

# Legal / Financial Issues

Planning Together for the future

- What documents do you need to consider?
- When do you begin?
- Who do you go to?



## Legal and Financial Planning

It is very important for families to begin legal and financial planning early on when caring for someone with memory loss. Why?

- Persons with early memory loss have the ability to be involved in future decisions that will affect their lives.
- They are legally competent to sign these documents. As time goes on, they will lose this ability. Then the only recourse is Guardianship.
- There is time now to talk as a family about these documents, so that everyone is on the same page.
- There is time to organize your documents, choosing one location for easy access when needed. This information can then be shared with individuals who would be involved in carrying out your decisions.
- The cost of future care may need to be met through Medicaid. Medicaid planning needs to be done many years ahead. Families need to prepare for this even if it is never needed.
- This planning needs to be done with an attorney specializing in Elder Law who is knowledgeable about Medicaid planning.
- You need a personalized approach – everybody's situation is different!
- You may qualify for tax credits (house / income) based on the care you are giving.

Call the Alzheimer's Association Helpline at 1-800-272-3900 for names of Elder Law attorneys and for information on Tax Credits

Please note the two brochures included in your handouts:

***Money Matters by the Alzheimer's Association***

Gathering / reviewing financial documents

Involving the person with memory loss

Seeking financial advice

Costs you may face

How to cover the costs

***Legal Plans by the Alzheimer's Association***

Legal capacity / Guardianship

Legal documents

Who to go to / How to prepare

What to discuss

*Life consists not in holding good cards but in  
playing those you do hold well.*

*By Josh Billings*

**My Journey**

By Chip Gerber

"I had been busy preparing for my future when suddenly a future,  
not of my liking or planning, took over my life and made  
a future of its own.

The long goodbye set in and I suddenly had to look at the new future,  
face it, get rid of any denial that was there  
and make plans on how to deal with the new future  
that forced itself into my life."

At 51, Chip Gerber had a full life. As a licensed social worker and court-appointed guardian for the elderly, he often represented abused and exploited seniors in court. He loved his job, having a zest for the work that was important to him.

Then came the day when he couldn't remember why he was in court, or even who he was representing. "I thought it was because of stress, and the overload of my job," Gerber said. But it continued to happen. According to Gerber, he couldn't follow his own notes or keep up with required paperwork. He panicked – literally.

Over-stressed by his concern, his worry and anxiety led to hospitalization and ultimately, to diagnosis. He had Alzheimer's disease. Gerber joined the estimated 4 million people nationwide with the disease, and the 10 percent younger than 65 diagnosed with "early onset AD." That was six years ago. At the time of his life when everything was wonderful – his career, his family, his plans for an enjoyable retirement – it all came crashing down.

### **Shock and denial. Depression.**

Gerber had a growing realization that all the plans made with his wife, Sharon, would now take a different path. He was familiar with the effects of the disease – both his mother and grandmother had it. Even so, he did not expect it to come calling.

Now, six years later, he is experiencing some of the progressive symptoms of the disease. He no longer knows his address or his phone number. He uses some words inappropriately, substitutions that sometimes mystify his wife, Sharon. "He told me when I was going out not to forget my e-mail," she said. "He meant my purse."

Gerber was placed on Aricept, a widely used medication that helps slow memory loss. "It stabilizes it to some degree, although it is like using an aspirin for a brain tumor," Gerber said. "There is no known cure."

He and Sharon wear bracelets, acquired through the Alzheimer's Association, that make them part of the "safe return system." Gerber's bracelet has identification on the back with a phone number. It's there in case he gets lost. Someone will come and get him and return him home. For Sharon Gerber, her bracelet identifies her as a caregiver for someone

with Alzheimer's. "If I were in an accident and couldn't speak, the bracelet would let someone know to look out for him," she said.

The diagnosis of Alzheimer's initially left the couple shell-shocked and led to chronic depression. Part of the process involves grieving, Gerber said. "It's a lot to work on," he said. "My plate was full."

"I immediately felt the need for support and the need to meet others like me," he said. The couple was referred to support groups, both for individuals with early onset Alzheimer's and also caregivers. "It's stimulating to relate to others, exchange ideas and stories," he said. "We can be open and free, make new friends. Alzheimer's friends stay by you."

### **Chip Gerber found a new cause.**

He has become an advocate, a voice for those with the disease. "This is my world now," Gerber said. "I want to change it for the better." He means it. He traveled to Tallahassee to participate in the Florida Alzheimer's Summit 2003, and also attended the National Alzheimer's Association's 15th annual Public Policy Forum in Washington, D.C. He has spoken from a platform he knows well, testifying to the need for Alzheimer's research funding. "Our focus is to try to educate politicians, to get them behind funding Alzheimer's research," Gerber said. "Money is keeping us from finding a cure."

"Even if we don't find a cure, we can help with prevention," said Sharon Gerber. As a third generation victim of the disease, Chip Gerber is naturally concerned about the future for his two children and seven grandchildren. He plans to continue to speak to civic, church and any other audiences as long as he's able. "I've had considerable invites," he said.

Keeping as active as possible and stimulating his mind are goals that Gerber pursues. Besides his speaking engagements, Gerber keeps an on-line account of his daily life, called My Journey. "I didn't know anything about the computer until I got Alzheimer's," Gerber laughs. "The computer has opened up my world. I relate daily with these friends. We promote awareness, support, and education – with the emphasis on support." He has had hits on his site from as far away as India, he said. "One of the saddest days for me will be when he can no longer be on the computer," said Sharon.

Reading his journal has helped her get to know him even better, she said. Instead of pushing the couple apart, Alzheimer's has brought them closer. It is not the future they envisioned together, but they make it work. "She has so much to offer," said Gerber of his wife. "We are like a hand in glove. We've been through the good and the not so good. We take our vows seriously."

Sharon Gerber is active in caregiver support groups, including a local one as co-facilitator. "Before Alzheimer's, I wouldn't even speak in public," she said. "I'm amazed at what I've done since." Confronting Alzheimer's has led them to confront other issues as well, like end-of-life decisions. "We've had to deal with some things that couples deal with later in life like death and dying – so many areas that are not thought of until you are seniors. We have made all the decisions that can be made," Gerber said. His activism has helped Gerber focus on more than the end of life. His work, he feels, will leave a legacy of insight and learning to benefit not only his family, but also others.

"The long goodbye to some feels like a curse, but I feel it has been a blessing. I'm looking at the long run. We have a long good-bye with this disease. I have time to tell my wife how much I love her."

**"One thing I've learned quick is  
there's life after diagnosis."**

As the disease progresses and changes take place, Gerber hopes to maintain as long as he can. He remains active with his church, St. James United Methodist in Palatka, as well as continuing his journal and advocacy. "Some with AD choose to keep in the closet and that's sad," he said. "I find doing the opposite helps me. It helps me handle life in a way to bring hope. I can't maintain all levels, but I can maintain a sense of value and worth.

*Taken from the Palatka Daily News by April Curtis, May 14, 2003.*

Finish each day and be done with it.  
You have done what you could;

some blunders and absurdities have crept in;  
forget them as soon as you can.



Tomorrow is a new day;  
you shall begin it serenely and with too high a spirit to be  
encumbered with your old nonsense.

By Ralph Waldo Emerson

I like living.  
I have sometimes been wildly despairingly, acutely miserable,  
racked with sorrow, but through it all I still know quite  
certainly that just to be alive is a grand thing.

By Agatha Christie, *An Autobiography* (1977)

## **What I've Learned** by Maya Angelou

I've learned that no matter what happens, or how bad it seems today, life goes on, and it will be better tomorrow.

I've learned that you can tell a lot about a person by the way he/she handles these three things: a rainy day, lost luggage, and tangled Christmas tree lights.

I've learned that, regardless of your relationship with your parents, you'll miss them when they're gone from your life.

I've learned that making a living is not the same as making a "life."

I've learned that sometimes life gives you a second chance.

I've learned that you shouldn't go through life with a catcher's mitt on both hands; you need to be able to throw something back.

I've learned that whenever I decide something with an open heart, I usually make the right decision.



I've learned that even when I have pains, I don't have to be one.

I've learned that every day you should reach out and touch someone. People love a warm hug, or just a friendly pat on the back.

I've learned that I still have a lot to learn.

I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

## **Brilliant Insights From Persons Living with Memory Loss**

1. I'm used to having everything here between my ears.
2. I've been trying to tell my friends what is happening. Some respond by saying that there's nothing wrong with me. I know they're trying to help, but it's so frustrating. I've been to three doctors and I know what is happening to me.
3. I want my doctor and my family to be straightforward with me.
4. Information is power. It eliminates ignorance which eliminates fear.
5. I don't want to rely on people to do for me what I can still do for myself.
6. If I forget what I wanted to say, I don't let it bother me. It goes along with the territory.

### **What Do I Want From a Friend?**

I want to have fun together like we used to  
To be able to communicate and put our feelings out  
To feel comfortable – to be myself  
Compassion – but not pity!  
An offer to drive me somewhere  
**NO VOODOO REMEDIES!**  
Please don't act differently to me!

7. I am coming to the stage where I have accepted that I have Alzheimer's. For awhile I was pretending that I was not coming down with this, that they would find out what was really wrong. I just couldn't get past the bitterness.
8. My husband keeps me sane.

9. My daughter is bossy. I now let her be in charge once in a while.
10. I lost my confidence, so I stopped driving.
11. It was devastating for me not to drive. It took me a long time to look at signs before it sunk in.
12. When people hear Alzheimer's they think it's just your memory. They don't understand the emotional component that's tied in with it. I have low days, they are frustrating and scary.
13. Why does my brain not stay with me?
14. I forget little things. It bothers my wife more than it bothers me – and that bothers me!
15. I'm old enough to make my own decisions as long as I'm willing to live with the consequences.
16. It is hard when someone else tells you what to do. I want to say, "Mind your own business, Sweetheart."
17. Trust – that's the whole thing.
18. Its nice to come to a group like this where there's a common interest – even if it's not one you would ever choose to come to.
19. Its easier to do things together, each taking a part.
20. I think the family members can see this much better than we can.
21. Talking about leaving signs for ourselves – we could leave a sign on the bathroom mirror stating, "You look great today!" If we forgot that we put the sign there, even better!!

<p>When my heart is broken, he is there to mend it. by Jan Soukup</p>
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22. Nothing stays the same, you have to learn to adapt.

# Learning Together II Leaders Manual: Family Members

## Focus: Legal / Financial Issues

Handouts for workbooks (3-hole-punched, paper clipped to take home)

1. Welcome individuals. If there are new people, ask them to introduce themselves (without giving a snapshot view) and mention confidentiality.
2. Note the focus for this session is on Legal and Financial Issues. I would like to introduce a very special guest, Attorney \_\_\_\_\_. Before we split into our 2 discussion groups, I asked Attorney \_\_\_\_\_ to talk about the documents that we encourage families to complete. These documents give families the opportunity to make decisions together on finances and health care.  
*All of the information talked about tonight is in your handouts.*
3. Begin dialogue with attorney (combined group – 20-25 minutes):
  - **What documents should be completed?** (Durable Power of Attorney for Finances & Health Care / Living Will)
  - **Who do you go to?** (Specialist in Elder Law)  
*Call our Helpline for names*
  - **When should you do this?** (NOW!)
  - We will talk more about these documents in our separate discussion groups. **Does anyone have a question they would like to ask before we split into our 2 groups?**
4. Continue dialogue with attorney (family group only):
  - **Does anyone have questions on the documents that were mentioned?**

- **Who needs to receive copies of these documents?** (Give copies to all designated individuals & physicians involved in person's care; keep a copy at home & in your car.)
- **What if someone is no longer competent to sign a Power of Attorney?** (Guardianship)
- **Are there other documents that should be updated? For example, wills that have been completed in the past? The deed to the house?**
- **Are there any problems families should be aware of with the new privacy laws?**

*Open for Questions / Comments*

- **Are there tax credits that a family member who cares for someone with memory loss qualifies for?**  
*Call our Helpline for more information on tax credits.*
- **What is a Living Trust?**
- **Would you share some general tips on Medicaid planning?**
- **How soon should this kind of planning be done?**
- **Should you go back to the attorney at any time? For example, if a nursing home were needed?**

*Open for Questions / Comments*

- **Thank attorney for coming / initiate applause.**