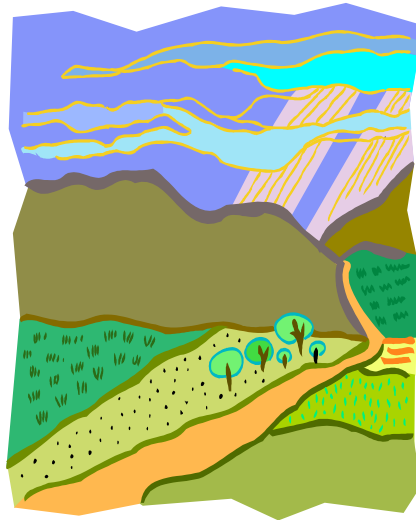


Health Decisions

Knowing your options

- Treatment decisions
- Hospitalization
- Emergency plan checklist

**Hoping for
the
high road**



**Planning
for the
low road**

Considering Surgery

Surgery can be a traumatic experience for people with memory loss if their families do not consider several factors before making a decision. The somewhat cold, unfamiliar world of a hospital or clinic can be unsettling for most people, but for the individual with memory loss, the shift from familiar surroundings to a clinical environment can magnify memory loss and difficult behavior. Add to that the possible negative effect of anesthesia and drug interactions.

“Think of what it is like for any of us during a hospital stay. Our sleeping patterns are disturbed and anesthesia and narcotics make us all less aware of our surroundings,” says Eric Tangalos, MD, from the Mayo Clinic, Rochester, Minnesota. “During hospital stays, the Alzheimer’s patient loses track of space and time and can show his or her worst side.”

Restoring these individuals to their pre-operative mental and functional state can be quite challenging or never occur. “Surgeons often want to do surgery with the best possible intent, but the family needs to use extreme care in making the decision,” says Geri Hall, PhD, from the University of Iowa Center on Aging. “All too often I’ve seen families make decisions based on the idea that surgery would solve a problem, only to have very poor outcomes.”

In general, the aged fare badly during emergency surgeries, but families can carefully evaluate elective surgeries in terms of anticipated benefits and risks, Hall says. When deciding upon surgery, families should first consider the individual’s wishes. The Association urges individuals with the disease to have advance directives in place as guideposts for family members regarding treatment and care.

Decisions also should be based upon several factors, including the individual’s stage in the disease, capacity to handle a change in routine and environment, and the benefits of the procedure. “I wouldn’t opt for surgery for my mother unless I thought it would improve her quality of life,” says Elizabeth Figueroa, caregiver to her mother with Alzheimer’s and

program director for the Cobble Hill Health Center in Brooklyn, New York. "If it's surgery for an acute condition and I'm given an option, I would consider pain management." Figueroa notes that the choice to pursue surgery or not is very individual and personal to each family, and Tangelos stresses that each situation should be judged on its merits.

Is the surgery worth it?

In 1997, Wally Reed, MD, a retired anesthesiologist from Arizona and caregiver to his wife with Alzheimer's, was faced with the dilemma of deciding whether or not to allow his spouse to undergo surgery for a hip fracture. After considering the risk, he asked the physician to let his wife's fractured hip heal on its own, and it did. "I was convinced that the post-operative cure could not be carried out," he says.

The patient's ability to rehabilitate is critical in determining whether to choose surgery. Caregivers must keep in mind that the individual with Alzheimer's has trouble learning and problem solving. Major surgeries, such as hip surgery, increase the risks of lowering the quality of life. An elective operation will reduce pain, but the individual could become less mobile because of the inability to learn to use a new hip.

Some surgeries do enhance the life of a person with the disease. An example is cataract surgery. The procedure can be done on an outpatient basis and not disrupt the person's daily routine. The elimination of cataracts also may lead to fewer hallucinations.

Still, surgery can lead to increased confusion and decreased mental status in the individual with Alzheimer's, so families must weigh the consequences. "Is the risk of abrupt decline and functional loss worth the potential benefit from surgery?" asks Hall.

General anesthesia may make the patient extremely confused post-operatively. For someone in the early stages of the disease who is able to perform daily activities, the general level of the person's mental status will decline temporarily, but this may not be the case for a person in an advanced state. "As the disease progresses, the risks of surgery to mental status and function increase exponentially, as does recovery time," Hall says.

For the normal elderly person over the age of 70, it will take three to five days to restore their mental and physical status for each day of a hospital stay, Tangalos notes. But for the person with Alzheimer's, it could take longer. If the individual is in the end stage of the disease, palliative care might be a better alternative than hospitalization.

What to do if surgery is the choice

If a family decides to proceed with surgery, they should share as much medical information about the person as they can with the surgeon and arrange a discussion between the individual's physician and the surgeon.

Families also may want to pursue aggressively the least invasive procedure and ask if it can be performed on an outpatient basis. Less invasive operations could lead to briefer hospital stays and better options for those with the disease. The family needs to meet with the anesthesiologist in advance and discuss the type of anesthesia and be clear that the person has Alzheimer's. To reduce post-operative confusion, choose a local or regional (spinal) anesthesia that may not heighten confusion as much as general anesthesia and ask that any post-operative pain medications be scheduled, rather than "on demand," so the patient does not have to ask for it.

Moreover, many families think the pain medication will heighten confusion so they refuse it for their loved one. This may cause increased pain and decreased post-operative mobility, thus precipitating agitation, confusion, pneumonia, and prolonged recovery.

When the person enters the hospital, family members may want to take turns staying overnight and spending time during the day with the patient. It's a good idea to involve a social worker in discharge planning to assist a family in mobilizing resources to meet additional needs. Also, consider family members' needs for respite and anticipate additional demands on the caregiver at discharge.

With foresight and planning, families can shield the person with Alzheimer's disease from some of the unpleasant consequences of surgery and hospitalization.

Taken from the Alzheimer's Association Newsletter Advances, Volume 21, 1

Emergency Planning

As a caregiver, do you have a plan in case something would cause you to be hospitalized or away from home suddenly?

Here are some suggestions:

- Have an emergency contact and a back up emergency contact who could come immediately and stay the first few hours until a more permanent cover person can get there – a neighbor or someone very close by, if possible.
- Make sure your emergency contacts have:

a key to your house, instructions on how to get in if necessary, security codes if needed, and instructions on where to find your emergency book or file.
- Have an emergency book or file with all vital information pertaining to you and to your loved one, such as:
 1. Instructions for your emergency contact to follow once they get to your home (who they should contact for help, etc.)
 2. Names and phone numbers of family members or friends with whom you have made arrangements to be a more long-term cover person
 3. Names and numbers of places you have checked out for short-term respite stays, if needed
 4. A list with any specific care needed by your loved one who is left at home
 5. A list detailing what medications, prescription and over-the-counter, that are being taken by you and the person left at home, where the medications can be found, dosages and times of day the meds need to be taken, etc.
 6. All doctors' names and numbers

7. Your lawyer's name and number
 8. Copy of Durable Power of Attorneys for Finances/Healthcare
 9. Copy of Living Wills
 10. Copy of insurance cards
 11. Copy of Social Security cards
 12. Copy of Medicare/Medicaid cards
 13. Copy of Do Not Resuscitate Orders
 14. Brief medical histories
- Have a prominent sign on the refrigerator noting location of emergency book or file.
 - Everyday Concerns

Does someone know you are ok in the morning and evening?

Have you arranged for a neighbor to call? Look for paper? Look to see if your blinds are raised or open? Is there someone who calls you once or twice a day?

If you have e-mail: Do you have a code that you use daily to let someone know you're ok? AM? PM?

Do your neighbors know your spouse/parent has memory loss?

- Phones

Consider whether a portable phone, a phone in/by your bathroom or bed, or a Life Line response system would be useful? Post a simple, large sign by each phone to help cue a person with memory loss to call 911 in an emergency.

- Personal Identification

Does your loved one have some form of ID on him/her at all times? Have you applied for a Safe Return ID through the Alzheimer's

Association? The Safe Return Identification Program is a national program to identify, locate and return individuals with dementia who wander. Almost 60% of those with dementia will wander at some point in their illness. Because it is not possible to predict who will wander, it is recommended that any ambulatory person with memory impairment be registered in the Safe Return program. Benefits include identification materials, registration in a national database, a 24-hour toll-free number to contact, and coordinated outreach to police, emergency rooms, etc. There is a one-time \$40 registration fee and \$20 annual program administration fee.

Please Note: Assistance is provided in wandering situations even if the person is not yet registered in the Safe Return program. Please call our 24-hour Helpline at 800-272-3900.

Hospitalization

Hospital Emergencies: What Can You Do Now

Planning ahead is the key to making either an unexpected or a planned trip to the hospital easier for you and your loved one. Here is what you should do now:

- Know who you can count on. You need a family member or trusted friend to stay with your loved one when he or she is admitted to the emergency room or hospital. Have at least two people you can call on to go with you or meet you at the hospital at a moment's notice so that one of you can take care of the paperwork and the other can stay with your loved one.
- Pack an "Emergency Bag" containing the following:
 1. A sheet of paper listing the person's name, nickname, address, insurance companies (include policy numbers and pre-authorization phone numbers), Medicare and Medicaid card numbers. Also include important numbers such as,

doctors (include addresses), key family members, minister and helpful friends.

2. A list of all current medications and dosage instructions, including medicines taken that have ever caused a bad reaction and a list of any allergies to medicines and foods. This list should be updated when there is any change.
3. Copies of important paper's such as Durable Power of Attorney, Health Care Power of Attorney, and Living Will.
4. Extra adult briefs (*i.e.*, Depends) if the person usually wears them. These may not be easy to get in the Emergency Room if you need them.
5. A change of clothes in case the person's clothes become soiled or torn and a plastic bag for soiled clothing.
6. A card that says, "My companion has memory loss. Thank you for your patience." You should avoid talking about your relative's memory changes or behaviors in front of him. This can be upsetting and embarrassing to your relative. These cards are available through your local Alzheimer's Association.
7. A writing pad and pen so you can jot down information given to you by hospital staff.
8. Pain medicine such as Advil, Tylenol, or aspirin.
9. A sealed snack such as a pack of crackers and a bottle of water or juice for you and your loved one.
10. Pack comfort items. Things to help your loved one feel safe and secure such as favorite clothes or photos.

At the Emergency Room

Offer physical comfort and verbal reassurance to your relative. Stay calm and confident. Do not assume your loved one will be admitted to the

hospital. Do not leave the ER to go home without a follow-up plan. If you are sent home, make sure you have all instructions for follow-up care.

Before a Hospital Stay

If your loved one is going to the hospital for a planned stay, you have time to prepare and ask your doctor questions. Ask your doctor if the procedure can be done as an outpatient visit. If not, ask if tests can be done before going to the hospital to shorten the hospital stay. Ask if your doctor plans to talk with other doctors. If so, find out if your relative can see these specialists before going to the hospital. You should also ask questions about anesthesia, catheters, and IV's. General anesthesia can have side effects. Ask if local anesthesia is an option and if you will be allowed in the recovery room.

Before Going to the Hospital:

If your insurance allows, ask for a private room if possible. It is more quiet and calm. Let your loved one take part in the planning for the hospital stay as much as possible. Plan ahead. Make a schedule with family and friends to take turns sitting with your relative during the entire hospital stay. Shortly before going to the hospital, decide the best way to tell your loved one that the two of you are going to spend a short time in the hospital.

During the Hospital Stay

Have someone stay with your loved one at all times if possible – even during medical tests. Know that a strange place, medicines, tests and surgery will make a person with Alzheimer's disease more confused, and in need of more help with personal care.

Assume your relative will have problems finding the bathroom and using his/her call button, and alert staff to these needs and the need to be checked on more often than normal.

If Anxiety or Agitation Occurs

1. Remove street clothes from sight.
2. Post reminders or cues if this comforts your relative.

3. Turn off television, the telephone ringer and the intercom.
4. Talk in a calm voice and offer reassurance. Repeat answers to questions.
5. Give a comforting touch or redirect your loved one.
6. Listen to soothing music.
7. Slow down; try not to rush your loved one.
8. Try reminiscing with your loved one, sharing stories and photos.

Working with Hospital Staff

Remember that not everyone in the hospital knows the same basic facts about memory loss and Alzheimer's disease. You may be their best teacher of what works with your family member.

- You can help the staff by giving them a list of your loved one's normal routine; personal habits: likes and dislikes; possible behaviors, what might cause them and how you handle them; and signs of pain or discomfort. Make the list easy to read with headings and short, simple statements, leaving copies with the chart and/or at the nurse's station.
- Decide with the hospital staff who will do what for you loved one. For example, you may want to be the one who helps your family member get a bath, eat, or use the toilet.
- Think about placing a poster above the head of the bed with key information, including names of people important to your loved one and the relationship (spouse, cousin, friend).
- Tell the staff about any unusual behaviors, hearing problems or communication problems your relative may have and offer ideas for what works best in those instances.
- Make sure your family member is safe. Tell the staff about any problems with wandering, getting lost, suspiciousness or falls.

- Do not assume the staff knows your loved one's needs. Tell them in a nice, calm manner.
- Ask questions when you don't understand hospital procedures, tests or when you have a concern.

Only a life lived for others is a life worthwhile.
Albert Einstein

Make Contact with Local & National Resources

- Alzheimer's Association Cleveland Area Chapter
- 24-hour Helpline at 1-800-272-3900
- www.alzclv.org
- Substitute Caregiver Program:

This program offers reimbursement for families in need of short-term substitute care for a person with memory loss. The care may be provided in the home, adult day center, or at a facility. Participating in the program allows the caregiver to have respite for medical treatment, obtain short-term stress reduction, plan long term for the person with memory loss, or for other reasons. Friends, neighbors, or others, may be reimbursed for care received.

- Specialized brochures available at no cost. For example:
Steps to Facing Late-Stage Care: Making End of Life Decisions & Late-Stage Care: Providing Care and Comfort During the Late Stage of Alzheimer's Disease

National Alzheimer's Association

- Alzheimer's Disease Education and Referral (ADEAR) Center at 1-800-348-4380
- www.alz.org

Some Lessons That Come from Caring

Many lessons come our way through the experience of caring. Usually, however, the caregiver is so tied up in the day-to-day demands of the job that there is little time to reflect on and become mindful of these lessons. Planning some time alone can be most valuable as you consider your current situation and future options.

Things change.

The only thing in this life that you can really count on is that things will change. Nothing lasts. No matter how hard you try to hold on to the moment that you are savoring, it eventually does slip away. So do the trials, however. Negative events are not a never-ending pattern.

If you try to hold on hard enough to the way things used to be, you stand a good chance of not seeing the good that comes out of the change that you've been resisting. "He never admitted that he needed me," said one woman. "Now that he's not always fighting for his way, I see a side to him that is new to me and I like it, despite the tragedy that has befallen us."

You are not a fortune teller.

You cannot predict how anything will turn out. You may use your best judgment, and try to apply lessons learned from other situations, but you can never be sure. So don't deny yourself any possibility just because you are afraid that things will not work. Especially don't try to apply "rules" blindly. You might miss something wonderful. One lady's family was going to forgo taking their grandmother to the circus because people with Alzheimer's are not supposed to tolerate crowds. But in the end they did take her, and everyone had a wonderful time. Be prepared for anything, but don't count on anything either.

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.

Agatha Christie, An Autobiography (1977)

You are not a mind reader.

You have no way of knowing what is on people's minds unless you give them a chance to tell you. We often assume what others are thinking and spend a lot of energy trying to make sure that they don't get the wrong impression. We attribute motivations to others based on our own feelings and expectations. We do this with a person who has Alzheimer's disease just as much as we do it with neighbors and family. One lady resigned from her bridge group because she felt embarrassed by what she thought the others were thinking of her husband's peculiar behavior. They thought she had resigned because she didn't like them.

You are not a magician.

You cannot be everything, do everything, and fix everything. If you could, you would have absolute control over everything; and if you had absolute control, you would have absolute responsibility. No one can handle such a burden. So many caregivers think that they are responsible for everything, and when they fail to deliver they feel guilty. Guilt is the biggest and most useless energy drain of all.

No matter how much you try, there are some things that you will never be able to control.

Other people and their behavior is one. We can influence their behavior by our actions, but we cannot control it. Therefore, it is best to accept people as they are.

There are things that you and only you can control. One is how you feel. No one can make you feel bad, guilty, ashamed, or even good. The key is to identify the things you can control so that you can put your effort where it will bear some fruit.

The world is filled with kind people who would love to help if they only knew what you needed.

No one can possibly know what you are going through. No one's imagination is good enough. Everyone wants to believe that you are coping just fine. So you have to let people know that you could use help, and tell them specifically what kind of help you need.

There is no such thing as reciprocity, especially from a person with dementia.

You should not give with the expectation of getting in return. Do it for yourself, and only if you really want to. Remember, you do have control over your own feelings.

Don't judge and don't worry about being judged.

Because we really don't know their true circumstances, we should not judge other people. One lady told us of having seen a man in dirty clothes and a ragged little boy walk into a liquor store with twelve cases of empty beer bottles. People in the store looked askance at the man. "Drinking like that and he can't even buy decent clothes for the boy," they muttered. She wondered which of them could have been sure that he hadn't, in fact, been up since dawn collecting the bottles from the roadside so he could buy clothes for the boy. Then she realized that just as she was unable to judge that man, no one was able to judge her and the job she was doing taking care of her husband.

No one can really know our circumstances, especially when the cognitively impaired person has such a good social facade. They cannot accurately judge us either. One caregiver said, "If I must justify myself to people, they are not worth the effort."

Every question has a thousand right answers. You just have to open your mind to the possibilities.

This is even more the case with a person who has Alzheimer's disease. Freed of social constraints, she can see so many more possibilities. Where is the best place to sleep? The answer is wherever you are comfortable when you get tired, such as in front of the TV. Do you find yourself saying more and more often, "Why not?" or "So what?" That's a good sign, because that means you are redirecting your energy and your values so that they will do the most good.

Little things mean a lot, sometimes more than the big things.

For one thing, the little things happen so much more often and are so much more accessible. Life is made up of little things like getting mail,

eating ice cream, and having coffee at the kitchen table. Every moment is precious, because it will never come back. Concentrate on what you are doing at the moment. If you lose the moment, you lose everything, because for the person with dementia, that's all there is.

The little things are there for us to extract beauty, healing, and strength from. When a person cannot see these little things for what they are worth, that is when burnout is setting in.

Relationships mean everything.

Everything is possible when there is mutual trust and respect. The person with dementia, just like anyone else, will resist control but accept guidance.

We must be prepared to change.

The following quote was in a notebook one lady left with me. She had not indicated the source. "Certain coping mechanisms have been serving us for a lifetime, perhaps not well, but at least we knew how they worked. We would set our sights on an objective and move steadily toward it. There are times when we see that our objective is not where we thought it was and that is when we have to change course."

*Believe that life is worth living and your belief
will help create the fact.
William James*

I gain strength, courage and confidence by every experience in which I must stop and look fear in the face . . .

I say to myself, I've lived through this and I can take the next thing that comes along . . .

We must do the things we think we cannot do.

Eleanor Roosevelt



Brilliant Insights From Persons Living with Memory Loss

1. If you don't have purpose, you feel useless. If I can help you, please let me.
2. Try to accept each day. If today is not that great, then tomorrow will probably be better, and it usually is.
3. I feel blessed that my family has recognized and accepted this – pretty much.
4. It was very interesting to find out what others do in their spare time.
5. I've got to look at the world out there and say, "Yeah, I can do that!"
6. I have to do the best with what I have left.
7. Pets bring you peace. They understand you and forgive you.
8. We have to take what comes our way and appreciate it.
9. If you have your sense of humor, it is worth more than any medicine.
10. I persevere; I've had a lot of struggles in my life.
11. I can't ride my bike anymore, but I've always wanted to tap dance. Maybe I'll give it a try.
12. Getting to know each other makes it easier to absorb this. I don't feel lost anymore.
13. When I am here with so many other people, it makes it easier.
14. You can remember back further than you can remember the present.
15. You have yourself. You have to believe in yourself.
16. What we need is a sign on our back that says, "I'm not stupid, I just have Alzheimer's disease!"

17. I'm thankful I came here. It freed me to talk about this.
18. We've lost a lot of memory, but our mind is not gone and we can still do a lot of things for a long time.
19. When you start to say something, you don't know what word to throw in.
20. My word is there. It's just not coming out.
21. Sometimes you can't remember the name of something, but you know how it works.
22. My main problem is memory. I get distracted, I make lists. If I can remember which pocket I put the list in, I'm fine.
23. You need to find something that fits you so that you can get immersed in it.
24. I told my neighbor that I have Alzheimer's. I didn't want him to wonder what was wrong if I didn't recognize him.
25. I'm still here. I still know who I am. Let me still be part of life.
26. There's nothing that hurts me more than when someone says, please sit down when I don't want to.
27. We have to have faith and wait for researchers to stumble upon something to help.
28. I used to be so active when the kids were over. Now I just sit and savor the time.
29. You asked about strengths that I see in myself. I came here.

Learning Together II Leaders Manual: Family Members

Focus: Health Decisions

Supplies:

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

Support Group List

Family roster

Sign-up sheet for social group

Discussion handout (copy at end)

1. Quote by Eleanor Roosevelt

Note to leaders: For some families here tonight, this series is coming to a close. All of these families received a call to talk about this and to offer additional support, if needed.

1. Recognize individuals who are completing this series, offering them the opportunity to share words of wisdom that might be helpful to the newer individuals. (Leaders will get names ahead of time.)
2. Handout roster of names, addresses, phone numbers, emails so that they can keep in touch.
3. Pass out current list of support groups for family members. There are 33 to choose from. The main difference between these and this 10-part program is that these support groups are ongoing and only for the caregiver. Families are encouraged to check these out, visiting more than one if the first is not a good fit. Often families from Learning Together make plans to attend one of these support groups together.
4. In January we hope to start a monthly social outing. On the Westside, families are planning a once a month lunch at a restaurant. We would like to put something like this in place on the eastside.

Pass around a sign-up sheet for anyone who is interested in planning this social outing.

5. Focus discussion on emergency planning. Persons with memory loss are often at higher risk for unexpected health crises. It's important to be prepared. Note handouts containing information on elective surgery, emergency tips, and hospitalization.
6. Hospitalization can really catch you off guard. It can be a nightmare for someone with memory loss. Has anyone had an experience with this? Open for group discussion, adding tips from handouts.
7. Discuss planning ahead for an emergency, for example:
 - Have an emergency contact, and a back up who could come immediately, if needed?
 - Have an emergency book or file with all vital information pertaining to you and to your loved one?
 - Have a prominent sign on the refrigerator noting location of emergency book or file?
 - Consider what facility you would choose for your loved one if something unexpected happened with his/her health?
 - Talk with your family about what you would want done if something happened to you?
8. End on an upbeat note. It can be handing out/reading quote by Eleanor Roosevelt, p. 16 or an acknowledgement of something positive someone said during the group, a positive step someone has made, or a summary of key points.

I gain strength, courage and confidence by every experience in which I must stop and look fear in the face . . .

I say to myself, I've lived through this and I can take the next thing that comes along . . .

We must do the things we think we cannot do.

Eleanor Roosevelt

