Medical/Dental History (name, birthdate, blood type, doctor, telephone number)
  41. Personal Records (name at birth, birthdate, place of birth, birth certificate, baptismal name, baptismal certificate, location of certificate, bar/bat mitzvah name, record)
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**NOTES**

- location, communion records, location, confirmation name, certificate location, school records, graduate, school, diploma location)
42. Employment History (name, date of employment, company, address, telephone number)
43. Parents' records (name at birth, birthdate, country of birth, birth certificate location; name at death, cause of death, date of death, burial location, death certificate location)
44. Pet Medical History (name, date of birth, breed, sex, veterinarian, telephone number)
45. Home Inventory: fixtures, furniture, equipment, appliances (owner of property, item, description, model number, receipt/warranty location, purchase price/value, promised to)
46. Collections: books, photos, knick knacks (same as for home inventory)
47. Business Inventory: fixtures, furniture, equipment, appliances (same as for home inventory)
48. Miscellaneous Inventory: fine art, antiques, jewelry, furs (same as for home inventory)
49. Family Pets (owner of pet, pet's name, breed, papers location, promised to)
50. Other

***C. ETHICAL CONSIDERATIONS:***

You may find it very difficult taking over your parents' life. Some adult children feel like snoopers. Some have an uneasy feeling digging so deeply into another's personal affairs. Still others disagree with the decisions their parents have made. In our culture, the ways in which we spend money and the way we treat our bodies are driven by personal beliefs. Though families may share values, oftentimes each generation sees things differently.

- What are you to do when confronted with a situation regarding the expenditure of your parents' funds on things that you don't believe to be worthy, though they supported their entire life?
- What are you going to do when you have a personal debt and you do not have the funds to cover it and Mom's estate does and you are the beneficiary of the estate?
- When is enough treatment to arrest disease or decline too much? When is it time to simply let go?

Here are some questions I have developed to help my clients arrive at ethical value based decisions.

- Is it kind?
  - Is it in your parents' best interest?
  - Are you making the decision your father would have made if he were able?
  - What treatment, if any, should you instruct the doctor to give your mother now that she is no longer aware of her surroundings? How will it effect her quality of life? What were her beliefs regarding the afterlife?
  - Are the assets being spent for the care and benefit of your parent?
  - Is asset allocation driven by a desire to protect your inheritance?
-

**Cautions:****Financial**

*The money isn't yours, even though you write the checks. Keep receipts. Keep a separate accounting. Maintain a separate credit card for the sole benefit of your parents. I suggest that you never commingle funds. Never make joint purchases. If you decide to gift your child a birthday present from Grandma and Grandpa, I recommend that your siblings' children receive similar amounts.*

**Medical**

*Doctors have the perspective that it is their job to treat a patient and try to eradicate disease. You, as an individual and you as your parent's agent may be called to make decisions regarding treatment. Ahead of time you might want to consider under what circumstances it would be better to let Mother go untreated and let nature take its course. You can get compassionate help making these decisions from your local hospice. Hospice is a program that helps terminally ill people. They have an expertise in pain management, comfort management, the grief process and more.*

***In summary.** Learning to manage and protect your parents assets might seem like a big undertaking. However, once you create the structure, you will know exactly what you should be doing to set your personal affairs in order. This is good solid how to live your life information. Congratulate yourself on your willingness to take on the challenge.*

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**PART 2****A. FOSTERING A QUALITY LIFE FOR YOUR PARENT**

Your first duty is to create an environment that is safe. Safety is two-dimensional: physical and psychological. Of the two, physical safety will be easiest to insure.

**Physical Safety**

Consider:

- adaptive devices: grab bars, ramps, walkers, easy grab eating utensils, Velcro clothing
- water safety gauges that prohibit the temperature from exceeding a safe limit
- room monitors, similar to baby monitors, that allow you to hear a call for help
- hospital beds that manually or electrically can raise or lower a person's body position
- pulleys that help people come to a sitting position from a reclining one
- chairs that electronically raise thereby easing transfers
- adaptive seats for toilets and showers
- bed side commodes and urinals; incontinence products
- simplification of the environment; reducing patterns; creating contrasts (example: white plates set off by a strongly contrasting colored place mats); and enhancing depth perceptions through the use of colored strip tape
- triggering the memory of the older adult by labeling (with words and pictures) the contents in drawers, cabinets, and closets
- emergency warning systems that by a touch to a bracelet or necklace dial a number in case a loved one has fallen or is otherwise incapacitated (e.g. Lifeline)
- doormats that are attached to a buzzer that alert you that someone is walking out the door
- Safe Return, a national computerized identification system, sponsored by the Alzheimer's Association, which assists in reuniting individuals who stray from their families

**NOTES****Psychological/Emotional Safety and The Reduction of Oppositional Behavior:**

Creating an environment in which a person feels emotionally safe does take some finesse. Fortunately, many authorities offer us direction.

Naomi Feil writes in her book, *Validation Theory*, that we should never argue with the older adult.

Now I want you to think about how big a thought that is: never, under any circumstances, ever, no matter how outrageous the comment, argue.

If you become accomplished in this one skill, you will have traveled a great distance in accommodating the needs of your loved one and reducing oppositional behavior.

Bernard is a good example of what not to do.

*Bernard visited his aging father, Raymond, twice a week. He would arrive and be greeted by a critical voice--half directed at Raymond half to God--coming from a man shaking his head from side to side. "I must have been a bad father to my son. He must hate me. He never comes to see me." Bernard twice weekly would reply, "But Dad, this is the second time this week I've been here". Raymond, looking victimized, would continue to shake his head from side to side. Bernard grew to hate his visits with his father. He felt as he did when he was a child: he had failed to live up to his father's expectations. Bernard would give anything, if during this last chapter of his father's life, the two men could be reconciled. Bernard longed to hear his father's approval. Instead, when he looked upon the shrinking image of the man he called "father", he grew increasingly despondent. Walls, gulfs, schisms and wars can develop out of a single thought. The one thought for Raymond was that his son didn't care enough to visit. The one thought for Bernard was that nothing he did was ever good enough for his father. Bernard called to hire me. He was psychologically drained from the weekly rejection. He asked if I could oversee the care of his father.*

**NOTES**

*The process of getting to know Raymond included long conversations about "his Bernard". Raymond was truly proud of his son's accomplishments in life. He was lavish in his praise and admiration. However, Raymond felt that Bernard was too busy to spend time with an old man he could no longer look up to.*

*I counseled Bernard. I suggested that he play with this notion of not arguing with his father. I challenged him to look behind the words and discover what feelings were being shielded. Bernard was eager, in fact desperate enough, to try. He hated the idea of his father dying with so much antipathy between them. The next time Bernard arrived for his visit, he was greeted by the now too familiar comment. But this time instead of a defensive retort, Bernard responded, "Dad have you been feeling lonely?"*

*An "aahaa" moment. Raymond stopped shaking his head and looked into Bernard's eyes and replied "It's so good to see you".*

For every child who has experienced the angst of not feeling appreciated by his parents, moments such as Bernard experienced are treasures.

I should know better, but I too had succumbed to fruitless arguments with my parents on more than one occasion.

My Father:

*In the last year of my father's life, he had lost all interest in anything save one, the stock market. That is not quite correct. His attention was actually on one particular stock. He had total faith in its growth potential though it had done absolutely nothing in the several years he had owned it. Since my uncle was our stockbroker, everyone in the family owned this same stock. During a telephone conversation I had with Dad a few months before he became terminally ill, he asked me how many shares of the stock I owned and at what price I had bought them.*



**NOTES**

*"I don't know," I responded.*

*(Some years earlier I had rolled over a 401K IRA account to my uncle's care and trusted him to invest wisely.)*

*Dad said that was the dumbest thing he had ever heard and insisted that I tell him the details he sought.*

*Again I said with emphasis, "Dad, I really don't know. The funds are in an IRA that I don't intend on touching until retirement. I just don't follow it closely. I read the quarterly reports and am satisfied if I see the account has grown.*

*That wasn't good enough for Dad. He shouted, "O.K. Eileen, if you don't want to tell me that's your business. But it isn't necessary for you to lie!"*

A year after his death it occurred to me that I could have shared with my father a nice moment rather one scarred with hard feelings. All it would have taken on my part was to say: "Dad, the numbers escape me at the moment, but if you give me five minutes I'll look them up and we can continue this conversation." That's all it would have taken to give my father the enjoyment of talking with his eldest daughter on the only subject that currently held his interest.

My Mother:

*One afternoon when I arrived at the board and care home for the third time that day, my mother looked up at me with disgust and said "Well, it's nice that you could find the time in your busy life to visit me. You haven't been here in weeks and you only live a few blocks away." With a knee jerk reaction I blurted "but Mom I was here at breakfast time and again at lunch."*

*She said, "No you weren't."*

*I said, "YES, I was".*

*She said, "NO, you weren't".*

**NOTES**

*I said, "Ask the staff".*

*She said, "They're all liars".*

*A point was reached in this verbal boxing match at which I could not decide who was crazy, The Mother or The Daughter.*

*But worst were my feelings of hopelessness. Would this conflict never end? WOULD IT NEVER END?*

*The next day I was reminded of the words and wisdom that I preached to others: "DO NOT, UNDER ANY CIRCUMSTANCES, ARGUE". Words are symbols. What was my mother trying to communicate? What was I unable to hear?*

*On the next visit, I came fortified with Naomi Fiel's axiom, and thus better prepared for my mother's wrath. Instead of my defensive posture of the day before, I inquired: "Are you bored?" She relaxed and admitted that she found nothing in common with her roommates who enjoyed watching "I Love Lucy" and playing "Solitaire" all day. I offered to take her for a walk and to read to her. She seemed genuinely receptive to both ideas.*

If I had told my mother that her roommates had many other interests in addition to the two she identified, we would have been locked in battle again. She would have needed to defend her position because, in her world, the truth was they did not have her interests. She would have felt compelled to defend this worldview, the only one she knew, and locked into defending, she would have been locked out of emotional safety.

Sometimes it's not so easy to avoid argument, especially when it involves the knowledge that you are right and the other is wrong. But ask yourself this:

"Would I rather be right (or validated or agreed with) than have harmony (peace, lack of conflict)?" Is being "right" *in fact* more important than being "right" *in feeling*?

**Validate**

Prior to each conversation with the older adult, mentally affirm your goal. State that it is your intention to have a peaceful encounter with Mom. Commit to only reinforcing what promotes your goal and to relinquish anything that impedes it.

Remember that there are only two possible outcomes to argument.

One: The argument becomes an eternal battle of wills that can never end because the arguments are being waged in different realities. Therefore, resolution can never be achieved. In this scenario, right and wrong are perceptions not absolutes.

Two: You might exert your will and win a momentary victory. The spoils include the fact that this victory is achieved at the cost of emotional debilitation for your parent.

The triumph is therefore tainted. It becomes hollow and one that you will find that you would gladly abandon. Furthermore, the "success," is fleeting. You may be certain that in a day, or an hour, or even a few minutes, the battle will begin all over again.

As Naomi Feil would tell us, validate your parent by responding to the emotional rather than the literal content of the communication.

For instance, if Dad says, "It is Christmas time," ask, "How you would like to decorate your room?" Avoid the temptation to say "It's November, and remember we celebrate Thanksgiving, not Christmas in November".

If Mom says, "You never call," avoid the temptation to give her a reality check by showing her your phone bill. Instead tell her, "It makes me feel good to know how much you enjoy our conversations."

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**NOTES**

Initially this does take discipline, but the rewards will be abundant.

***In summary:*** *Physical and emotional/psychological safety contributes to a sense of well being. Only this sense can lead to an improved quality of life...to what I think of as "life abundant." This is a life filled, not with the possibilities that we enjoy, but with comforts and reassurances. Physical safety can be obtained by our re-visioning the outer world in someone else's terms. Sometimes this is nothing more than reassigning rooms, or uncluttering the environment. Sometimes it means acquiring necessary adaptive equipment.*

*Psychological and emotional safety can be most effectively obtained by setting aside our own assertions to be "right" in favor of reassuring or validating the assertions of our parent. Another dimension of safety is to increase all things and activities that bring joy and decrease all those that create stress.*

*I am reminded of a short story by O. Henry, titled "The Last Leaf." In it, a young woman, critically ill, believes that when the last autumn leaf is gone from the vine on the wall outside her bedroom window, she too will die. During the night the leaf blows away, but an old man – a neighbor – paints a copy of the original on the wall. In the morning, the woman looks out of her window and sees the portrait of the leaf. Believing it to be the original, she is inspired to live. It was the appearance of reality, not reality itself, which made the difference.*

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**B. FAQ**

Most adult children, at some point in time, become overwhelmed and confused by the choices they must make on their parents' behalf. The following are the most frequently asked questions of me and here are the responses I offer.

*Q. "How do I determine the right time to take over my parents' personal and financial life?"*

A. The right time is just before your parent is no longer capable of doing it for himself. You can determine this by observing the degree of stress he is experiencing in handling every day affairs. Ask yourself how much time your parent is devoting to paying the bills, sorting the medications, and doing the grocery shopping. Is he talking about how overwhelming it is to maintain the status quo? Does he seem worried or distressed? Is the level of care Dad is giving your mother adequate to meet her needs? Are your parents clean? Are they well fed? Is the house clean? Is there an adequate amount of food in the refrigerator? Are they socially isolated? When your parents reach the point that the ordinary activities of daily living are approaching overwhelming, when you expect that a crisis could occur, that is the time for you to step in.

*Q. "How much control should I take?"*

A. Determining the degree of assistance your parents' require is a subjective matter. As competent adults they are entitled to make life decisions that may differ from your standards. The fact that they choose to eat frozen dinners or eat out does not constitute a cry for help. However, if they are going without eating or are only eating vanilla ice cream then you are looking at a red flag. The fact that they donate money to seven different charities is their prerogative. If the pattern of giving has changed significantly in the past year, you have cause to be alarmed. If they have subscriptions to twelve publications and three of them are for Reader's Digest, that is a matter of concern. If they pick up the check for dinner,

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**NOTES**

they have the right. If they haven't been paying the bills or have forgotten to pay property taxes or have paid them twice, you have cause to take action.

Your ability to take over is predicated on how well the legal documents discussed above have been drafted. In my experience the transfer of power is less imposing if the adult child who is named to be successor trustee of the trust, becomes co-trustee with Mom and Dad during a period of time while each or at least one is still competent. This allows for a seamless transition when the time comes that neither is able to perform the necessary tasks well. Co-trusteeship allows the adult child to manage financial affairs without having to have medical or judicial declarations of incompetency.

*Q. "How will Mom or Dad react to my actions?"*

A. If your parent will agree that it is time for you to take control and is willing to sign a notarized statement that she wishes you to have her powers of attorney and additionally she is willing to resign as trustee of the trust, you are indeed fortunate. Not many of us are that lucky. Usually, people want to hold on to control. All of us fear the loss of control. Older adults have already experienced multiple losses. They have lost sensory acuity, lost mobility, lost memory, lost friends and loved ones, lost options, lost opportunities, lost energy, and now they are faced with losing decision making ability.

If your parent resists, you will have to go to the next step. Step two involves doctors attesting to the fact that Mom is no longer competent.

If that does not work, a court must adjudicate Mom as incompetent and authorize a conservatorship. As alluded to above, conservatorship can be cumbersome, expensive and humiliating. Usually the only difference between someone who is in need of a conservatorship and someone who is not, is his willingness to cooperate. Of course there are instances when conservatorships are advisable, such as when family

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members are victimizing an individual or when there are no family members who are available or competent to assist.

Once you have obtained legal authority, I recommend preserving as much of your parents' dignity as possible. Allow them to participate in ways that give them the illusion of control. For instance:

- sit down and write out the checks with them
- discuss the monthly statements
- talk about medical treatment alternatives
- discuss social and recreational opportunities
- ask their advice about other matters
- take the time to make them feel their life, their opinion, they're being, still matters.
- ask Mom for her menu suggestions for Thanksgiving
- ask her opinion on which dress you should wear to the Christmas party
- ask her to help pick out the invitations to your daughter's birthday party.

The important thing is not to follow your parent's advice; the important thing is to ask for it. In other words try to communicate to your parent how valuable she is to you despite the fact that you are now invoking power of attorney.

*Q. "How do I approach professionals to elicit the most help in making my tasks easier?"*

A. Refer back to the section on choosing the right professional. After you have identified people who you feel are ethical, compassionate and competent, ask them to educate you. Seek to know the many alternatives that might be available in every area that impacts your parents' life. This will help to make your decision making easier.

*Q. "How do I talk to professionals? What should I say?"*

A. My approach is to ask questions rather than to make statements. Let me share with you several that I have found helpful.

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**To the doctor:**

"Doctor, do you think my mother might benefit from taking an antidepressant?"

"Doctor, may I ask why you prescribed Paxil instead of Prozac?"

"Doctor, what is your recommendation regarding Dad living on his own?" "Would his health and safety be better if he had in home support?"

"Doctor, do you think Mother might benefit from additional assessments to determine the cause of her memory loss, incontinence, etc?"

"Doctor, Mother has end stage Alzheimer's, might it be kinder not to treat her pneumonia, and just let nature take its course?"

"Doctor, what are Dad's treatment options. If we don't treat, what is the prognosis?"

**To the attorney:**

"Are there some legal mechanisms that you might suggest to Dad that will help preserve his assets and make transfer of authority easier in case of an emergency?"

"Have you had any experience with trusts that have given the successor trustee the role of co-trustee prior to need?" "How has it worked in family situations similar to ours?"

**To the stock broker:**

"I wish to access money on a monthly basis to pay for in home support for my parents. Can you suggest ways to make this money available?"

This approach accomplishes at least two things. **First**, it makes the professional less defensive than if you assumed you knew more than he and less offensive to you than if you assumed you knew nothing. **Second**, older adults have an elevated respect for the professional. A suggestion made by the doctor oftentimes carries more weight than the same suggestion made by you. Seeking to partner with the professional community is a good strategy for maximizing the safety net you wish to provide your parents. For instance, you could ask the doctor to tell Dad he must no longer drive the car, that he must have help in the home, or that it is time

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to place Mom in a skilled nursing facility. Thus the way has been paved when you must take the keys, hire the help or place Mom. It will also reassure you to know that you have sought and received input from recognized and respected individuals in the community.

Q. *"How do I talk to my parents about end of life issues?"*

A. This is very difficult for many people, but let me assure you that the conversation will be worth the effort. It is important to know what treatment, and/or what interventions, if any, your parents may want, because you may be called on to make these decisions on their behalf. Once again, you might want to employ the assistance of a professional to facilitate the conversation. Short-term interventions may or may not be appropriate depending on the overall prognosis. A frame of reference for decision making prior to need is important. During a crisis, the emotions of the moment may outweigh more prudent judgment. Most people take a middle of the road position on treatment...somewhere between wanting everything done and nothing done. Some invoke the standard that they want interventions that will get them through a critical period but not treatments required on an on-going basis to sustain life.

Do you know your parents' wishes regarding funeral arrangements? Would they like to be cremated, buried, with a view of the ocean, under a tree, where the sun is always shining? Do they want a wake, a viewing, a party, a memorial service? How much money would they like spent on the funeral? Coffins can be very costly. Would your parent want to spend \$10,000.00 on a box that will be viewed for a matter of hours; do they want their friends to have one last party on them? Is there any particular music they would like played at the service? Ideally your parents will have included this information in a letter of instruction that is attached to their trust and will. However, if the letter does not exist, put the information regarding funeral arrangements in writing and have your parents sign the paper. In addition to alleviating emotional duress, such a document will reduce potential conflict between family members.

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*Q. "Are there other important end of life issues that I should discuss with my parents?"*

A. We all want to die in our own beds. Painless. Blissful. A national survey revealed that most people were not afraid of dying. What they were afraid of was being out of control, being a burden on others, and suffering.

As your parents' agent you cannot promise them that they will die in their own beds and in their sleep. But you are in a unique position to ameliorate their fears.

Keep talking to your parents. Keep asking their advice. Involved them conversationally, even if you doubt they comprehend what you are telling them. Allow them to give voice to their concerns. The inflection of your voice, the emotion with which you speak can give them a sense of still being in control and not being a burden on you. Afterall, they had the good sense to set up a trust, give you authority and make your job easier. In that regard they did call the shots. For most of us it is difficult to watch the slow deterioration of someone we love. It is as though he dies small deaths daily, weekly, and monthly. The emotional pain for us and for them can be excruciating. However, the physical pain can be controlled. I recommend that as your parent approaches the end of physical life you contact your local hospice agency. Hospice staff is expert on **two** things.

The **first** is pain control. Unlike other medical professionals, hospice personnel are not in the business of eradicating disease. They are in the business of comfort. They are knowledgeable about palliative treatment. They are not concerned whether your mother becomes addicted to morphine; their goal is to keep her out of pain. They can advise you that withholding food and hydration at the end reduces and does not increase discomfort. They can reassure you that the decisions you make not to treat are humane; they are consistent with the standard described by your parent while preparing the power of attorney. **Second**,

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hospice staff is expert in grief counseling. They can offer support to the dying patient as well as each family member.

*Q. "Will my parents think that I am wishing them dead? Wishing to steal their money? What will my siblings or other family members think? What will my parents' doctors think? What will their attorney, stockbroker, CPA think?"*

A. We all become susceptible to what other people may think at one time or another. Caring for aging parents is one of the times. We are probably most vulnerable to it because we lack self-confidence in our ability to do it right. We lack that confidence because in fact we are the children, they are our parents, and we played a role that involved them telling us what to do, not us telling them what to do. Stepping in and taking over upsets the natural order of things. Even when we are capable adults, we become caught up in an uncomfortable dynamic. We are mourning the loss of our own past relationship with our parent. And when we take over, we must create a new one. This change creates other waves of change. Your siblings and their children, your parents' siblings and their children, and your children, will all be effected by the reorganization.

I recommend that you seek support. This will help you stand strong in your resolve that you are doing the right thing for your parent. If you have adequately set up the appropriate legal mechanisms, you can have complete assurance that you are assuming and exercising authority as Mom and Dad predetermined. Support comes in many forms. Support groups with other adult children going through similar experiences are helpful. Also, many geriatric care managers are excellent coaches and will walk the journey each step of the way with you. Find someone. But remember you are in charge. If you have been appointed, you are responsible. While you may decide to keep the family informed, you need not seek nor gain each player's approval.

*Q. "When do I know it is the right time to place my parent in a facility?"*

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A. There are as many answers to this question as there are people. As in most matters, it is important to obtain the best information possible. I recommend that a declining adult receive a geriatric psychiatric evaluation (gero-psych eval). This is an interdisciplinary assessment that attempts to identify the reasons a person is manifesting the symptoms he is experiencing. The team usually consists of a physician, neurologist, geriatric psychiatrist and others as deemed appropriate based on a person's medical history. The tests that are run will determine what factors are contributing to your parent's debilitation. Many things can cause dementia. Memory loss can be the result of dehydration, vitamin deficiency, thyroid conditions, depression, drug/alcohol interactions, AIDs, Parkinson's' disease, strokes and more. Alzheimer's type dementia is a brain disease. It has a gradual onset and gets progressively worse. Currently there is no cure. However, many medications can be helpful in addressing some of the behavioral issues associated with the disease.

Obtaining a diagnosis will be useful to you in determining a plan of care. If some simple remedies can reverse the symptoms your mother is experiencing, she might be able to resume her life with minimal assistance. If she has a progressive degenerative disease, more involved planning is called for.

Good diagnostic information is only one factor in determining whether your parent can adequately be maintained at home. Finances are another. Typically, it is more expensive to live at home with 24-hour care than it is to be in an assisted living facility that provides room, board, and personal care. Social factors are a third. For many older adults, running a home has become stressful. Marketing is a chore. Meal planning is burdensome. Some older adults benefit from an assisted living alternative because it offers them freedom from daily chores, as well as many opportunities for socialization that are not available to them in their homes.

***An equation: more fun + less stress = an increase in quality of life.***

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**C. PLACEMENT**

There is much to know about alternative living arrangements and levels of care. You should become familiar with some of the terminology when investigating the best placement for your parent.

**Levels of Care:****Assisted Living: RCFEs**

These facilities are non-medical and are licensed by the State Department of Social Services, Community Care Licensing Branch. The type of licensure is called RCFE (residential care facility for the elderly). Such homes vary in size. Small homes, licensed for eight or fewer residents, are typical family dwellings. They offer room, food, personal care, recreational activities and transportation to medical appointments. Usually, an individual receives much more attention in a small facility than they do in a larger one. Larger programs, as a rule of thumb, offer a person greater independence. They are structured like a residential hotel. Residents have small individual apartments; meals are served in a communal dining room. Planned activities are conducted throughout the day. Outings are arranged and transportation provided.

All RCFEs must have passed a State Fire Marshall inspection as well as met all the regulations for licensure by Community Care Licensing. Look for the license. Make sure it is current. Ask about the training provided to the staff and administrator. Ask about staffing ratios. Ask how many of the staff provide direct care to the residents. Look at the meal plans, the activity plans. Ask about additional services and personal assistance that the program might offer. Does staff help with bathing, shaving, dressing, or feeding (if necessary)? Can the program accommodate someone who is or becomes incontinent? Does staff do laundry? Are there additional charges for these services? Does the facility conduct a needs and service evaluation and plan? Are you, as a caring relative, invited to participate in its development? What are the rules regarding visitation? Lights out? Smoking?

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**NOTES**

etc. (A complete facility evaluation questionnaire follows this section.)

For many older adults being placed in a "home" reminds them of the movie "The Snake Pit". This movie depicted extreme neglect and abuse of mental patients. Resistance to placement is often still caused by the memory of this bleak and depressing film.

I recommend that you tour a few facilities with your parent. You can obtain a list of them in a targeted geographic locale from Community Care Licensing, the Long-Term Ombudsmen's office (an excellent community resource mandated to monitor quality of care in licensed facilities), or your local chapter of the Alzheimer's Association. Arrange to have lunch during your tour. Make it a relaxed visit. Take time to interact or chat with other residents. Perhaps your parent can even engage in some of the facility's activities.

**RCFEs with Dementia Waiver**

RCFEs wishing to serve people with a diagnosis of dementia have to meet a higher standard than other programs. Staff must be trained in the specific needs and treatment strategies for those with dementia. Some are locked facilities for those who wander.

**Cost**

The cost for placement in a facility is determined by the services offered, location, quality, décor, etc. Some facilities (but very few) will accept Medicaid. Insurance does not cover the cost of a RCFE. Private pay may run from \$1200.00 a month to \$6,000.00 a month.

**Skilled Nursing Facilities (SNFs)**

Skilled Nursing Facilities are licensed by the Department of Health Services. They have a significant medical component. They are designed to care for those with more needs than can be handled adequately in a RCFE. Persons with complex medication regimes, needing total care, or dependent on IVs, respirators, feeding tubes, oxygen, etc. are more likely candidates for this environment.

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**NOTES**

Upon being discharged from a hospital an individual might be placed in a SNF. An example would be if Mom fell, broke her hip and needed a period of recuperation and physical therapy. In such a case Medicare (or the HMO which has bought her Medicare) would cover the cost up to 99 days as long as Mom was making progress toward a goal and had not yet achieved the goal.

Another example might be if Dad had a stroke. Once the medical crisis has passed, he will be discharged to a SNF. Again Medicare will cover up to 99 days. The reason for this plan is that it is less costly to the insurance company to have a person in a SNF than a hospital.

However, if Mom is to be a permanent resident of a SNF, it is an out of pocket expense. Insurance will not cover it. On going residential placement is never covered (unless of course your parent as a long-term care policy that addresses the specific placement). With that being said, if your parent is admitted as private pay to a skilled nursing facility and after an extended period of time, runs out of financial resources, a SNF, unlike a RCFE, may not discharge her. The SNF must accept Medicaid reimbursement at this point. For that reason, your parent should always be the one designated to meet the financial obligation, not you.

**When to Place**

The time to think about placement is when it is time for the caregiver. If a spouse is a caregiver, the demands on her might be extraordinary. It is not atypical, in fact it is frequently the case, that the well spouse dies before the one being cared for. When the stress level is such that the caregiver's well being is in jeopardy, it is time to place.

***A note to the caregiver:*** you are only able to give what you have. If you have stress, you will give stressed care. Neither you nor your loved one will benefit from this situation. Avoid the temptation to feel guilty. I assure you, it is in your best interest, as well as your loved one, that you do what best supports quality of life for you both. Placement does not mean abandonment. You can still see your loved

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**NOTES**

*one daily. You can still be there to feed her her meals. You can still take her home for the weekend. You are still the same loving concerned relative you were prior to the placement. And remember: placement need not be permanent. Try it for a while. See if it is working for you. After an interval of time, evaluate how you and your loved have adjusted to the new arrangement.*

It bears repeating: the time to place is when it is time for the caregiver.

**Food for Thought**

- Statistically, the caregiver deteriorates more rapidly than the person being cared for in a similar period of time.
- Love and physically caring for someone are not synonymous.
- Quality of life often improves for both the care recipient and the caregiver when professional help is used.
- Out of home placement does not mean you are abandoning or deserting your loved one. You are still a primary relationship, available to comfort, support, and provide reassurance.
- Out of home placement many times results in improved health due to better nutrition, medical attention and socialization opportunities.

**A Final Personal Note**

My father was my mother's caregiver for 5 years. He was ill suited for the job. Running the home and attending to her needs were stressful, but he refused help. He died before she did.

After his passing, my mother had several medical emergencies that resulted in the need for out-of-home placement. I chose a small, 5 bed board and care facility, 5 minutes from my own home. The convenience, cost, and cleanliness attracted me. The administrators' team approach was harmonious with my own. The highly personalized attention given to my mother was critical in meeting her needs.

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**NOTES**

*Was the transition difficult?*

Absolutely!

*Was it beneficial?*

A resounding yes!

Mother's body and spirit were tenderly cared for until her passing. It gives me comfort to know that she experienced the greatest peace of mind she had known in her adult life during her last 6 months.

The following pages contain a copy of a questionnaire I designed for my clients who wished to determine what facility would best meet the needs of their loved one.

**CHOOSING A LONG TERM CARE FACILITY**

Questions to be asked of the administrator/marketing director/admission's director:

1. **PHILOSOPHY:** Describe how the care you give might meet the needs of individuals with dementia? How would this care differ from the care you provide others?
  2. **PRE-ADMISSION ASSESSMENT:** Discuss your process. What criteria do you use to determine eligibility? Please discuss exit/transfer criteria, financial criteria, advanced directives and other pertinent policy information.
  3. **ADMISSION:** Discuss the methods you employ to help residents and their families during the initial transition period.
  4. **ASSESSMENT:** How do you develop a personal care plan? How important are the resident's and family's preferences in your plan? How do you maintain an individual in optimal health? How often do you reassess a resident? How do you determine whether you are doing a good job of caring residents? How do you insure quality of care?
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**NOTES**

- 5. PROGRAM:** How does the plan of care you develop reflect a resident's preferences and rhythms? How do you keep residents alert and active? What kinds of activities do you have for residents daily, weekly, and monthly? What special activities do you provide?
- 6. STAFF:** What is the staff to resident ratio? In what types of training does the staff participate?
- 7. PHYSICAL ENVIRONMENT:** Describe your facility. How does the design of the facility make the care you offer better? How is security and fire safety guaranteed? Is there a safe place for residents to go out of doors?
- 8. SPECIAL FEATURES:** What is special about your program?
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**FACILITY TOUR FOLLOW UP**

Answer the following questions for each facility you visited.

Facility Name:	License Type	Number of Residents
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#1	_____	_____
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#2	_____	_____
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#3	_____	_____
----	-------	-------

#4	_____	_____
----	-------	-------

#5	_____	_____
----	-------	-------

1. How were you greeted?

#1	_____
----	-------

#2	_____
----	-------

#3	_____
----	-------

#4	_____
----	-------

#5	_____
----	-------

2. How well were your questions answered?

#1	_____
----	-------

#2	_____
----	-------

#3	_____
----	-------

#4	_____
----	-------

#5	_____
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**NOTES**

3. On a scale from 1 –10 (worst – best) how would you rate the physical environment (was it safe, secure, comfortable, adapted, homelike, close to community resources such as shopping, restaurants, health and social agencies, recreational/cultural centers)?

#1 \_\_\_\_\_

#2 \_\_\_\_\_

#3 \_\_\_\_\_

#4 \_\_\_\_\_

#5 \_\_\_\_\_

4. On a scale from 1 –10 (worst – best) how would you rate the residents' care? Were residents clean, well dressed and groomed, treated with respect (in an age appropriate manner, as individuals)?

#1 \_\_\_\_\_

#2 \_\_\_\_\_

#3 \_\_\_\_\_

#4 \_\_\_\_\_

#5 \_\_\_\_\_

5. On a scale from 1 –10 (worst – best) how would you rate the food (were the meals appealing, were snacks available, could residents make special requests, were individual diets considered)?

#1 \_\_\_\_\_

#2 \_\_\_\_\_

#3 \_\_\_\_\_

#4 \_\_\_\_\_

#5 \_\_\_\_\_

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6. On a scale from 1 –10 (worst – best) how would you rate the activities available to residents? Were residents encouraged to engage in social or recreational activities? Was an activity schedule available for you? If so, did it reflect diverse interests, such as spiritual observances, physical activity, cultural events, community outings, arts/aesthetics, education?

**#5** \_\_\_\_\_

[illegible]