

A red mailbox on a wooden post in a field under a blue sky with clouds. The mailbox is mounted on a weathered wooden post and has the name 'KUBIN' painted on it in white. The background is a bright blue sky with scattered white clouds and a golden field in the foreground.

A Caregiver's *Survival Tips*

*Lessons Learned
in Letters from Madelyn*

KUBIN

by Elaine K. Sanchez

TAKING CARE OF YOURSELF

This is the most critical, and often the most difficult task a caregiver must do. Every airline will instruct you to put on your own oxygen mask before you try to assist others. The same principal applies to caregiving. If you don't pay attention to your own physical, emotional, and spiritual needs, you will run out of air.

Lessons from the book ***Letters from Madelyn, Chronicles of a Caregiver***

- **TIME**

Set aside some quiet time for yourself each day to do something you enjoy:

Read... Meditate... Listen to Music... Take a Nap... Go for a Walk

Let your loved one know this is YOUR time, and you do not want to be disturbed.

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- **CREATIVITY**

Seek a creative outlet:

Garden... Paint... Sew... Knit... Carve

Creating something beautiful provides a sense of accomplishment and replenishes the spirit.

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- **SOCIAL/RECREATION**

Schedule at least one outside social contact each week. Go to:

Church... Support Groups... Golf... Cards... Coffee or Lunch with Friends

Regularly scheduled social gatherings will give you something to look forward to. It will also provide a release valve for the pressure and tension that builds up when you are caring for someone who can no longer care of himself/herself.

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- **PHYSICAL**

Take care of your own physical health:

**Eat right... Exercise... Learn how to lift without hurting yourself...
Pay attention to your own aches and pains**

You will not be able to care for your loved one if you allow your own health to deteriorate. Call the doctor if you are experiencing any new or unusual physical ailments.

- **SPIRITUAL**

Feed yourself spiritually:

Read... Pray... Meditate

Realize there is a power greater than yourself, and don't hesitate to ask God for help. Faith can give you strength to transcend your loss, your grief, and the daily drudgery of caregiving.

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- **EMOTIONAL**

Set your feelings free:

Write Letters... Keep a Journal

Writing about your anger, fear, frustrations, and sadness can get negative emotions out of your head. Putting unhappy thoughts on paper helps you release them so you can spend your emotional energy on the more positive aspects of your life.

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- **HUMOR**

Find reasons to laugh:

Watch Funny Movies... Read Jokes... Giggle with Friends

Laughter releases endorphins in your brain; it eases tension and makes you feel lighter, happier, and healthier.

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- **EQUIPMENT**

Visit a medical supply store for:

Safety rails... Grab bars... Ceiling hoists... Lifts

Installing the right equipment will enable your loved one to maintain some independence, and it will protect you from unneeded physical strain.

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- **ATTITUDE**

Chose your attitude:

Positive... Hopeful... Grateful

At some point you may realize that there is absolutely nothing you can do to change your situation. Your loved one's life is not going to end easily. You will have every reason to feel burdened, frustrated, sad, and angry. But if you allow those emotions to take over, they will sap your physical and mental strength. Realize that you are not all powerful. Ask for help when you need it, and be thankful that there is one thing you can have absolute control over – your attitude. Choose it wisely.

Helpful Website:

National Family Caregivers Association

www.nfcacares.org/connecting_caregivers

Caregiving advocacy organization with tips and statistics on caregiving in America.

Resources to Help Care for a Loved One at Home

There are numerous resources and organizations designed to help elderly and disabled people stay in their homes:

- **Non-medical personal care providers** can be hired to help with activities of daily living (ADL's), such as bathing, dressing, and using the toilet. It is not unusual to ask these individuals to clean house, buy groceries, do laundry and minor repairs. Depending on the need, they may work a few hours a day, or they may live in and provide around-the-clock companionship.
- **Meal services** are available in many communities through senior centers or Meals on Wheels programs.
- **Adult Day Centers** provide a group setting where seniors and disabled individuals can go for recreation, rehabilitative therapy, meals, and health care. Financial assistance may be available, and fees are sometimes charged on a sliding scale, based on a person's ability to pay.
- **Senior Transportation** to medical appointments, shopping, and senior centers is available in many communities at low or no cost.
- **Personal Emergency Response Systems (PERS)** are alarm devices, generally worn on a cord around the neck. In the event of a fall, a sudden illness, or some other serious problem, the user pushes the button and an emergency message is sent to a hospital or police station.
- **Home Health Care** is prescribed by a physician and is provided by licensed professionals, such as nurses and therapists. Care includes rehabilitative therapy, administration of medications, wound care, and other medical help. Medicare may pay for a prescribed number of visits, providing the patient is not able to perform basic ADL's – such as bathing, dressing, and using the toilet.
- **Respite Care** services are provided for the benefit of the caregiver and can take place in-home, at senior centers, assisted living facilities, and skilled nursing facilities. Some services are free and provided by volunteers, others are fee based.
- **Hospice** care is available for people in the last stages of life. The emphasis is on providing comfort and minimizing pain for the patient, while providing social and spiritual support to the family. More than 90% of hospice care is provided in-home. There are over 2,500 hospice organizations in the U.S. Many are associated with home health agencies or hospitals. Ask the patient's doctor to help you know when it is time to call Hospice.

Helpful Websites:

www.RetirementConnection.com

A comprehensive resource for Boomers, Seniors, Caregivers & Providers to search more than 150+ topics in National, all 50 states, and select city directories. The website delivers a quick and thorough reference of providers and services; education on the vast social, wellness, and medical options.

www.eldercare.gov

A public service of the U.S. Administration on Aging, this site locates government agencies and community-based organizations anywhere in the U.S. Go to this site to find a listing of resources in your town.

www.Medicare.gov

Provides comprehensive information on Medicare/Medicaid benefits as well ratings for long-term care facilities in your area.

www.hospiceweb.com

This site will help you locate a hospice organization near you.

Selecting an Assisted Living Facility

Assisted living facilities provide a room or an apartment in a home-like environment where a person can maintain a certain amount of independence. Assistance is available to help with ADL's – Activities of Daily Living, which may include eating, bathing, dressing, and toileting.

- Costs average approximately \$3,000 a month, and include two to three meals a day, housekeeping, laundry, 24-hour call system, social activities, and security. If additional services are required for things such as administration of medications and incontinence, it can cost more.
- Assisted living costs are not covered by Medicare or most health insurance policies. Expenses are paid out of personal assets or long-term care insurance policies.
- There are no federal guidelines regulating assisted living standards, so it is up to the family to determine if it is a safe and comfortable environment for their loved one. Things you should look for when you tour an assisted living facility:
 - **Does it stink?**
If it smells like urine or feces, beware. That may be an indication that the facility isn't clean, or it could mean that residents with incontinence issues are not getting enough attention.
 - **How's the food service?**
Outside of your visits, mealtime may be the only thing your loved one has to look forward to each day. Ask if you can eat lunch or dinner with residents. Is the dining room clean and attractive? Is the food edible? Are the servers friendly?
 - **Do they treat the residents with respect?**
Observe how staff interacts with residents.
 - **Is the bed comfortable?**
Ask if you can lie down on one of the beds. Is it lumpy? If it's an automatic bed, do the controls work? How is the pillow?
 - **What's included in the basic monthly fee?**
Are there additional costs for cable TV, telephone, assistance with ADL's, medication assistance, meals, housekeeping, laundry, or linen?
 - **Who works at the facility, and what are the hiring standards?**
 - Are there physical, occupational, or speech therapists on staff?

- Is there a professional nurse on duty around the clock?
- What are the minimum qualifications and training requirements for employees?
- Are background checks and drug testing mandatory?
- **How does it feel?**
Walk around; observe the interaction between residents and the employees. Visit the public and gathering places – outside patios, recreation areas, dining room, and restrooms. Are they clean, nicely decorated, and well-lit? Is there happy chatter? Does it feel comfortable and pleasant, or does it feel oppressive? If you were making the decision for yourself instead of a loved one, could you imagine yourself being comfortable in this environment?

Helpful websites:

www.aarp.org

AARP provides a comprehensive website with links to hundreds of helpful articles about aging, health, caregiving, long-term health insurance, Medicare, and Medicaid.

What You Need to Know about Skilled Nursing Facilities

Skilled nursing facilities are licensed by states and the federal government. They provide a level of service only available from trained professionals. They serve two different types of people:

- Individuals who have been discharged from the hospital following an accident or illness but are still in need of skilled nursing care, therapy, and recuperation before they are well enough to care for themselves.
- Chronically ill individuals who are not expected to improve and who require 24-hour supervision and/or assistance.

According to AARP, costs average \$66,000 per year for a semi-private room, \$75,000 a year for a private room. The average stay is about 2.5 years.

Medicare will pay 100% of the costs for the first 20 days under the following conditions:

- The patient has been hospitalized for an accident or illness three days prior to admission to a skilled nursing facility
- The services needed are directly related to the ailment for which the patient was treated in the hospital
- Skilled nursing care or formal therapy is required on a daily basis
- The physician certifies that inpatient care is required for recovery

Medicare will pay from day 21-100 after a daily deductible is met, as long as the patient continues to meet the above requirements. Supplemental insurance plans may pay the deductible amount.

- Medicare will **not** pay after day 100, regardless of an individual's need for skilled nursing care. After day 100, nursing home care is paid out of personal assets, proceeds from long-term care insurance, or Medicaid.
- Medicaid is a federal program designed to meet the needs of people with little or no net worth. Medicaid will pay nursing home expenses for individuals with approximately \$2,000 in total assets, and \$1500 or less in annual income.
- If your loved one is a veteran, he/she may have benefits. Contact your local bureau of Veterans' Affairs.

Selecting a Skilled Nursing Facility

Most hospitals have social workers who will give you a list of area skilled nursing facilities that have rooms/beds available. They will not be able to make a recommendation, so the decision of where your loved one will go after he/she is discharged from the hospital is up to you.

Not all facilities are created equally. You would not want to put a loved one into a nursing home without inspecting it first. Schedule appointments to take tours. It is good to visit more than one facility in order to make comparisons. After you've narrowed it down to a couple of finalists, stop back in unannounced and observe:

- How quickly does the staff respond to call lights?
- Are the residents participating in activities and conversations, or are they sitting alone in hallways and wheelchairs?
- Does the atmosphere feel friendly and upbeat, or do people appear to be sad or cranky.
- Do a quick gut check – how does it feel? Do you think your loved one's physical needs will be met? Is it esthetically pleasing and comfortable? What if you had to live here?

Know What You're Signing

- Make sure you understand the terms of the contract. What is covered in the daily rate? What additional charges should you anticipate? Is the daily fee reduced if the resident is hospitalized or goes on vacation?
- If you are the Power of Attorney for your loved one and you are signing the contract, make sure to add your title to your signature. Be careful not to obligate yourself financially for your loved one's care unless that is your intention.

Visit Often, Ask Questions

- By the time people need to live in a skilled nursing facility, they have lost a great deal of independence. Visits from loved ones give them something to look forward to and it brightens their day. It also gives you an opportunity to observe:
 - Has your loved one been bathed? Are his/her clothes and bedding clean? Do you see any evidence of bedsores?
 - What's the condition of the room, the bathroom?
 - When you turn on the call light, how long does it take for someone to respond?
 - Does the staff call your loved one by name? Is the interaction between staff and residents friendly and efficient, or rough and uncaring?

- Join your loved one for lunch or dinner. How's the food, the service, the appearance and behavior of the staff?
- Do you sense that your loved one is getting appropriate social interaction? Medical attention? Physical therapy?
- Can you go home knowing that your loved one is being treated with respect and dignity he/she deserves?
- Are you confident that the staff is aware of and will follow your loved one's wishes regarding end of life issues?

Be an Advocate

- Establish a relationship with the administrator, supervisors, charge nurses, and aids. Understand their jobs are tremendously demanding and often thankless. Be kind, be appreciative, be respectful. Understand that the demands on staff are sometimes unpredictable and can quickly become overwhelming. Oversights happen – mistakes are made.
- When something goes wrong, bring it to the attention of a person who has the authority to make it right. If the problem persists, go to that person's supervisor. If it still doesn't get resolved, find out how to file a formal complaint.
- Being an advocate for an elderly or disabled person is like being the parent of a very small child. These precious people are extremely vulnerable, and someone needs to watch out for them.

HELPFUL Websites:

www.aarp.org

AARP provides a comprehensive website with links to hundreds of helpful articles about aging, health, caregiving, long-term care, Medicare, finances, etc.

**Bonus Materials

How to use the Caregiver Information Form

As a society, we've become accustomed to preparing for death and making decisions about what will happen to our belongings when we're gone. We are less likely to plan for our own care if we suddenly suffer a life-changing illness or injury.

Ask yourself these two questions:

If something happens and you are no longer able to care for yourself,

1. Who will take care of you?
2. How will they pay for it?

Use the Caregiver Information Form to answer basic medical and financial questions. Fill it out and give copies to the people who will be most likely to provide care for you.

There are two additional documents that are critically important in planning for disability:

1. Advance Directive – Dictates your choices for end-of-life care and life support
2. Durable Power of Attorney – Authorizes another person to manage your finances

Free forms are available on the Internet. However, it is highly advisable to meet with an attorney to discuss the myriad of options and legal issues.

Caregiver Information Form

Name		Blood Type
Birth date	Social Security #	
Physician	Phone #	
Primary Insurance	Phone #	Policy#
Supplemental Insurance	Phone #	Policy#
Long Term Care Insurance	Phone #	Policy#
Prescriptions		
Over-the-counter medications		
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
Allergies or other medical issues		
_____	_____	_____
_____	_____	_____
_____	_____	_____
Who will take care of you in the event of an illness or accident?		
Name	Phone #	
Who will handle your finances if you cannot pay your own bills?		
Name	Phone #	
Do you have a Durable Power of Attorney? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Where is it?		
Do you have a trustee? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Name	Phone #	

Do you have a signed Advance Directive? Yes No

Where is it?

Attorney's Name

Phone #

What assets are available to pay for your care?

Monthly Income

Bank Accounts

Investments

Real Estate

Life Insurance Policy (cash value)

Safe Deposit Box

Personal Property

Other

Will documents, codes, passwords or keys be necessary to access these items? If so, where are they?

If you should require skilled nursing care and cannot remain at home, where do you want to go?

1st Choice

2nd Choice

What other family members and friends need to be notified in the event of an emergency?

Name

Phone #

Name

Phone #

Name

Phone #

Name

Phone #

Special Instructions: