

Learning Together: Questions, Decisions, & Tips Description of 4-Part Program

- Targets persons experiencing cognitive loss who can participate in decisions affecting current and future care and who are seeking answers to their own questions and concerns.
- Two-fold purpose
 - ❑ To provide opportunities for persons with Alzheimer's disease or a related disorder to get their questions answered, to share their concerns and feelings with others, and to be proactive in developing strategies to face the future
 - ❑ To strengthen the entire family for the journey ahead, with special emphasis on involving the individual with memory loss in current and future decisions
- 4-part series offered once a week
- 2½ hours time frame
 - ❑ 6:00 - 6:30 PM for refreshments
 - ❑ 6:30 - 8:30 PM for program
- Each session includes
 - ❑ Educational piece for entire group
 - ❑ Three separate discussion groups: one for persons with memory loss, one for spouses / partners, & one for adult children / other relatives & friends
- Facilitators
 - ❑ 1 Alzheimer's Association professional staff facilitating series & co-facilitating group for persons with memory loss.

- 2 Alzheimer's Association professional volunteers: one co-facilitating group for spouses / partners; one co-facilitating group for adult children / other relatives & friends.
- 2 Alzheimer's Association family volunteers: one co-facilitates group for spouses / partners; one co-facilitates group for adult children / other relatives & friends.
- 1 Alzheimer's Association masters level student intern who co-facilitates group for persons with memory loss.

➤ Presenters

- Session I Graduates of *Learning Together* program: Person with memory loss and family member
- Session II Physician specializing in dementia
- Session III Specialist in memory loss research

➤ Rotating sites throughout five-county service area

➤ Fee: none

➤ Attendance

- 10-15 families / 35-50 individuals
- Program is open to 1-2 guests per session: Alzheimer's Association staff may sit in on any discussion group; Trustees and professionals from the community may sit in on discussion group for persons with memory loss.

➤ Space requirements

- 1 meeting room accommodating 35-50 individuals
- 2 meeting rooms accommodating 12-18 individuals each

➤ Refreshments: Coffee, tea, lemonade, cookies, & pretzels

Learning Together: Questions, Decisions, & Tips Outline of Program

➤ Session I What Are Your Questions?

- Introductory comments: introduce self, goals, confidentiality, brief overview of program / packets, clarification of term “Alzheimer’s disease”.
- Dialogue with *Learning Together* graduates: person with memory loss and family member share insights, adding what they hope for these new families.
- Introductions: table by table
One member from each family introduces their family, telling what part of town they are from; leaders introduce themselves, sharing professional / family experience.
- Discussion group for persons with memory loss: individuals share how they got their first names / a word they might use to describe themselves (used as icebreaker, round robin technique). Facilitator offers opportunity for questions or concerns to be addressed during the series. Discussion focuses on learning to live successfully with memory loss (Making the Most of Our Memories handout). Individuals are asked to name one or two activities they enjoy (round robin technique). These may be written on flip chart to compare interests. May read / discuss Brilliant Insights handout if time permits.
- Discussion groups for family members / friends: individuals give snapshot view of their current situation, adding what they hope to gain from this series. Group ends with opportunity to mention any questions or concerns they would like addressed during the series.
- Evening ends with highlights from group for persons with memory loss.

➤ **Session II Medical Perspective**

- Dialogue with physician: reaffirm before dialogue that persons with memory loss are part of the audience, need for limited use of the term “Alzheimer’s disease”.
- Discussion group for persons with memory loss: individuals are asked for input on speaker, given opportunity for additional questions. Facilitator discusses how the brain works and shares tools from Memory Tools Basket. Opens to group for additional tips (may list on flip chart). Facilitator offers tips on communication, moving discussion to incidents or feelings of frustration. Signs are created to capture these feelings as well as affirmative comments. Group invited to read individual quotes from Affirmations handout.
- Discussion groups for family members / friends: individuals are given the opportunity to ask additional medical questions. Discussion then focuses on communication and practical tips.
- Evening ends with signs from persons with memory loss.

➤ **Session III Research Update**

- Dialogue with specialist in memory loss research
- Discussion group for persons with memory loss: facilitator opens for comments on speaker, additional questions. Individuals discuss change (*Holding on Versus Letting Go* technique). Facilitator asks each person to mention 1-2 strengths they see in themselves (round robin technique), opening to group for strengths they see in this person, adding strengths facilitator sees. These are written on cards for each to take home.
- Discussion groups for family members / friends: individuals discuss legal planning & helpful strategies for decision-making.
- Evening ends with highlights from group for persons with memory loss.

➤ Session IV Decisions for Today and Tomorrow

- Family photo shoots as families arrive: with rose, without nametags! (Photos mailed to each family.)
- Facilitator discusses ways to support the Association, highlights *Safe Return* program, shares memory tips from group for persons with memory loss and Memory Tools Basket.
- Discussion group for persons with memory loss: facilitator lights candle (optional), opens for comments on what individuals enjoyed or didn't enjoy about the series, suggestions they have to improve the program. Discussion focuses on gratefulness. Each person is asked to share 1-2 things they are grateful for (round robin technique, written on paper hearts for each to take home). Ends by reading their Brilliant Insights (Open to group to read individual quotes). Takes group photo.
- Discussion groups for family members / friends: facilitator lights candle (optional). Opens to group for topics needing wrap-up, positive changes or plans, affirmative comments. Asks group to complete evaluations.
- Reconvene: facilitator offers opportunity for family members / friends to share what they value most in one another. Asks group to join hands in a large circle, offers closing comments.
- Long-stemmed roses (with water tubes) are given to each person with memory loss.
- Group photo

A Special Note to Facilitators

Please use this format only as a guide, changing it as needed to support the questions that arise in each individual group. It is always best to trust your own inner voice and the wonderful guidance individuals with memory loss and their families offer. By doing this we will avoid the pitfall of focusing too much on the task and not enough on the spirit behind what we do. It's more than information.

For persons with memory loss, it is like holding up a mirror – reflecting back to them all that remains. This affirmation of their non-cognitive gifts diminishes fear, helping each to feel more confident and hopeful.

For family members and friends, it is the assurance that they will find the strength and the answers they need as they travel this journey – and that we will be there to stand by them.

It's all about hope.

Hope that you will get up in the morning
And still be able to tie your shoes,

Hope that you won't get worse fast,

Hope that your kids won't get it -
That they'll find a cure in the next generation,

Hope that your wife won't suffer too much,

Hope that you never lose your sense of humor.

Herb Farr, diagnosed with Alzheimer's
disease at age 59

Facilitator's Notes

Session I

What Are Your Questions?

➤ Objectives

- Understand goals and format of series.
- Identify individual questions and concerns.

➤ Room Design

- Common meeting area: classroom style (long tables aligned 3 across with outer tables angled toward presenter) or restaurant style (round tables accommodating 6-8 individuals staggered to view presenter)
- Discussion groups: circle of chairs open or around table

➤ 6:00 to 6:25 PM Refreshments and Registration

- Alzheimer's Association staff & family volunteer welcome each family, check off names on registration sheet, and add information on additional family members / friends.
- Families receive information packets with nametags attached.
 1. Each individual with memory loss
 2. Each separate household of family members or friends
- Facilitators visit with families, helping them to feel comfortable.

➤ 6:25 to 6:30 PM Families Seated.

➤ 6:30 to 7:10 PM Welcome and Introductions

- Alzheimer's Association staff asks families to arrange their chairs to face the front.
- Introduces self & welcomes families.

- Affirms relaxed atmosphere, e.g. welcome to get refreshments or use restroom at any time, gives location of restrooms.
- Explains goals of program.

Learning Together is one of many programs the Association offers. It is usually the first program persons with memory loss attend with their families.

Our main purpose is to offer clear and accurate information.

You will learn about the latest medications and research as well as practical tips on keeping your memory functioning at its best.

People tend to feel more confident after a program like this. I would like to read a few quotes from families who attended a recent series:

I was a hard sell to get here, but I'm glad I came.

I feel better after the meetings - and I still feel better the next day.

This is the first time I've laughed since I got the diagnosis.

At first I thought it was too early for our family. If someone asked me now, I would say the earlier the better.

I also think you will find it very reassuring. At the end of one of our recent groups, a spouse said,

We came to this series with such heavy hearts. We needed some kind of lifeline; and, even though there is no cure, we now have a sense of hope.

We hope you will feel comfortable during this series and ask any questions that you have.

Please know that everything you say will be kept confidential.

- Describes format for series.

I would like to take a few minutes to explain this series in more detail. In your packets you each have an agenda that describes the focus of each evening. (Wait while families turn to this agenda.) As you can see, we won't be bored! (Highlight various topics and handouts.)

Each evening consists of two parts. One part will be an educational program for all of us to hear together.

The second part will consist of separate discussion groups, one for persons with memory difficulties, one for spouses and partners, and one for adult children and other relatives and friends. These groups will focus on your questions.

Each week you will receive additional handouts on various topics. You may want to bring your folders back each week to add this information.

You are very welcome to invite others in your family or close friends to this special series. They may attend as often as they can and will also receive an information packet. Do you have any questions about the series?

- Initiates introductions of families & facilitators (table by table).
 1. Asks representative from each family to introduce who is with them this evening and what part of town they are from.
 2. Facilitators introduce themselves, noting professional and/or family experience.
- Introduces graduate family from previous *Learning Together* series (interview person with memory loss first then family on each question):
 1. What kinds of things were happening that made you concerned about your memory loss? What was the assessment like? What was your reaction?

2. You came to this program. Was it useful to you? How? Was it reassuring?
3. Have you told others in your family? Their reaction?
4. What about your friends? Their reaction?
5. We have many new people here tonight who are trying to learn to live successfully with memory loss. What do you want to say to them?

Initiate applause.

- Clarifies Alzheimer's disease term.

I'd like to clarify a few terms before we move into our separate discussion groups. The first is the term dementia. We hear so much about this word. Dementia is a broad term used to describe a loss of mental functioning that interferes with a person's daily life.

Dementia can be caused by several disorders. The most common is Alzheimer's disease; but there are several other disorders that can cause dementia as well, for example, Vascular Dementia, Frontotemporal Dementia, or Dementia with Lewy Bodies.

The Alzheimer's Association serves families living with any type of dementia. Our focus here is not on any one specific diagnosis – but on living successfully with memory loss.

As one wife said, "My husband's memory is like a dictionary. Some pages are missing. If we need information on one of these pages, it's gone; but there's a whole dictionary left."

- Alzheimer's Association staff notes upcoming break.
- Offers directions to separate discussion groups.

➤ **7:10 to 7:20 PM Break**

➤ **7:20 to 8:20 PM** **Discussion Group / Persons with Memory Loss**

- Alzheimer's Association staff offers welcoming comments, facilitates introductions (round robin style).

It's good to have all of you here tonight. As you can see by now, this is a very welcoming place. It's also a safe place. You can say whatever you are thinking or feeling – and it will go no further. I'd like to take a few minutes now to get to know each other better. I thought it would be fun to share how we got our first names? May I start with you? How did you get your name? May follow with question on a word they would use to describe themselves. (Allow time for person to respond.)

- Opens for questions and concerns

This series is designed especially for you. It's your time to ask any questions. For example, one man asked if Aricept caused a runny nose. It does! It could be a question on anything to do with memory loss. Does anyone have something they want to ask? (Co-facilitator writes down questions / inspirational comments from the group.)

- Making the Most of our Memories (Handout copies.)

This series is about learning to live with memory loss. There are many ways to do this successfully. This handout lists several tips. Let's start with the first one. (Open after each for comments and additional tips.) Next week I will be bringing in a whole basket of memory tools from people who have attended these groups.

- Facilitates discussion of what individuals enjoy doing.

Living with memory loss successfully also means holding on to the things that you enjoy. What do you enjoy doing? May I start with you? (List on flip chart, compare interests.)

- Offers opportunity for graduate from *Learning Together* to add additional comments; reads Brilliant Insights handout if time permits.
- Co-facilitator reads humorous or inspirational comments.

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➤ **7:20 to 8:20 PM** **2 Separate Discussion Groups: 1 for Spouses / Partners & 1 for Adult Children / Other Relatives & Friends**

- Professional volunteer offers welcoming comments.

I just wanted to say how glad I am that all of you are here tonight. It isn't easy to come to a series like this, but I think you will find that it is a safe place, where you can say exactly what you are thinking or feeling – and it will go no further. It is also a place to get your questions answered.

- Offers personal comments about professional and/or family experiences; asks family volunteer and graduate from *Learning Together* to share comments.
- Facilitates introductions around.

I'd like to go around now and ask each of you to introduce yourself. It would be helpful if you said a few words about your situation and what you hope to gain from coming to this series.

- Offers opportunity to voice questions or concerns they would like addressed during this series. (It can be helpful to frame by category, e.g. asking about medical questions, practical, day to day concerns, driving, safety in the home, etc.) Co-facilitator writes down questions to give to Alzheimer's Association staff. (Questions are then grouped by category for facilitators to use in remaining sessions.)

➤ **8:20 to 8:25 PM** **Families Reconvene**

➤ **8:25 to 8:30 PM** **Wrap-up for Families**

- Co-facilitator from group for persons with memory loss shares descriptive comments and other highlights from the group; highlights next week's program.

➤ **8:45 to 9:00 PM** **Wrap-up for Leaders**

➤ **Handouts and Supplies Session I**
What Are Your Questions?

- Box of tissues for each break-out group / key if needed
- Coffee: decaf, regular, filters, measurer, coffee maker, carafes
- Tea: herbal, regular, carafe
- Sugar / artificial sweetener / cream / stirrers
- Lemonade or ice tea / ice water / 3 pitchers / spoon
- Cookies / snacks: 2 trays, 2 basket
- Napkins / plates / cups
- Roster / curriculum
- 4 Notepads / 10 pens: registration table, discussion groups
- Nametags: prepared, blank, 2 sharpies
- Signs / masking tape
- Microphone set-up / extension cord

Registration table

- Individualized packets for persons with memory loss with personalized name tags attached (red stars)
 1. Agenda with synopsis of facilitators
 2. Brilliant Insights
 3. Flyers on Eastern or Western Region Offices
 4. For You the Person with Memory Loss
 5. Helpline card inserted in pocket
 6. If you Have Alzheimer's Disease (brochure)
 7. Letter from President Reagan
 8. Overview of Memory Loss (specialized *Helpline* packet)
 9. Ten Ways to Maintain Your Brain

- Individualized packets for family members / friends with personalized name tags attached (blue stars for spouses & partners; gold or silver for other family members / friends)
 1. Agenda with synopsis of facilitators
 2. Brilliant Insights
 3. Flyers on Eastern or Western Region Offices
 4. Helpline card inserted in pocket
 5. Living with Early Onset Alzheimer's Disease (if needed)
 6. Maintain Your Brain brochure
 7. Overview of Memory Loss: AD & Related Disorders

8. Recommended Resources
9. Safe Return Application
10. Services for Families
11. Services for Persons with Memory Loss
12. Welcome to our Homepage
13. Words of Wisdom

Persons with memory loss group

- Making the Most of Our Memories handout
- Brilliant Insights handout
- Flip chart / marker

Facilitator's Notes

Session II

The Medical Perspective

➤ **Objectives**

- Receive clear and accurate medical information.
- Have an increased understanding of the individuality of persons experiencing cognitive disorders.
- Identify ways to enhance individual and family communication.

➤ **Room Design**

- Common meeting area: classroom or restaurant style
- Discussion groups: open circle of chairs or around table

➤ **6:00 to 6:25 PM Refreshments and Registration**

- Alzheimer's Association staff and family volunteer welcome each family, check off names, and add new information.
- Alzheimer's Association staff visits informally with physician prior to the start of the program. Reaffirms points sent in formal letter, e.g. who is in the audience, the need for clear descriptions of medical terms, the preference of saying memory loss rather than Alzheimer's disease, & the need to keep the focus on early issues.

➤ **6:25 to 6:30 PM Families Seated.**

➤ **6:30 to 6:35 PM Welcome and Introductions**

- Alzheimer's Association staff asks families to arrange their chairs to face the front.
- Welcomes families, introduces new family members and guests, and describes format for the evening.

➤ **6:35 to 7:30 PM Dialogue with Physician on Medical Issues**

 Dementia

We hear a lot of terms in the medical community. One of these is dementia. What does this mean? (Possible responses by facilitator: The term dementia, then, is used to describe certain symptoms - it's not a real diagnosis. That's why the tests are so important - to figure out what is causing this. Dementia, then, isn't a normal part of aging.)

How is dementia related to Alzheimer's disease?

What about the term Mild Cognitive Impairment (MCI)? What does this mean? (Add questions on related disorders represented in current group.)

Open for questions.

 Assessment

Our next questions are about the testing that is done when someone has memory loss. How accurate is it? What is the doctor looking for on a CT scan or MRI? Do you recommend one over the other? Should they be repeated?

Are there actual physical changes in the brain? (Possible responses by facilitator: Damage in the brain, then, is like scar tissue. These physical changes, then, are the reason individuals may have trouble finding the word they want to say or balancing a checkbook – the messages aren't always getting through.)

Is there a relationship between small strokes and Alzheimer's disease? Could depression cause memory loss? How does a doctor rule this out? (Possible follow-up response: Trying an anti-depressant, then, can be useful in ruling this out as a primary cause of memory loss.)

Open for questions.

 Symptoms / Treatments

There are several medications approved by the FDA now for memory loss. I'd like to ask you about the first class of drugs approved by the FDA, the cholinesterase inhibitors. These are Aricept, Exelon, or Razadyne. How do these work in the brain? Is one better than another? (Possible response: All of these medications, then, work in a similar way.)

What should a family expect from these medications? (Possible response: If a family didn't see any clear improvement, this doesn't mean, then, that the drug isn't working.) What about side effects, e.g. gastrointestinal distress, runny nose, nightmares? Any tips on handling these? Can these medications help with related disorders such as Vascular Dementia, Lewy Body disease, Pick's Disease? (Note related disorders in current group, Exelon for Lewy Body.) How long should you stay on these medicines?

What about the latest medication called, Namenda? What does this do in the brain? Do you recommend that people try this also? If they wanted to, would they continue to take their other medication, such as Aricept, Exelon, or Razadyne? What about side effects? (Possible response: So this regulates a different chemical in the brain called glutamate; then you could take this along with your other medication.)

Is it common to experience mood shifts? I remember one wife saying, "My husband has become so quiet. He isn't interested in doing things like he did before." Is depression a common symptom? Are there medications that can help? Side effects? Is depression common for family members to experience also? (Possible responses: It isn't uncommon, then, to have these kinds of feelings. It sounds like anti-depressants can be useful.)

Do some medications make cognitive problems worse? (Possible follow-up responses: You need to be careful, then, with things like cough medicine, antihistamines, medications for pain, or incontinence. If it says anti-cholinergic, you need to check with your doctor.)

What if there is a very sudden loss of functioning? Is this to be expected? When should you call the doctor? (Possible responses: A sudden change, then, usually means an infection of some sort or possibly a small stroke. It's important, then, to call the doctor.) What about the impact of alcohol? Stress? Fatigue? Not having enough fluids? Nutrition?

Open for questions.

➤ 7:30 to 7:40 PM **Break**

➤ 7:40 to 8:20 PM **Discussion Group / Persons with Memory Loss**

Alzheimer's Association staff offers welcoming comments.

What did you think of the doctor? Any other questions you have?

Focuses discussion on how the brain works.

The doctor talked about what causes memory loss, how it relates to what is happening in the brain. Let's take a look at the brain (passes out picture).

As you can see there are many different parts of the brain. Each is responsible for a different activity. If there is a problem in one area of the brain, like the area responsible for speech, it makes it hard sometimes to find the right word. For someone else, this part of the brain may be working very well, but there might be problems with recognizing familiar landmarks.

Short term memory is stored in the middle of the brain. This is a common place for messages to get stuck. It makes it difficult to remember things that just happened, for example, who was just on the phone.

Each person's brain is different. What is happening to one person may never happen to another. The main message here is that all of these difficulties are related to physical changes in the brain. It's not a matter of just trying harder.

The trick is to learn ways to compensate for the problems you are experiencing. For example, if short term memory is a problem, then you need to store information outside of the brain. (Go over memory tools basket / handout, open to group for input, list ideas on flip chart.)

When you are talking with someone and you get stuck for a word, what do you do? (List on flip chart) Did you know that ninety-three per cent of communication is not through words? It's through body language. There are a lot of ways to get our messages across.

- Focuses discussion on frustrating experiences.

One way to get your message across is by writing it down. I have some blank signs with me tonight. (Hold up a blank sign.) I'd like you to think about times when you have felt frustrated, what you would want to say when this happens?

I'll write your comments on these signs. At the end of the evening, I'll read these to the whole group. No one will know who said what!

I'll give you an example. I recall one woman who didn't want her husband to help her so much in the kitchen. On her sign she wrote, If I need help, I'll ask! Does anyone have an example of something frustrating? (Write comments on hand-held signs, e.g. Wait, I'm not finished! Hello, I'm here! My turn!)

Does anyone ever feel left out when people are talking? In one of our other groups, a man said that sometimes he felt like an empty chair. Does this ever happen to you? What could you do in a situation like this? What could you say?

Is there anything you say to yourself when things like this happen? (Open to whole group for positive comments they could say to themselves; writes these positive mottos on signs also, e.g. I'll deal with it, I'm still the same person, I'll do the best I can, Maybe they'll find a cure.)

Here are some thoughts from other groups like this. (Handout Affirmations for Persons with Memory Loss – can open to group to read individual quotes.)

- Ends by reading signs; notes that these signs will be read to the whole group when we reconvene.

➤ **7:40 to 8:20 PM** **2 Separate Discussion Groups: 1 for Spouses / Partners & 1 for Adult Children / Other Relatives & Friends**

- Professional volunteer offers welcoming comments.

Are there any other medical questions?

I'd like to take a few minutes to talk about how the brain works (note handout on brain). As you can see, each part of the brain does something different. If there is damage in one area of the brain, like the area responsible for speech, it makes it hard for that person to find the right word. For someone else, this part of the brain may be working very well, but there might be damage in the visual-spatial area. This would make it hard to recognize familiar places and things. Each person's brain is unique. What is happening to one person may never happen to another.

Families often ask about the stages of disorders like Alzheimer's disease. I'd like to say a few words about this. At this point in time, we cannot stop these disorders from getting worse. However, how fast this happens varies from person to person. It can be anywhere from two to over twenty years. At present the average length of time for someone with Alzheimer's disease is about eight years. For most people, losses are gradual, over many years.

Families learn to enjoy the present much more than they did before. Often families plan trips that they had put on hold. One of our families celebrated the fiftieth anniversary of their parents one year early. It was a wonderful celebration.

What I urge you to remember is that the Association will be a steady resource for you over these years. You can call as often as you need to as new questions arise.

- Facilitates discussion on communication

I'd like to focus now on the topic of effective communication. One of the earliest losses for many people with a disease like Alzheimer's disease or

Vascular dementia is in the speech area of the brain. This affects the giving and the receiving of information – and it's not just words. It's your emotions as well. I'd like to share a few communication skills and then open to all of you for additional tips.

*The first is talking **face to face** - with good eye contact. If you are trying to convey important information, you really need the person's undivided attention. Try to **limit distractions**, like the TV. It is helpful to **use nouns** when giving information. They're the name of the game! Repeating these key nouns helps the person hold on to what you are saying. (Open to co-facilitator and families for additional ideas.)*

*It's easy to fall into the habit of talking at rather than with someone who has memory loss. This is usually task-oriented conversation, such as, "Did you shave this morning" or "There's a sandwich in the fridge", or "You need a jacket today". Keeping the person connected through social conversation is vitally important. It can be as little as five seconds. For example, "I really like it when you help with the dishes." It is sharing personal information, feelings, preferences, and experiences. **It's the human connection!***

Are there specific problems you're running into with communication?
(Open to co-facilitator / families for additional tips.)

- Focuses on practical tips / questions from Session I.

One of the questions you asked last week was how to handle repetitive questions. (Open to co-facilitator for comments and then group.) Another had to do with handling frequent mood changes. (Open to co-facilitator / group.) A common practical question has to do with holidays. Holidays can be very stressful. Routines that are working well are often disrupted. There can be too much stimulation - with small children or a large number of people talking at once. It can be hard to sort out all of this stimulation. This can cause periods of anxiety. (Open to co-facilitator / group.)

- Summarizes key tips, e.g. simplifying surroundings, knowing what's important to hold on to and what to let go of, looking at our response rather than expecting the person with memory loss to change, **LIVING IN THEIR WORLD.**

➤ **8:20 to 8:30 PM Families Reconvene / Wrap-up**

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➤ **Handouts and Supplies Needed for Session II**
The Medical Perspective

- Box of tissues for each break-out group / key if needed
- Coffee: decaf, regular, filters, measurer, coffee maker, carafes
- Tea: herbal, regular, carafe
- Sugar / artificial sweetener / cream / stirrers
- Lemonade or ice tea / ice water / 3 pitchers / spoon
- Cookies / snacks: 2 trays, basket
- Napkins / plates / cups
- Roster / curriculum
- 4 Notepads / 10 pens: registration table, discussion groups
- Nametags: prepared, blank, 2 sharpies
- Signs / masking tape
- Microphone set-up / extension cord
- Donation envelopes on refreshment table
- Flyers on upcoming programs / events
- Pens, blank paper on each table in main room
- One Day at a Time (on family tables)

Discussion group for persons with memory loss

- Affirmations: Persons with Memory Loss (Put some on large colored signs to hang around the room before group begins, e.g. I'm still here.)
- Picture of brain
- Memory Tools Basket / handout
- Twenty blank signs on sticks / markers
- Flip chart / marker

Discussion group for family members / friends

- Facts: About FDA-Approved Cholinesterase Inhibitors
- Facts: About Memantine
- Picture of Brain
- Medication Alert
- Prescription Assistance
- Steps to Enhancing Communication

Facilitator's Notes

Session III Research Update

➤ Objectives

- Have an increased understanding of research initiatives.
- Have an increased awareness of the need for early planning, especially legal planning.

➤ Room Design

- New design for common meeting area:** tables are grouped together to create 4-5 separate discussion groups; each set of tables accommodates 3-4 families.
- Discussion groups: open circle of chairs or around table

➤ 6:00 to 6:25 PM Refreshments and Registration

- Alzheimer's Association staff and family volunteer welcome each family, check off names, and add new information.
- Facilitators visit with families.

➤ 6:25 to 6:30 PM Families Seated.

➤ 6:30 to 6:35 PM Welcome and Introductions

- Alzheimer's Association staff asks families to arrange their chairs to face the front.
- Welcomes families, introduces new family members / guests.
- Mentions family roster

Next week we will pass out a roster of your names, addresses, phone numbers, and e-mail numbers. This way you can keep in touch with one another. Please let me know if you would rather not be listed on this roster.

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➤ **6:35 to 7:20 PM** **Dialogue with Researcher**

- What is the University Memory and Aging Center? What types of research do they do? Is there an age requirement for persons with memory loss? (Note trials for family members.) If a family wanted to be involved in research, what would be the first step? (Note handouts.)
- There are several medications approved by the FDA now for memory loss, Aricept, Exelon, or Razadyne. What has the research shown about these?
- What about Namenda?
- Are there other medications soon to be released by the FDA?
- What about over the counter medications:
 1. Vitamins (E, Folate, B6, B12, others)?
 2. Herbal (Fish Oil, Gingko Biloba, etc.)?
- If someone is taking extra vitamins or herbal supplements, should they tell their doctor?
- Open for questions.
- What is the research showing about the causes of Alzheimer's disease and family history?
- What does the research show about different lifestyles: (Maintain your Brain)
 1. Diet? Cholesterol and homocystine levels?
 2. Exercise? Stress?
 3. Education? Other?
- Open for questions.
- Wrap up – “We are more than memory machines!”

➤ **7:20 to 7:30 PM** **Break**

➤7:30 to 8:20 PM Discussion Group / Persons with Memory Loss

- Alzheimer's Association staff pulls input on speaker.

What did you think of the speaker? Was the information useful?

- Facilitates discussion on accepting change: holding on versus letting go

Tonight we're going to talk about making decisions. We can't get too far in life without facing some tough decisions. I expect I have a few experts in this group on making choices!

On the left side of the board we have written, "Holding On". On the right side we have, "Letting Go". There are certain things that we know we want to hold on to. There are others that we'd just as soon let go of. As you can see, there's a big space between these two.

I have a few examples of choices. Where would you put this card? There's no right place! (Hold up one card at a time, e.g. taxes, traveling, gardening, holiday parties, shopping, babysitting. Ask where to place each on the board.) As you can see, not everyone agrees about where each card should go. For some, shopping is fun; for others, it's low on the list!

What are some things you want to let go of? (Write each on card, ask where to place, e.g. how close to letting go versus holding on.)

What about things to hold on to? (Place cards on board)

Sometimes you may decide to move something from the holding on side a little closer to letting go.

Babysitting can be like that, or cooking. You can choose to cook simpler meals or limit babysitting. (Pull ideas from group on how to do this, e.g. consider what times of the day are best for you, plan activities for these times, give yourself extra time to get ready. If you feel frustrated – take a break.)

Driving is another very difficult decision. (Write driving on card.) I recall one man who commented, "It isn't easy being a passenger." Another person said, "I can't drive anymore. I used to be able to get the keys, get in the car, and go. Now I have to wait until they are ready." What are some of your thoughts on this?

I have one more quote from a gentleman in a recent group, "I named my daughter after my mother. That was a mistake. Now she thinks she is my mother. She wants to take my car keys away."

What do you think? Some of you have had to stop driving. How are you handling this?

If you were still driving, but your family began to be worried about this, what would you want them to do? (Pull specific examples.)

You may choose to limit when you drive, e.g. during the day, locally. (Place card halfway on line) At some point driving will have to be all the way over here. (Moves to the letting go end) Often in these groups, it's the person with memory loss who will decide to stop driving. Others in the family and friends pitch in to help. It works out. (Note adult children in the group who drive their parents to the program.) Other thoughts on this? Something else we should write on a card?

What about the house? Sometimes people find a house and yard too much to take care of anymore? Some people who are living alone choose to move to an assisted living community. What are some of your thoughts on this?

Sometimes it's very difficult to let go of something. Work is like this. I remember one woman who made the decision to stop teaching. Her name is Carol Hocevar. This was a very difficult decision. (Note handout, "You Are Still the Same Person You Spent Your Life Becoming". Write "working" on a card.)

I'd like to read her words on this, "I knew something was wrong at school. I was having difficulties with remembering students' names, keeping track of changes in daily schedules, remembering where I put something that I had just been working on".

She talks about receiving the diagnosis of Alzheimer's disease. "My first reaction was that I could conquer this problem. After all, I was a teacher and taught children how to think and remember information. That didn't work. By the end of the school year I was anxious to be out of the class room."

Carol next tells about how she began volunteering as a tutor. "Now I work with only one child at a time helping with math or reading. The only thing I have to remember is the child's name. I write it down on my schedule. I didn't have any trouble with the children."

"I'd been doing this for 38 years – it came naturally – no immediate memory required. I have the satisfaction of knowing that I still have a lot to give to others."

What do you think about her comments?

Carol's story teaches us that we are more than memory machines. Our ability to love and to enjoy being with each other is what life is really all about. This is what we will hold on to.

- Focuses discussion on individual strengths

We have been talking a lot tonight about making decisions – deciding what to hold on to and what to let go of. This takes a lot of strength. I see a lot of strength in each of you.

I'd like to take some time now to think about these strengths. It's something we don't take the time to do very often. May I start with you? What do you think your strengths are? (Co-facilitator opens to group for additional strengths they see in this person and offers own comments. Strengths are written on cards for each to take home.)

We've had a good discussion tonight. Was it helpful to talk about holding on versus letting go? Should we have done this differently?

- End with highlights from the group: tips they use, humorous or inspirational comments.

➤ **7:30 to 8:20 PM** **2 Separate Discussion Groups: 1 for Spouses / Partners & 1 for Adult Children / Other Relatives & Friends**

- Facilitates discussion on legal planning

When to begin – NOW!

Who do you go to:

1. Specialist in Elderlaw, e.g. spouse from one of our recent groups was an attorney – even he went to a specialist!
2. Call our *Helpline* for names / highlight *Helpline* service.

What documents to consider:

Facilitator holds up legal and financial brochures.

1. Durable Power of Attorney for Finances & Health Care
2. Living Will
3. Update other documents, e.g. will, deed to house.
4. You may qualify for tax credits if you care for someone with memory loss (note handout on tax credits available through *Helpline*).
5. Questions?

How:

1. What do I say to the person with memory loss?
2. What if there's disagreement in the family? (Meet together with your physician or attorney; consider a neutral third party to be the POA.)
3. 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.)
4. Future considerations? (Copies need to be wherever the person is living & on hand for any trips to the hospital.)
5. Should I go back to the attorney at any time? (It's a good idea to revisit the attorney if there is a need for a nursing home.)

- Facilitates discussion on driving. Moves on to other decisions families have mentioned during previous sessions, turning to co-facilitator for personal insights and helpful tips.

Driving Tips

Schedule driving test: *Helpline* has list of places to call.

Involve person with diagnosis in decisions related to driving as much as possible, e.g. scheduling test, choosing alternatives.

Enlist help of physician; involve others in family.

Compensate for what is being taken away, e.g. who will be responsible for arranging how a person will get where they need to go, is the person still able to use public transportation.

Staying Alone / Living Alone

How can we monitor cooking?

Taking medications?

How do you know when it's no longer safe for someone to be left alone at home?

What do you say to the person?

What if the person doesn't agree?

As the disease progresses, persons gradually lose the ability to fully understand dangers to themselves or to others. Self-awareness originates in the outer cortex of the brain and can be lost early on.

This means that you may have to make decisions without the person's support. This can lead to a lot of self-doubt and guilt. Both of these reactions drain much needed energy. (Open to co-facilitator and group for input.)

A good question to ask yourself is whether this is a matter of safety or health? If yes, then draw the battle line there and let the guilt go. If no, try and back off to save your energy for when you must act.

What if others in the family don't agree?

Sometimes a daughter or son is at a very different place than their parent who is the main caregiver. This is often seen in decisions like driving.

Research shows that most adult children giving care are two years ahead of spouses in thinking of themselves as caregivers and in using services (Rhonda Montgomery).

Communicating openly about these differences can be very useful. (Note Getting Started program; open for comments.)

➤ **8:20 to 8:30 PM Families Reconvene for Wrap-up**

- Ends group by reading signs from group for persons with memory loss.

➤ **8:45 to 9:00 PM Wrap-up for Leaders**

➤ **Handouts and Supplies Needed for Session III
Research Update**

- Box of tissues for each break-out group / key if needed
- Coffee: decaf, regular, filters, measurer, coffee maker, carafes
- Tea: herbal, regular, carafe
- Sugar / artificial sweetener / cream / stirrers
- Lemonade or ice tea / ice water / 3 pitchers / spoon
- Cookies / snacks: 2 trays, basket / napkins / plates / cups
- Roster / curriculum / signs / masking tape
- 4 Notepads / 10 pens: registration table, discussion groups
- Nametags: prepared, blank, 2 sharpies
- Microphone set-up / extension cord
- Donation envelopes on refreshment table
- Flyers on upcoming programs / events
- Pens, blank paper (on family tables)
- University Memory & Aging Center brochure & flyer (on family tables)
- Eighteen Things We Can Learn from a Dog (on family tables)
- How We Get Through Tough Times (on family tables)

Discussion group for persons with memory loss

- Holding On and Letting Go* activity cards / blank cards / markers / red yarn / masking tape
- Update's article on Krouciks
- Paper cards to list strengths
- You Are the Person You Spent Your Life Becoming

Discussion group for family members / others

- Facts: About Genetics & Alzheimer's Disease
- Update's article: AD Risk Factors
- Steps to Understanding Financial Issues
- Steps to Understanding Legal Issues
- Ten Top Tips on Making Decisions
- Driving packets / Adult Day Centers (10 copies on table)
- Enhancing Your Home
- Helping Children and Teens (15-30 copies on table)
- Activities at Home

Facilitator's Notes

Session IV

Decisions for Today and Tomorrow

➤ **Objectives**

- Appreciate personal strengths.
- Strengthen connections between families.
- Have the opportunity to evaluate series.
- Know that the Alzheimer's Association is there to stand you.

➤ **Room Design**

- Discussion groups: circle of chairs open or around table
- Common meeting area: large open circle of chairs

➤ **6:00 to 6:25 PM Refreshments, Registration, and Family Photo Shoots**

- Alzheimer's Association staff and family volunteer welcome each family, check off names, and add new information.
- Ask each family to pose for photo with long-stemmed rose.
PLEASE NOTE: ask individuals to wait until after photo to put nametags on.
- Facilitators visit with families.

➤ **6:25 to 6:30 PM Families Seated.**

➤ **6:30 to 6:40 PM Welcome / Annual Report / Safe Return**

- Describes format for evening, notes annual report.

Families often ask me where our financial support comes from for these programs and for all the other services we offer for families and professionals. Over seventy-five per cent of our support comes from individual donations.

We couldn't offer these kinds of programs without this wonderful help. I wanted to mention that everything we send out has our logo on it. If you receive a request for a donation that does not have this logo, it is not from us.

Our main events are our annual dinner in the spring and our Memory Walk in the fall. Our Memory Walk is at the zoo, with over 4,000 people – all ages! It's a wonderful day for families.

There are other ways besides giving money that can help our organization.

Highlights Safe Return program

Our National Alzheimer's Association Safe Return program is an identification program for persons with memory loss. It is especially helpful for active people! If you get turned around while you are out walking or driving, this program can help you get home.

I had one woman who ran six miles a day. She joined the Safe Return program so that she wouldn't have to worry if she took a wrong turn.

Often a spouse will order a bracelet also, indicating that they are caring for someone with memory loss.

Here is what the kit looks like. (Show kit, explain cost, note that the ID number helps throughout the country.) Some ladies choose to put the ID number on a fancier bracelet from Things Remembered at the Mall. Often children get this as a present for their parent.

Does anyone have a Safe Return bracelet or necklace on? Does anyone have any questions?

□ Highlights Memory Tools Basket

A disorder like Alzheimer's disease makes it hard to hold on to information within the brain. The secret is to store information outside of the brain. Here are a few tips from families who have attended these groups:

(Hold up tape recorder with suction cup attachment for phone.) This idea came from a lady who wanted some way to hold on to information received over the phone, like doctors' appointments. A wonderful plus has been the chance for her to record conversations with dear friends who are out of town. She can enjoy these over and over!

Here's another handy tool. (Hold up phone with large buttons; show how pictures can be added in place of numbers for direct dial.)

Here is an idea for baking. (Hold up plastic report cover with large recipe card inside.) This cover makes it possible to cross each ingredient off with a marker right after you add it. When it's done, you wipe the cover clean.

And now for a few tips from our group! (Highlight tips, open to any additional comments / tips.)

□ Directs families to separate discussion groups.

➤ **6:40 to 7:15 PM** **Discussion Group / Persons with Memory Loss**

- Co-facilitator offers welcoming comments, lights candles on table (optional).

I'm lighting these candles as a symbol of the strength and love that is here. It's hard to come to the end of a series as wonderful as this one has been. The good news is that there will continue to be many opportunities to see each other. (Note upcoming Learning Together II series.)

- Alzheimer's Association staff opens for individual comments on the series.

We have been offering programs like this one for over ten years. Many of our best ideas have come from individuals living with memory loss – like you. I'm interested in what you thought of the series. May I start with you? Was it useful to you? Is there something we should do differently to make it better? (Pull input round robin technique. Take time to acknowledge each person's contribution to the group.)

- Focuses discussion on gratitude

We have covered a lot of ground these past few weeks and learned a lot about each other. I have been impressed with your attitude about life. You have talked more about what you can do than on what you cannot do.

You have often expressed gratitude. I'd like to go around now and ask each of you to say one or two things you are grateful for. May I start with you? (Write comments on individual hearts to take home.)

- Reads *Brilliant Insights* from their group (May open to members of the group to read)

WOW! (Initiate applause.) One thing is for sure - we're a lot more than memory machines aren't we! I have enjoyed being with each of you very much and look forward to seeing you at our monthly programs. Thank you for teaching me so much! (Co-facilitator adds own thank you)

- May take group photo.

➤ **6:40 to 7:15 PM** **2 Separate Discussion Groups: 1 for Spouses / Partners & 1 for Adult Children / Other Relatives & Friends**

- Asks families to complete evaluations
- Family volunteer lights candles on table (optional), notes that this is the last evening in our series.

I'm lighting these candles as a symbol of the strength and love that is here. It's hard to come to the end of a series as wonderful as this one has been.

The good news is that there will continue to be many opportunities to see each other. The most popular of these is the Learning Together II program. (Explain program, note handout.)

- Alzheimer's Association professional volunteer facilitates discussion on any topics not fully covered in previous sessions.
- May open for comments from the group on any positive changes or additional plans that have come from attending this series.
- May end with self-affirmations.

Sometimes it's a phrase that you hear during a program like this that just sticks with you or something that you have come up with on your own:

- *A plan is just a plan*
- *Let the world take a few turns.*
- *Living in their world*

Does anyone have something that they would like to add?

Sometimes it's a positive statement you say to yourself:

- *I have to be there for my husband – not just my mother.*
- *I can only do so much.*
- *I've done a good enough job today. I don't have to be perfect!*

Does anyone have something that they would like to add?

➤ **7:15 to 7:25 PM** **Break**

➤ **7:25 to 8:15 PM** **Families Reconvene: Affirm Personal Strengths.**

- Room design of one open circle is preferred, but can have families sit together at 5-6 large tables.
- Extend special thank you to facilitators for volunteering their time to be with these new families.
- Alzheimer's Association staff asks family members to express what they value most in each other.

Tonight's session is a celebration of hope – in us and in the treatments that are on the horizon. It is also a celebration of strength – in each of us and in those we love.

I'd like you to take some time now to think about these strengths. What do you value most in the members of your family or your close friends who are here with you tonight?

I'll give you an example. I remember a couple from a series a few years ago. He had just been diagnosed with Alzheimer's disease. When it came to this part of the evening, he turned to his wife and said, "You were always there for me." She then turned to him and said, "In spite of everything, you could always make me laugh!"

I'd like to go around now and have you say what you value most in each other. You don't have to worry, because I'll help as we go along. A short word or phrase is just fine.

Would it be all right if I started with you? What do you value most about your husband? (Ask each person to speak directly to the other person.)

(Facilitators are asked to sit with the families; may add a personal thank you to the group or mention something they have learned or been touched by during the series.)

- Families are asked to light individual candles to affirm the strength and love that is here.

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I want to thank you for these wonderful comments. There's a lot of love in this room. Candles have long been a symbol of love. We would like to now light a few candles and ask that you pass this light along until everyone's candle is lit. (Wait until all candles are lit.)

When there are dark days, trust in the love that surrounds you and hold tight to this. Be especially kind to yourself.

We wish for you many bright days to treasure – and plenty of laughter, too! (May open to group for other wishes.)

Lastly, hold onto hope – in yourself and in the future as we work together to find a cure. (Ask families to blow out the candles.)

➤ 8:15 to 8:30 PM Closing Comments and Group Photo

We have a special way to end these programs. I think you will like it. You'll need to stand and hold hands. (Encourage people to make the circle as small as possible.)

Now I'd like you to look first at the person on your left and then at the person on your right. One of these faces may be more familiar than the other! As I look around at all of your beautiful faces, I am struck again by all the love that is here. It's a good feeling isn't it? Truly you are not alone.

You may have come in as strangers but you are leaving with many new friends. Also, there is a whole group of volunteers and staff at the Association that you haven't even had a chance to meet. They are there for you as well. We will continue to stand by you to offer information, ideas, and support. Please don't ever hesitate to call us.

I'd like to end with a group photo that we will send to all of you along with your individual ones. The roses we are passing out have been donated for you by _____. Thank you so much for coming to this series!

➤ **Handouts and Supplies Needed Session IV**
Decisions for Today and Tomorrow

- Box of tissues for each break-out group / key if needed
- Coffee: decaf, regular, filters, measurer, coffee maker, carafes
- Tea: herbal, regular, carafe
- Sugar / artificial sweetener / cream / stirrers
- Lemonade or ice tea / ice water / 3 pitchers / spoon
- Cookies / snacks: 2 trays, basket
- Napkins / plates / cups
- Roster / curriculum
- 4 Notepads / 10 pens: registration table, discussion groups
- Nametags: prepared, blank, 2 sharpies
- Signs / masking tape
- Safe Return kits (2)
- Brilliant Insights from current group (on family tables)
- What Matters Most Is How You See Yourself (on family tables)
- Camera / film / ribbons / scissors
- Donated roses with water holders / vases
- Donation envelopes on refreshment table
- Flyers on upcoming programs / events
- Table cloths / special napkins
- Candles in paper holders / matches (5)

Discussion group for persons with memory loss

- Brilliant Insights from current group
- Paper hearts / thin markers
- Learning Together II flyers / DASN

Discussion groups for family members / friends

- Why Families Choose the Safe Return Program / Safe Return Applications
- Affirmations: Family Members
- Evaluations / pens for family members and friends
- Roster of family names / addresses / phone / e-mail
- Learning Together II / DASN / Support Group flyers (includes on-line)

Facilitator's Notes

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