



## **Making it Work for ALL Generations**

### **Melinda Reed RN, No Worries Full Service In-home Care**

I have this picture hanging on the wall of my office which says:

**“Plan ahead-It wasn’t raining when Noah built the ark.”**

That’s probably why you are all here today...but not to talk about building an ark-which given the amount of rainfall in Oregon this month might be a good topic for Angela to get scheduled next month! You’re here because you are one of the every four households in the U.S. who provide care for a loved one or because you are seeing friends with health problems. You want to know how to make it work as you and your loved ones get older or ill.

In 45 minutes I am going to review some of the most important hints on; Preparing for aging or ill loved ones, Transition points and what to do, Dementia, Suicide in the elderly and the Resources I think are the most helpful. I’ll stay right on schedule and leave 15 minutes at the end for questions. I have packets for all of you that includes my outline, articles I think are particularly helpful, and a Resource Guide-which is also on the No Worries web site: [www.noworriescorp.com](http://www.noworriescorp.com).

Let’s start with recognizing that we are all going to be caregivers, or that at some point we will need caregivers.

Washington County printed the following statistics in a brochure on caregiving:

\*25.8% of all caregivers give from 3.6 hours to 8 hours of help a week to a loved one.

\*14% of caregivers spend between 8 and 9 hours a week caring for a loved one. A third of this percentage report giving up vacations, hobbies, or other activities, and say they have less time for their families. 13% experience mental or physical health problems due to caregiving demands.

\*19% of caregivers spend an average of 9 hours a week helping a loved one, mostly with personal care such as bathing or dressing. 30% of these caregivers-especially those between ages 19 and 34 are those who are employed-report experiencing some family conflict over caregiving.

\*23.5% (around ½ million caregivers) spend approximately 27 hours a week caring for a loved one.

\*12.3% (around 3 million households) give 40 or more hours a week to caregiving. More than 40% of these caregivers have full-time or part-time jobs, but more than 30 reported

having had to give up work entirely; 15% took early retirement; 26% took a leave of absence. 34% say that no one else helps them give care.

The experience you have will be unique. Every family, every person is different. However, there are ways for everyone to “Make it Work.” That is why I am here today. To help you know how to “Make it Work.”

### **Preparing for aging or ill loved ones**

Preparing begins with looking at our attitudes about health. When we were in elementary school we didn't think twice about getting glasses so that we could do well at school. For some reason the minute we turn 40 we want to go into denial and ignore the signs that we might need to do something to continue to enjoy a quality life. Our Human Resources Manager just had back surgery. She has trouble bending over. When she came back to work she brought her grabber. Suzi understands that it's better to use assistive devices then to try and get by without them. Suzi is more valuable with her grabber then without it. No matter how much we try to deny it we are all getting older and accommodations are going to have to be made to continue to have a quality life. The most important accommodation is to get things in order. In my business we see families torn apart because preparations were not made. Here are some suggestions:

-Figure out what you want to have happen when you die and then go see an attorney. The Oregon Bar Association has a very inexpensive and comprehensive publication to help you. I have the order form in your packet of information.

-Part of that planning will include Advance Directives decisions. I have paid for the OHSU packets but I was reading in the AARP bulletin and they suggested an internet site you can print off the Advance Directives information for free. The National Hospice and Palliative Care Organization, [www.caringinfo.org](http://www.caringinfo.org)

What is the difference between Advance Directives and the POLST (Physician's Order for Life Sustaining Treatment)? Let me read from an article in your packet by Elizabeth Stone:

“One morning 18 months later my mother briefly lost consciousness and fell to the floor. Her aide called 911 for help getting her back in bed. EMS wanted to take her to the hospital. By then my mother was in home hospice care and had been promised she would never be taken to a hospital. I argued by phone with the EMS worker to no avail. He had a copy of her hospice directive but not the proxy allowing me to enforce it. Besides, he said, ‘How do I know you're her daughter? You could be anyone.’ My mother was taken to the hospital. She died en route.”

Paramedics have to follow Doctor's orders. A POLST is a Doctor's order and is signed by a Doctor. An Advance Directive is not signed by a Doctor. An Advance Directive is usually all that is needed unless a spouse or family member is not in attendance.

Facilities require a POLST form as part of the admission paperwork. To find out more-or to order POLST forms-you can go to: [www.polst.org](http://www.polst.org) or [www.ohsu.edu/ethics](http://www.ohsu.edu/ethics)

-You have all probably heard about HIPPA-our National Privacy Act. HIPPA can be a good thing but it can also cause families to be excluded. In your packet is a Medical Release of Information Form. This is a helpful document to have so that you can be informed and included in receiving health care information about your loved one. Make copies and have your loved ones fill them out now...before you need it!

-What do you really know about your loved one? Included in your packet is an inventory published by AARP that will assist you in knowing what information is important. Fire Departments also give out cards that have important information about Doctor, hospital of choice, medications, allergies and emergency contacts. You can imagine how important this information is to have available to emergency responders.

So now what? You have everything in order. Things seem to be going along fine and then you start noticing that your parents home is messy. Mail is laying on the desk unopened. Your mom's hair which usually is cared for and styled is looking like it hasn't been done in a while. Your Dad is wearing the same thing he was wearing when you visited a few days earlier. You are starting to realize you are at a transition point where you need to find out if your parents need help.

### **Transition points**

#### **What do you look for?**

**Meals:** People living alone get tired of cooking for themselves. Shopping becomes a problem. Meals on Wheels provides for a meal and also contact with the volunteer that delivers the meal. There is a misconception that you can only get Meals on Wheels if you need financial assistance. That is not correct. Those that can afford can pay for it. Nutrition plays a considerable role in an aging person's health and quality of life, and should not be overlooked.

**Transportation:** No one wants to quit driving. The Wall Street Journal stated in an article titled *Coaxing Seniors Out From Behind the Wheel*: "Drivers who are 75 and older have higher crash rates per mile traveled than all groups but 16- to 18-year olds...Already, more than half of Americans age 65 or older who can't drive-almost four million people-stay home on any given day because they lack transportation..." Many seniors are taking advantage of safe driving classes offered for seniors through AARP and other organizations. Others are needing assistance with public transportation services or hiring caregivers. Family members do not need to worry as Oregon now has an anonymous procedure for asking for a senior driver evaluation if a loved one no longer seems safe driving a car. For more information on DMV's medical programs see: [www.oregondmv.com](http://www.oregondmv.com)

**Home Upkeep:** Upkeep is important and can usually be easily arranged. Home Modification is the key to continuing to live safely and independently. Many services are available for making home modifications. Lighting, lift chair, grab bars, comfort-height toilets, handheld shower fixtures, door handles that are easy to grasp, phones that have volume switches and more involved modifications depending on need will make a huge difference in independence. A company called “In Your Home” provides home improvement services from basic updates to major remodels. In Your Home also provides home maintenance services and can be reached at: 503.443.2424 or [www.iyh.biz](http://www.iyh.biz)

**Money and Bills:** Senior fraud is a real problem these days. It is important to make sure safeguards are put in place to protect loved ones. It is also important to recognize that bill paying is a hassle for people of all ages. This is probably one area where help is most appreciated.

**Homemaking and Personal Care:** It is hard for people to accept help. Couples don’t like the intrusion to their privacy and women who are used to running the house do not like others doing what they have always done. It is important when arranging for help to make sure that although everyone wants their “money’s worth” it is important to not create helplessness by having someone do what they are still able to do for themselves. People are amazed at the difference a caregiver for a morning a couple of times a week will make.

**Safety:** Falls can be devastating if no one knows of the fall. A Medic-alert or Lifeline systems provide a “safety net” for both the senior and the family. These systems are very reasonable and are essential if someone is living alone. Lifeline can be reached at: 1.800.543.3546 ext. 3050 or [www.lifelinesystems.com](http://www.lifelinesystems.com)

How to “Make it Work?” In your packet is an article titled, “Dad Keeps Firing the Help” by Mark S. Lachs, MD, MPH in Prevention Magazine. It is a great article and I would recommend reading it.

The National Family Caregivers Association printed the following to help us remember the perspective of the senior:

**To My Children by Hazel White**

My children are coming today. They mean well, but they worry. They think I should have a railing in the hall; a telephone in the kitchen. They want someone to come in when I take a bath.

They really don’t like me living alone. Help me to be grateful for their concern, and help them to understand that I have to do what I can do as long as I can.

They’re right when they say there are risks. I might fall. I might leave the stove on. But there is no challenge, no possibility of triumph, no real aliveness without risk.

When they were young and climbed trees and rode bicycles and went to camp I was terrified. But I let them go, because to hold them would have hurt them.

Now our roles are reversed. Help them to see. Keep me from being grim or stubborn about it. But don't let them smother me.

### **What to do?**

The hardest transition is having to accept that you hoped your parents would live to a healthy old age but now you are confronted with what has been called in *Taking Care* "extended decline and dependence." Unfortunately, we usually see a precipitating event/crisis bringing on abrupt transitions.

In your packet is an article by Elizabeth Stone "Mom's in the hospital-now what?" The most common events that we see are stroke, pneumonia or a worsening of a respiratory disease, a fall, sudden change in mental status, and many problems related to medications not being taken correctly.

I would like to briefly discuss the following (Please see the No Worries Resource Guide for complete information):

#### **Stroke:**

1-**Time lost is Brain lost.** There are drugs that can be administered if a person who has had a stroke can get to the hospital within 2 hours of having the stroke. The medication dissolves the clot that caused the stroke and most of the time there are no side effects from the stroke. However, if the person does not get to the hospital within two hours then the medication cannot be given and the person will most likely have effects from the stroke.

2-There is a type of stroke called a TIA or trans ischemic attack. Trans meaning that it happens and then goes away. TIAs should never be ignored. They are often warning signs and the person should call the Doctor immediately for instructions on whether to go to the Emergency Room or go directly to the Doctor's office.

3-The most amazing thing about strokes is that a person who has had a stroke can continue to improve-even when it seems like the progress is very slight the person is still able to improve and should be encouraged to continue exercises.

4-Stroke present in so many different ways that it is always better to be safe than sorry. Remember that 911 is free. Call the paramedics to come and assess if the person has had a stroke. Stroke symptoms can be:

- Sudden numbness/weakness of the face, arm or leg, especially on one side of the body.
- Sudden confusion, trouble speaking or understanding.
- Sudden trouble seeing in one or both eyes.
- Sudden trouble walking, dizziness, loss of balance or coordination.
- Sudden severe headache with no known cause.

#### **Falls:**

Falls can be devastating. All of a sudden a person loses their confidence because they are worried about breaking a hip and they quit doing the things they previously enjoyed. This starts a downward spiral of decreased activity and then loss of strength and eventually can lead to depression and other undesirable outcomes. It is important to note that most falls can be prevented. Why do people fall? Here are some reasons:

1-The person does not want to admit they are aging and refuses to reduce the clutter that can lead to a fall. The person also refuses to remove rugs-this is one of the most frequent cause of falls.

2-Age can cause a need to go to the bathroom quickly. When a person has been sleeping and they quickly get up and rush to the bathroom, they often will get dizzy and fall because the older person takes a little more time to get their blood pressure equalized with a change in position. Habits are hard to break but an older person must sit up at the side of the bed for a few moments before standing up and going to the bathroom.

Another problem is this delay may cause the person to lose some urine while walking to the bathroom. Falls occur frequently because the floor becomes slippery from the urine. If a little incontinence is a problem at night then it is a good idea to wear one of the many options for incontinence at night.

3-Age also causes changes in eyesight. Poor lighting leads to many falls. It is important to add lighting for safety.

4-Inappropriate shoes also cause falls. It is important that shoes be supportive. At some point high heels need to be a fond memory and not the cause of a fall. It is also important to have good fitting shoes. Different medical conditions can cause swelling in the feet. Poor fitting shoes that are tight on swollen feet can cause wounds that are often difficult to heal.

5-Toe nails that are long and mis-shaped can lead to falls. Toe nail care is very important for safe mobility.

6-Often falls are a result of the person refusing to use the walker, cane or other assistive device ordered by the Physician.

**Poor medication compliance:**

The World Health Organization has found only 50% of people typically follow their doctor's orders for taking medications. Why aren't people taking their medications correctly? There are many reasons including forgetting, not getting the instructions right, not wanting to take the medication, and the cost of the medication. Here are some hints to help you get the most out of your medications:

1-Have a correct list of your medications.

2-Use the same pharmacy for all of your medications.

3-Report side effects or allergic reactions to your Doctor and Pharmacist.

4-Drink a full glass of water when taking medications to make sure they don't lodge in the throat and cause damage.

5-Take medications at the proper time.

6-Use a pill box (mediset) to organize medications and follow a routine.

7-Throw away all medications that have expired because they can become toxic.

8-Check with your doctor before you stop taking any medication-even if you are feeling better.

**Urinary tract infections and accompanying confusion:**

Urinary tract infections are common in the elderly and can be very serious because they often result in confusion. Contributing factors are poor water intake, and poor hygiene due to arthritis and other conditions (the disposal wipes are a great option). Early diagnosis is important. A younger person would notice painful urination and frequent urination. The elderly have decreased sensation and may not feel pain and it may be normal to have frequent urination. Look for confusion, fatigue, and a strong odor to the urine.

**Diabetic management:**

It is getting more common that a diagnosis of diabetes can be the reason an elderly person seeks an alternative living situation such as Assisted Living. Poor vision, the inability to perform the task of capillary blood glucose monitoring, and complicated regimens can lead to the need for assistance. Many health plans have a pharmacist who helps manage the needs of those with diabetes and is a wonderful resource. The fact is, it is a big adjustment and time and attention in the early stages of a diabetes diagnosis can mean a healthy and enjoyable life.

**Dementia:**

With half of the people over the age of 85 having some form of Dementia I would like to spend some time talking about what you can do in this heart-wrenching situation. First, it is important to determine if the person has poor hearing or dementia. Poor hearing can mimic confusion. Here are the symptoms of Alzheimer's :

- Forgetfulness or disorientation
- Irritability or paranoia
- Difficulty performing familiar tasks
- Brief attention span
- Mental deterioration
- Loss of initiative

**-Early diagnosis and medications**

Several medical conditions such as a urinary tract infection, brain tumor, hypothyroidism, and depression can cause the same symptoms as Alzheimer's. Anyone with these symptoms should consult their physician for proper diagnosis. The reason early diagnosis is so important is there are now medications that can stop/delay the progression of Alzheimer's and other medications to treat accompanying depression.

**-Document the person's likes and dislikes**

A person with Alzheimer's will eventually forget their likes and dislikes. They will however know when something isn't as they like it but will not be able to explain why. As soon as possible, document the person's routine. Do they like their shower in the morning or at night, what are their eating patterns, do they like to wear pajamas to bed, do they like to listen to music, what hobbies have they been interested in, etc.

**-“Join the Journey”**

For example, a son went to visit his mother in an Alzheimer's facility. Each time he would come for a visit she would ask where his father was. The son would say, “Mom, he died some time ago.” For the mother, this was like the first time she had heard the

news and she would cry for three days. Each visit was filled with sadness. The son did not want to lie, but on one visit when his mother asked him where his father was he responded, "He's at work." They had a very pleasant visit and this technique facilitated many other pleasant visits.

**-Control the environment**

Simplify tasks and create calm. Overstimulation from noise, television, and crowding can lead to anxiety/agitation. Be careful of television shows. A person with Dementia can think they are "in" the show and become upset. Remember that a person with Alzheimer's is doing the best they can. Do not criticize but redirect if an action is not appropriate. Be aware that your tone of voice and behavior are often "contagious" and may be upsetting if unpleasant.

**-Get help**

- Volunteers
- In-home Care
- Adult day care
- Respite care

**-Placement**

No one wants to think about their loved one being somewhere else besides home. However, many people with Alzheimer's need more care than the loved one can provide. Usually, the loved one will have a health crisis before they will give up the many responsibilities in keeping someone with Alzheimer's safe. The problems can be wandering, aggressiveness, paranoia leading to violence, and needing constant care because they do not remember how to eat, toilet, dress, etc. The increasing numbers of people with Alzheimer's has resulted in specialty "Memory Care" facilities that can provide care in an environment that is safe and developed around the needs of someone with Alzheimer's or Dementia. When looking at placement I always suggest that the closer the better. Driving long distances to see a loved one can become overwhelming and in the end decrease the amount of time you can spend visiting.

The National Family Caregivers website: [www.nfcacares.org](http://www.nfcacares.org) and AARP's website: [www.aarp.org](http://www.aarp.org) both have excellent information on Alzheimer's, what it is, communication techniques, behavioral issues, preventing wandering, family involvement, tapping the power of music, and activity books.

What are the options when you get that call from the hospital? You can call for In-home Care Assistance or a temporary placement for rehabilitation might be the right option or a move to another living option may be for the best. How are such important decisions made when discharge planners are under pressure to discharge patients as soon as they become stable?

I would like to briefly discuss the following options:

- Return to home with family assistance
- Return to home with adult day care
- Return to home with In-home Care assistance

-Temporary placement for rehabilitation: I would just like to mention that many Assisted Living Facilities have developed small “Rehabilitation” wings. In some instances this is a great alternative to a nursing home.

-Other placement options

-Retirement Communities

-Assisted Living

-Foster Care

-Memory Care

In-home Care Agencies offer free assessments and are able to offer very good advice about whether going home is an option-it usually is unless there are financial constraints or the person is a two-person transfer. I also recommend contacting a company “All About Seniors.” They are like a travel agency for alternative living options. They are free and provide excellent advice on what options are appropriate. They will even arrange for tours of facilities and can be reached at: 503.659.3815.

Years ago I read an Ann Landers column that changed my perspective about placement options. It is in your packet. The title of the column is, “Strain of mom’s care wrecks woman’s health.” I also included a Dear Abby article that shows another side of the challenge of caregiving.

### **Seniors and Suicide**

I have included in your packet information from the Oregon Health Care Association regarding “Seniors and Suicide-What Caregivers Need to Know” and “Myths and Misunderstandings About Suicide.” Elderly citizens, the people who typically need caregivers, have the highest suicide rates of any population in the country.

### **Taking Care of Yourself**

I’m so sorry that we’ve run out of time to talk about taking care of you. (that was a joke) Isn’t that how you might be feeling in life...your needs come last-when there is time. I always tell my staff to follow the Fireman’s Code (I don’t know if there is such a thing but everyone understands the risks of Fireman):

### **You can’t help anyone if you don’t take care of yourself first**

I’ve given you all calendar books. You will be surprised if you keep track of your caregiving. Calendar books are good for two reasons: first, we get so busy we can’t remember what we did a few days ago and second, when your loved one says, “You haven’t visited me in weeks,” you will be able to look at your calendar or refer to the calendar you have for them and say, “Oh, look, I was here 2 days ago to bring you some groceries.”

Another thing you can do is buy a Polaroid Instamatic Camera. We had a client who would say to the caregiver, “You never do anything for me I don’t know why I am paying

for this.” The caregiver was getting very discouraged because the client couldn’t remember all she was doing for her. So, we purchased a Polaroid camera and the caregiver would take pictures of when they went to the hazelnut farm and got hazelnuts to make gifts for Christmas, or when a friend would come by to visit, and other fun things. The caregiver started a photo album. The client quite complaining and that photo album was her pride and joy-she would show it to everyone.

Your calendars will help you plan how to care for yourself and marking your calendar with times for self-care will become a life line for you. Remember that 1 week is an emergency and after that it’s time to get the help you need to stay healthy as a caregiver.

Your packet includes the article, “Caring for Caregivers” by Betsy Rubiner. It gives ideas on: Get Help, Take a Break, Find Support, Get a New Life, Consider a Companion, Splurge on Yourself, Cultivate Beauty, Remember Your Health, Don’t Forget to Laugh. It is an excellent article.

Kelly Greene wrote an article “Giving Hope to Caregivers” in the Deseret Morning News which states: “...63% of family caregivers suffer from depression-but that number drops dramatically for people who attend support groups.” Support groups are easy to find. The Oregonian consistently lists community support groups. Associations for the disease process also have support groups. Hospitals and Health Organizations have support groups. Senior Centers have support groups. There are also on-line support groups-some are specific for the disease and others are general caregiving groups.

This morning I had one of those “Ah Hah” moments where I realized that we are interacting with our caregivers of tomorrow. Last night I was busy typing up this outline and about 10:20pm the home computer flashes “Alan messaging.” I was surprised to be hearing from our son Alan, who lives in Texas, this late at night. My husband came over to the computer and we were laughing and sending notes back and forth and we finally dialed his cell phone because it’s more fun to actually talk. My son, asked about what I was doing and I asked about what he was doing. He is working hard on a project for work and was tired. At the end of the conversation he said, “You know Mom I kind of wish we were back on the water bed rocking each other to sleep.” What a moment. I was so grateful I had stopped what I was doing to talk to my son.

This morning I remembered an article I had read in preparation for this presentation. It is by Ann Patchett in Oprah magazine 2003 and is titled, “Caregiving: A Love Story.” The lead in is “When Ann Patchett was little, her grandmother drew her baths. Now grown-up, she feels privileged to return the favor.”

I realized the experience we have in caregiving is partly determined by the love and memories we have for that individual. Our children learn how to care for others through our example and how we have cared for them.

## Resources

- No Worries Resource Guide: [www.noworriescorp.com](http://www.noworriescorp.com)
- 911 (it's free)
- Washington County Family Caregiver Training call No Worries 503.641.4949
- AARP: [www.aarp.org](http://www.aarp.org)
- National Family Caregivers Association: [www.nfcacares.org](http://www.nfcacares.org)
- “Taking Care” The President’s Council on Bioethics offers their report on “Ethical Caregiving in Our Aging Society” a book of over 300 pages for free. Just request a copy [www.bioethics.gov](http://www.bioethics.gov)
- Aging Services [www.eldercare.gov](http://www.eldercare.gov)
- [www.networkofcare.com](http://www.networkofcare.com)
- Palliative Care and Hospice-all health care organizations (Providence, Kaiser, Legacy, etc.)
- Oregon Bar Association Publications-Legal Issues for Older Adults 503.620.0222, ext. 413
- Local Senior Center
- All About Seniors 503.659.3815
- In Your Home 503.443.2424 or [www.iyh.biz](http://www.iyh.biz)
- Family Memorial Services 503.736.0102 24 hrs/day
- Attorney-at-Law Tom Davis 503.644.9000 12220 SW First St, Beaverton, OR 97005
- McCann’s Pharmacy and Home Health Equipment 503.639.7377 15685 SW 116<sup>th</sup> Ave, King City, OR
- Lifeline Personal Response Service 1.800.543.3546 ext 3050 or [www.lifelinesystems.com](http://www.lifelinesystems.com)
- Meals on Wheels-Loaves & Fishes 503.736.6325
- Free Advance Directives Forms at [www.caringinfo.org](http://www.caringinfo.org)
- POLST (Physician’s Orders for Life Sustaining Treatment) [www.polst.org](http://www.polst.org)
- DMV’s medical programs: [www.oregondmv.com](http://www.oregondmv.com)