Legal / Financial Issues

Planning Together for the future

• What documents do you need to consider?
• When do you begin?
• Who do you go to?
It is important for each of us to plan for the future. This doesn’t change when you have memory loss. It becomes even more important.

You have the opportunity now to consider how you want your financial matters handled and who you would want to turn the financial reigns over to if needed.

You can also decide how you would want your own health care to be handled in the future. Talking these matters over with your family puts everyone on the same page and makes your wishes clear to everyone concerned. Now is the time to organize your documents. It is recommended to keep these documents in one place. Sharing this information with your family will enable them to carry out your decisions in the future.

Life consists not in holding good cards but in playing those you do hold well. By Josh Billings
Something Mysterious
Sidney Aldrich

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I have a long-standing relationship with this bank and it has served me well.

In fact, it is my one and only Memory Bank.
My Journey
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 online 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."

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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.

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.

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!!

When my heart is broken, he is there to mend it. by Jan Soukup

22. Nothing stays the same, you have to learn to adapt.
Exercise Your Brain: Creative Writing

Begin with a word that has meaning to you. An example might be the word FRIENDS. Write this word in large letters down the side of a piece of paper. After each letter, write a phrase about “friends” that begins with this letter.

For example:

F = Fun to be with
R = Ruth, my dearest friend
I = Interesting
E = Encourages me
N = Needs me
D = Delightful humor
S = Safe

You can use many different words for this brain exercise. Try not to use a word with too many difficult letters, like Q, or words that repeat one letter over and over, like SASSY.

You can also use the name of someone close to you, like your wife or daughter. For example, this person might use the name RUTH, writing down all the things that are special about her.
Here are two to get you started:

C = __________________________________
H = __________________________________
A = __________________________________
N = __________________________________
G = __________________________________
E = __________________________________
*  *  *  *  *  *  *  *
S = __________________________________
U = __________________________________
P = __________________________________
P = __________________________________
P = __________________________________
O = __________________________________
R = __________________________________
T = __________________________________


Learning Together II Leaders Manual: Persons with Memory Loss

Focus: Legal / Financial Planning

Supplies:
Flip chart
Marker
Handouts for workbooks (3-hole-punched, paper clipped to take home)
Discussion handouts (copies at end)
  1. Something Mysterious, p.3
  2. Brilliant Insights, p. 9-10
  3. What I’ve Learned, p. 8

1. Offer personal welcome to each person as you go around the circle.

2. If new individual, ask each person to introduce themselves. Note confidentiality.

3. Does anyone have questions on what the attorney said?

4. How many of you have completed a regular will? A Living Will? Leader may explain document or open to the group to explain. A Power of Attorney for Finances? Health Care? Open to the group / affirming need to complete these documents – so that you can have your say!

5. Read handout, Something Mysterious, p. 3. What do you think?

6. Read and discuss handout, Brilliant Insights, pp. 9-10.

7. Brain exercise: Creative Writing, pp. 11-12, using the word, “Friend”. Write word down side of flip chart; opening to group to complete phrases about this word; may continue with more words, e.g., “Change” or “Support.”
8. May read and discuss boxed in quote from *My Journey*, pp. 4-7. (Leader may read additional excerpts from this article to stimulate further discussion.)

9. May end with handout, *What I’ve Learned*, p. 8, opening to comments after each section.
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Sidney Aldrich

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