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Alzheimer's Los Angeles was founded by concerned family caregivers in 1980 and incorporated as an independent nonprofit in 1981. In 1984, the organization affiliated with the national Alzheimer's Association as an independent local chapter. In early 2016, after 31 years, Alzheimer's LA disaffiliated from the national entity, reaffirming our commitment to providing services that are tailored to the cultures, specific needs and circumstances of local Southern California families. Alzheimer’s Los Angeles is the leading community-based health organization providing programs that address the needs of people living with Alzheimer’s and other dementias and their family caregivers, in the three-county region of Los Angeles, Riverside and San Bernardino. Our mission is to improve the lives of local families affected by Alzheimer’s and dementia by increasing awareness; delivering effective programs and services; providing compassionate support; and advocating for quality care and a cure. We do this by offering supportive services to people with a diagnosis of a dementia and their families, by educating caregivers, the public and health care professionals, by advocating for improved local, state and federal public policy, promoting needed legislation and supporting research for Alzheimer’s Disease and Related Dementias (ADRD).

Serving as the local voice for people with cognitive impairment (PWCI) and their families, Alzheimer’s LA’s core programs are:

**HELPLINE**
Our Helpline 844.HELP.ALZ (844.435.7259) offers information, emotional support, and referrals for people with memory loss, caregivers, professionals, and general community members. Available in 190 languages.

**CARE COUNSELING**
Confidential Care Counseling and support helps families and caregivers of those with Alzheimer’s disease with care planning, education, coping techniques, respite and emergency assistance for low income caregivers.
Individual and ongoing sessions are available in person or by telephone, in English and Spanish.

**SUPPORT GROUPS**
Support groups are open gatherings for people to come together and share their experiences to better cope with and manage the challenges of dementia in a safe environment. They are held at various times and locations, and in multiple languages.

**EARLY STAGE PROGRAMS**
Information, education, family consultation, and support groups are available for those with memory concerns or who have been diagnosed in the early stages of the disease and their care partners.

**MEMORIES IN THE MAKING**
A unique fine arts program that offers a creative and non-verbal way of communicating and capturing precious moments through art. Small group classes are held throughout the community at various sites and in different settings.

**MEMORY MORNINGS ACTIVITY PROGRAM**
Every Friday morning, people living in the mid-stages of Alzheimer’s disease or other dementias and their family caregivers enjoy two hours of fun; cognitively stimulating activities that include, music, art, gardening, entertainers, field trips and more!

**MedicAlert® FOUND CALIFORNIA**
MedicAlert® Found California is a 24-hour, nationwide emergency response service for individuals with Alzheimer’s disease or other dementias who may wander and get lost or have a medical emergency. An identification bracelet provides emergency medical information and assists in the event of a wandering incident.

**COMMUNITY EDUCATION & OUTREACH**
Education is offered throughout the Southland region on a variety of topics and are available in multiple languages. Educational classes for caregivers include Savvy Caregiver, a free six-week course that provides family caregivers with basic knowledge, skills, and attitudes to provide care to a
family member who has memory loss, and Savvy Express, a three-session version of Savvy Caregiver. Outreach allows us to raise awareness through participation in health fairs and other community events.

**PROFESSIONAL TRAINING**

On-site and web-based trainings are offered to social workers, case managers, physicians, nurses and other professionals. Trainings can be customized to meet the specific needs of the training participants. Continuing education contact hours may be available.

¹ Our Memory Club® families have requested that the term ‘care partner’ be substituted for caregiver.
CREDITS

This manual was originally written in 2003 by Laura E. Rice-Oeschger, MSW, LCSW. Contributions and edits were made by Linda A. Weatherwax, BS, Dementia Specialist, Ann Arbor, MI, and Rachelle Dardeau, MS, MSW.

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INTRODUCTION TO GUIDE

Alzheimer’s Los Angeles, in collaboration with The Center for Aging Research and Evaluation (CARE) of Granada Hills Community Hospital, originally published this manual to promote the growth of a new type of program for individuals with Early Stage Alzheimer’s Disease and Related Dementias (ESADRD) and their care partners. It is our hope that those currently operating programs for adults with ADRD will be able to use this information to provide additional services to individuals who meet the criteria of ESADRD.

The Early Stage Alzheimer’s Project’s History

The original Early Stage Alzheimer’s Project was a collaborative effort. This project began in the fall of 2000 and was made possible by a grant from the UniHealth Foundation. In 2000, the project services included free memory screening, subsidized diagnostic evaluations, scholarships for the CARE Club, early stage activity program, community education events, and professional training. The Memory Club®, a support and friendship group for individuals with ADRD and their care partners, and The Graduation Club, a continuation of support and friendship for graduates of The Memory Club®, were also included. The Project has matured since its original inception to include The Alumni Club, an extension of the Graduation Club. Alumni Club is a group for care partners to participate in when the people living with ADRD are no longer in the early stages of the disease and cannot participate in a support group setting, however care partners can still benefit from support from each other. We hope this manual will encourage replication of the project and the development of additional programs to serve this unique and emerging population. The following describes our specialized ESADRD programming model.
The Early Stage Alzheimer's Support Services Replication Manual

Since the conception and launching of the early stage support group model, Alzheimer's LA has facilitated many groups for early stage persons with ADRD and their respective care partners. In order to share our program with a broader community of dementia care professionals, we are publishing this revised manual. We want to share this group model with those who can replicate it in their own communities.

In Chapter 1, the basic components of the Early Stage Family Intervention model, its goals and principles, its audience, and its challenges, will give you an overview of the Memory Club®’s mission. Later in the manual, you will be provided with a step-by-step procedure for getting a Memory Club® started. To ensure the feasibility of developing this project in your community, we detail:

- how to recruit candidates most likely to succeed in a support group environment.
- how to create cohesive and pertinent programming for this population, and
- how to go to the next steps - creating a “Graduation Club” and “Alumni Club” for those graduates of the Memory Club® series who want to continue receiving support.

Replication Manual Audience

This manual is written for support group leaders, social workers, psychologists, and other mental health specialists who are currently working in the field of ADRD. You will need to be able to identify the early stage persons who would benefit from a conversation-based support group format. Selection of appropriate support group participants, program planning and facilitation, and
family conferences all need a skillful, experienced person. It is assumed that the mental health professionals who read this manual will understand the need for separate and specific programming for this population.

Information about ADRD as it relates to early stage symptoms and issues will be discussed in Chapter 6. Alzheimer’s LA identified a great need in the Los Angeles County community for developing a program for families dealing with ESADRD. Those who fall into this early stage category clearly have special needs—needs that are not always addressed in traditional caregiver support groups and social adult day service settings. Often, community programs seem to focus primarily on individuals who fall within the broader range of moderate-to-severe dementia. For the critical time after a diagnosis, however brief or long, when an individual is capable of knowing, advocating, contemplating, reasoning and worrying about what lies ahead, the right kind of support can make a significant difference in how they live and proceed through life.

**Memory Club® Goals**

The Memory Club® is one component of the Early Stage Alzheimer’s Project and therefore, not intended to be an exhaustive response to all the needs of individuals dealing with ESADRD or their care partners. Our primary goal has always been to provide a forum for people with ESADRD and their care partners.

Each individual with an early stage diagnosis, along with his/her care partner(s), experiences a unique set of feelings, concerns, questions, and needs. We want to provide resources and the benefit of our experiences to those of you who would like to design and implement a group model for such individuals. This manual is a guide to assist you in meeting your goal of addressing the special needs of this population. Our goals are to:
• delineate the benefits of early stage support programs,
• highlight the special needs and concerns of those with ESADRD,
• accentuate the needs, concerns, and emotional costs for their care partners,
• provide a supportive and educational environment for individuals in the early stages of ADRD who can benefit from sharing, and
• offer a supportive and educational environment for care partners.

**Collaboration: The Key to Success**

We want to emphasize the importance of collaboration to the success of getting an early stage project off the ground. We believe that reaching out to other agencies and professionals in the community who are working in the gerontology/dementia fields is a key aspect to the success of early stage programming. We strongly suggest that you partner with agencies and individuals in your community, enlisting their help in sponsoring ESADRD programs, group meetings and events. You will reap the many benefits these collaborations can bring to your organization and your clients.

This manual presents new paradigms, approaches, and techniques for you to incorporate into your already existing support groups, or, ideally, into new groups designed specifically for the ESADRD population in your community. We recognize that it is not always possible for agencies to expand their services by creating new programs. Knowing this, we designed the manual to allow flexibility in the way its ideas are adapted and implemented. We encourage you to read this manual with the idea that you will most certainly need ancillary services within your community to develop a strong early stage support group.

**Replication Manual Objectives**
We hope that in this manual you will find most of the information you need to start an ESADRD support program in your community using the Memory Club group model. Our objectives for this manual include providing:

- detailed information about the family intervention model,
- practical considerations regarding preparation costs, organizational needs, etc.,
- programming theory and design, including themes appropriate for this specific group,
- techniques and insights into facilitating the Memory Club support groups,
- guidelines and protocols for participant recruitment,
- issues facing ESADRD families,
- detailed descriptions of each session, including agendas and suggested supplementary materials that complement each session and,
- a plan for ongoing support after the initial Memory Club series.

The Memory Club® model has worked effectively within Los Angeles County. We hope it will meet your needs and the very special requirements of this growing and underserved population. We have by no means completed our work with this population; there is always more to be learned, more to be done. The manual, and our continuing efforts to serve the ESADRD population, are ‘works in progress’ and will continue to be refined. There is a saying that speaks to our ongoing work: “No piece of art is ever finished, it just stops in interesting places.” We believe we have found an interesting place at which to stop and share our experiences to encourage the growth of additional programs designed for the ESADRD population.

Please join us as we continue to promote and advocate for the needs of individuals with ESADRD and their care partners, as we take on the continuing
challenge of providing meaningful, supportive care. You can always use us as a resource, and we hope you will share your success stories and new ideas along the way.
CHAPTER 1
Early Stage Family Intervention Model

Hundreds of long-standing support groups for caregivers of family members who have ADRD are located throughout the United States. Providing support groups designed solely for individuals in the early stages of ADRD that run in tandem with a support group for care partners is a fairly recent idea. Advances in diagnostic evaluations, coupled with increased community awareness of ADRD, have brought attention to the problems shared by an emerging population of individuals with early stage and young onset (onset of symptoms before age 65) ADRD – problems quite different from those of their care partners. As a result, special programs and projects have been initiated throughout the country to meet the unique needs of this distinctive population. The Memory Club® is one component of Alzheimer’s LA’s creative response to meet the needs of both the individual with ESADRD and his/her care partner.

Through our work, we have had the honor of working with hundreds of early stage families – people in ESADRD and their care partners. Their insights and our experiences have inspired and guided our work. By sharing the details of our program and the knowledge we have gained in the past, we hope to inspire our readers to help us broaden the support base for this growing population.

1.1 Early Stage Programming: Making a Difference

At some point, members of this vulnerable population begin to feel inadequate, alone, scared, etc. Without a safe and supportive environment, important questions such as, “Am I the only one who is having this much trouble, fear, and anxiety?” “Why do I feel incompetent in some areas of my life and capable in
others?” “Why am I so sad?” “Whom can I talk to about my fears?” “I feel so alone, and I’m becoming a burden to my family. What is happening to me?” often go unasked.

Likewise, care partners need their questions answered and are looking for a supportive environment where they can meet with a group of their peers. They want information on issues such as shifting of family roles, how to maintain respectful communication, taking a stand on safety issues such as driving, what to expect as symptoms worsen, and how best to prepare for the future. Clearly, their feelings and concerns need to be shared and validated. As is usually the case, no one understands what the person with ADRD or the care partner is going through better than someone who is facing those same challenges.

1.2 Benefits of Early Stage Programs

Early stage family intervention programs have much to offer and come in many forms, from activity-based programming to support, education, and social and peer groups. Our own model incorporates multiple modalities and has been designed to provide the following benefits to ESADR families as they confront difficult transitions:

- socialization, empathy and support from others who understand and are experiencing similar challenges
- meaningful interaction, activity and friendship for PWCI and their care partners
- involvement with a peer group which stimulates communication
- opportunities for the PWCI to make choices, assert feelings, and make decisions in a structured, supportive, and safe environment
• a safe arena to express normal feelings of frustration, anger, fear, and sadness – feelings that, in the wrong environment, could escalate into challenging or unsafe behavior
• a social and familial atmosphere where opportunities to meet and plan activities with other families are encouraged
• help in accessing the maze of services, and the myriad of care options

1.3 Early Stage Support

Several elements must be in place to assure a strong base for early stage support. These elements include experienced leadership, and a support group format that uses the right mix of qualities to meet the needs of this particular group. As you will see from the various group options available, we selected a group type that could be tailored to the needs of the Memory Club® agenda.

1.3.1 Support Group Leadership Qualifications

As a growing number of people are getting diagnosed earlier, there is a need for specialized groups to serve both the individual and the care partner. By their very nature, support groups require the leadership of experienced, professional facilitators who have had special in-group training. For those working with an audience made up of families facing the changes brought on by ESADRD, even more specialized experience is required. The facilitators ought to have knowledge and experience in the area of dementia care, with expertise in the issues of ESADRD. Issues will arise that require therapeutic intervention in a sensitive, skilled and supportive manner. In addition, the personal qualities of the facilitators also play a role in the success of each group. Successful groups are groups where the relationship between the facilitator and each participant is grounded in trust, empathy, open communication, and patience.
There are several common formats for support groups. Some level of screening is necessary in all group formats in order to ensure an appropriate match of service to need. The nature and depth of screening is based on the group model and goals, and the discretion of the support group facilitator.

1.3.2 Types of Support Groups

Four basic support group types and related attributes are outlined below:

**Open Group** - welcomes appropriate new participants at any time
- links with on-going groups
- limits number of participants to keep group at an ideal size
- does not close or experience periods of inactivity

**Closed Group** - associated with time-limited groups
- enrollment restricted in order to meet desired group Parameters, i.e., group size, structure, and cohesion
- lends itself nicely to reinforcing group trust, safety and cohesion

**Time-limited Group** - meets for a specific length of time
- recommends a brief time of inactivity to allow for group closure, new participant enrollment and group re-structuring
- may or may not permit participants to return, depending on goals and objectives of the group, discharge agreements, and program demand

**On-going Group** - meets on a continuing, uninterrupted basis
- welcomes appropriate new participants at any time
- discharges participants individually vs. as a group
- participants come and go without group inactivity

Group types listed above are useful for a general population. Attributes ascribed to these groups can be combined in several possibilities to better meet the overall goals of the group. For example, consider these options for ESADRD groups:

**1.3.2.1 A Closed Therapy Group** consists of three or more individuals with ADRD who meet regularly with a trained professional, usually a clinical psychologist or licensed clinical social worker, who facilitates one to two hours of group therapy. Due to the high level of interaction and insight required by PWCI in this model, a Mini Mental Status Exam score of 25 or higher is ideal and can be a helpful point of reference when selecting group participants.

**1.3.2.2 An Open Support Group** usually consists of at least four individuals with ADRD who meet bi-monthly or monthly to discuss their diagnosis in a traditional support group format, with sessions lasting one to two hours. Some support groups tack on additional programs like education, or exercise.

**1.3.2.3 A Time Limited Support Group/Program** is made up of at least four individuals with ADRD, meeting on a regular basis for six to twelve weeks, to discuss their diagnosis in a traditional support group format. A psycho-educational support format is a variation of this group type. Special topics or themes can be implemented. This model is often utilized to provide support to two significant players in the family—the person with ADRD, and the identified care partner. These two individuals make up the supported dyad. A successful variation on this model has been to host concurrent meetings: one for individuals with ADRD, another for care partners.
An **Open-ended Social Model Day Program** stays open at least four hours a day, at least once a week, providing activities for individuals with ADRD. Although these groups are indisputably supportive social model programs, they do not necessarily adopt a support group format, and do not usually address ADRD directly. Some versions of this type of program are now implementing an early stage support group within their week of day care programming. There are many skill levels a social model program can address; however, the appropriateness of activities for each skill level is paramount in providing services to the ESADR population.

This manual highlights a time-limited psycho-educational, closed support group model, a model we call the Memory Club®. We will explore and illustrate how you can implement a program like Memory Club® in your agency, facility, or organization.

**1.4 The Model**

Support group models may be adapted and implemented in many ways. It is the creativity, ingenuity, and energy of each specialized program that makes it unique. Again, it cannot be emphasized enough that the type of model you use should take into consideration the needs – both specific and general – of your target audience. For the Memory Club®, we chose a time-limited, closed group model for reasons discussed below.

**1.4.1 The Changing Nature of the Disease**

We found having specific programming blocks (8 weeks) allowed us to focus our educational goals, maintain group cohesion, and manage the needs of the
group as well as of individual members. Knowing what to expect, understanding the goals of the group, and being aware of its structure gives families a sense of control and inclusion. Additionally, keeping the Memory Club® time-limited and closed, with planned breaks, helps us as facilitators to create smooth transitions when the PWCI has progressed from the early stage to the mid-to-moderate stage and is no longer appropriate for the Early Stage programming. During each group series, group members’ ability to function in the Club is assessed. It is determined if the PWCI can express emotions regarding the diagnosis, is contributing appropriately, relates to the other group members, can identify what they are gaining from the group experience, and finally, is free of behavioral symptoms that disrupt the group process. Unfortunately, due to the progression of the illness, there comes a time when the group is no longer appropriate nor is it meeting the needs of the PWCI.

By the end of the last session, every member of our group must make a transition to another program within our agency or another service organization in the community. We have families whose transition consists of the relatively easy move into our Graduation Club, a Memory Club® transition support group program (see Chapter 8, “Transitions.”). To prepare families for the changes that occur over time, we stay aware of the psychosocial and medical issues of each group member. We understand the need to integrate on-going and regular family consultations. We meet with our members before the program begins and again, just before the last session. We also make ourselves available for in-person or phone consultations if a problem arises. Keep in mind each dyad’s longevity in early stage programs will vary.

1.4.2 The Need to Keep the Group Small & Familiar

If a support group is too large it can cause participants to feel left out,
misunderstood, and frustrated. Given the intensity of the emotional needs of individuals with early stage or young onset ADRD and their families, a smaller group with familiar faces provides an emotional safety net, and a stable and understanding group of peers experiencing similar challenges. We find that nine dyads (18 members altogether) is a workable size for a Memory Club® series.

1.4.3 A Psych-Educational Support Group

In addition to support from peers, participants in our Clubs are seeking information about ADRD. Persons with ADRD and care partners (the dyad) have common questions and needs, as well as concerns that are distinctly separate from one another. Subsequently, our goals for the psycho-educational support program include perspectives from both the individual with ADRD and the care partner, with attention also given to the larger family system. Without having current and accurate information about the disease, and guidance in coping with it, dyads and families are often left reacting to the inevitable changes in a “crisis mode.” As a result, tension, frustration, confusion, and isolation take hold and families become unnecessarily rattled.

1.4.3.1 Delivery Methods - The sharing of educational materials, resources and knowledge can be accomplished in several ways. In addition to brochures and handouts, we provide individuals and families with access to experts in the field. We look for professionals in our community who can provide valid, current information with compassion – information that relates to the members’ lives and is delivered with sensitivity to meet the varying needs and abilities to process the information. Utilizing professionals from our community as volunteer speakers has been one of our greatest assets; our families continue to rate these sessions as one of the most valuable aspects of the Memory Club experience.
1.5 Two Groups = One Memory Club®

The Memory Club® group model envelopes two separate groups, one made up of those with ESADRD, and one of their care partners, running conjointly and/or concurrently, depending on the session. These two “Small Groups” come together and become a “Large Group” for a brief time at the beginning of each session to hear about upcoming events and share news, information and resources. Most often, the group meets around a large table as couples. After spending a few minutes socializing as well as getting oriented to the space and to other members, they separate for approximately two hours of facilitated peer support unless there is a guest speaker.

Flexibility is one of the most important parts of the group process at the Memory Club. At times, the two groups may remain separate for the entire session, may reconvene at the end of a session to recap their feelings regarding the issues discussed earlier, or they may stay together at the beginning of a session to further discuss a topic presented the previous week. Programming content dictates the flow of the two-group meeting agenda. When the two groups meet, we speak of that as the “Large Group.” Sessions typically run for two hours with a ten-minute break and about 30 minutes scheduled for social time which is factored in as members begin arriving before the group starts.

1.6 Two A Typical Memory Club® Meeting (9:30AM-Noon)

We’ve explained the basic components of the Memory Club® – an eight week support and educational group series made up of members of an ESADRD dyad, with two peer groups running conjointly and/or concurrently. We have discussed program design rationales, why early stage programming is
necessary, and the key elements for creating a successful model in your community. The following is a brief look at a typical Memory Club meeting day to help you envision “the flow” and management of a typical session for the two groups.

9:30 - The coffee’s hot and the doors are open
Families begin arriving taking advantage of this time to chat with other group members, drink coffee, and have a light snack.

10:00 - Time to start
The meeting begins with a brief ten-minute check-in and welcome of the Large Group. All members gather together around a table or in a circle. Announcements are made, and a preview of the day’s agenda is provided. Additionally, during this time, Club members are encouraged to share news and announcements of their own.

10:10 - The Program
Programs have three possible scenarios, depending on the day’s agenda:

Scenario 1 - Facilitator starts a Large Group discussion.
Scenario 2 - Facilitator introduces a guest speaker to the group.
Scenario 3 - Large Group splits into two facilitated Small Groups, which run concurrently but in separate rooms or soundproof spaces.

11:00ish - Break time
Members need to take a break early in the second hour. Cups of coffee or water are refilled, while legs and backs are stretched. When meeting in Small Groups, it is not necessary to coordinate break times. Try to stagger breaks to avoid long lines in the restrooms and to keep the break time at a minimum.
11:00 and 11:45ish - That's a wrap

How much time is needed to wrap things up or process the day depends on the day’s topic or the needs of the group. If Small Groups were meeting, you can implement a brief closing with the Large Group. Another possibility is to leave Small Groups intact and use the last 10 or 15 minutes to go over the information covered during the session. We try to revisit major points discussed and acknowledge contributions made by individuals.

1.7 From Phone Call to Graduation: The Journey

Figure 1.1 effectively shows the steps taken by dyads – persons with ESADRD and care partners – interested in applying to become members of the Memory Club. The journey also reflects the support needed for those who do not fit the criteria for the Memory Club® and who must be referred to other support programs.

There are a variety of different ways people are referred to our Memory Club®. There are those who contact the Alzheimer’s LA Helpline and disclose they or a loved one has received a recent diagnosis of ADRD. These people are verbally provided a brief description of Early Stage Programs, including the Memory Club®, as well as sent follow-up literature. People may also find out about our Early Stage Programs in newsletter articles, through our website, marketing efforts, other agency referrals, their physician or by word of mouth.

During the initial phone contact, the program manager should explain to the caller(s) what early stage programs are offered, specifically highlighting the Memory Club®. Additionally, during this call, the manager should discuss the criteria for participating in the Memory Club® as well as get a sense about
whether the dyad would be appropriate for the Memory Club®. (see Chapter 3, 3.1). If the dyad seems to be appropriate candidates for the Memory Club, it is ideal to start the assessment/screening process over the phone by collecting some of their basic personal information such as contact information, symptoms, date of diagnosis, etc.

The next step is to schedule an in-office assessment to evaluate the appropriateness of the dyad for participation in the Memory Club®. During this time, you will continue to collect personal information and health history. You can administer the Mini Mental Status Exam (MMSE) or collect information about their most recent (MMSE) score. A score of 25 or higher on the MMSW is ideal. You will also request the care partner complete assessments that reflect their coping skills as well as their perception of their loved one’s coping skills.

If the dyad is appropriate for the Memory Club®, you can extend an invitation to participate in the Memory Club® at the time of this initial meeting, after the assessment is completed. Do not expect or require an immediate response regarding participation. Encourage the dyad to take the needed time to consider whether the group would be right for them but reinforce they would be an asset to the group dynamic. If the dyad is deemed not appropriate or ineligible for the Memory Club®, it is important to explain the reasoning clearly and offer them other more appropriate support options such as care consultation services.

Upon completion of the 8-week Memory Club® series, we offer, to those who are appropriate, continuation to the bi-monthly Graduation Club support group. (Refer to Chapter 8, “Transitions” for a comprehensive discussion of the Graduation Club.) After participating in Memory Club®, if you have identified a dyad that is not able to continue onto the Graduation Club, you need to meet
with them privately to discuss transitioning to more appropriate support options. Once in the Graduation Club it is important that you observe and reassess your clients and be ready to meet with those who are exhibiting significant declines in functioning.
Figure 1.1

**Early Stage Family Model: Typical Journey through the Program**

1. **Initial Phone Contact**
2. **Initial screening**
3. **In-office family assessment with PWCI and Care Partner(s) to determine eligibility for Memory Club®**
   - **Eligible**
     - **PWCI & Care Partner join Memory Club®**
     - **Memory Club® (8 weeks)**
     - **Memory Club® Exit Interview & Family Consultation to determine Graduation Club eligibility**
       - **Eligible**
         - **Graduation Club**
         - **Graduation Club Exit Interview**
           - **Care Consultation**
             - Care Plan
             - Referrals
             - Follow-up
             - Alumni Club for Care Partner
       - **Ineligible**
         - **Care Consultation (as needed)**
           - Care Plan development
           - Referrals
           - Follow-up and monitoring
   - **Ineligible**
     - **Care Consultation (as needed)**
       - Care Plan development
       - Referrals
       - Follow-up and monitoring
CHAPTER 2
Setting the Stage

2.1 Organizational Details

There are eight basic components to consider as you address feasibility issues and examine what resources are available to you for starting a Memory Club® in your community:

- a sponsoring agency backed up by collaboration with other agencies
- necessary costs
- recommended supplies
- necessary qualifications for staff facilitators
- marketing to your target audience
- space requirements and location
- scheduling for success, i.e., time of day and length of sessions
- limiting group size for success

If there is a high demand in your community for early stage programs, you might design several groups. For example, one group can be created for adult-children care partners and their parents with ESADR, another for spouse care partners and persons with ADRD, or a group for individuals with young on-set ADRD. We have found that combined groups, as described herein, work very well. However, the issues for adult children and spouses are different, as are the issues for those diagnosed before the age of 65. Clubs designed to speak exclusively to their needs and scheduled to match their lifestyles would certainly be most helpful. Nevertheless, the model presented here is a great beginning.
2.1.1 Sponsoring Agency & Collaborations

Alzheimer’s Los Angeles has had the good fortune of forming on-going, successful collaborations with agencies whose services complement our own. At the inception of the program, the Alzheimer’s LA regional office in the Greater San Fernando Valley collaborated with The Center for Aging Research and Evaluation (CARE) of Granada Hills Community Hospital to develop a partnership to launch this early stage pilot program. Now, more than 25 years later, we have been able to partner with other agencies similar to CARE to create thriving early stage programming. We encourage you to identify at least one other agency that will support your program. Co-sponsoring agencies can help in a number of ways, such as:

- donating space and/or staff, including interns,
- sponsoring speakers,
- co-sponsoring early stage educational events,
- providing food and beverages, and
- donating supplies.

There are countless ways in which agencies can collaborate on projects.

2.1.2 Expenses

The following table illustrates estimated minimal costs for implementing an 8-week Memory Club® series. The personnel estimates include prep time for assessments, organizing speakers, etc.
### Memory Club® Series Budget

<table>
<thead>
<tr>
<th>Personnel</th>
<th>Actual Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Manager ($25 hourly rate/74 hours)</td>
<td>$1850</td>
</tr>
<tr>
<td>Co-Facilitator - Consultant ($50 hourly rate/40 hours)</td>
<td>$2000</td>
</tr>
<tr>
<td>Benefits &amp; Taxes for Program Manager only (20%)</td>
<td>$370</td>
</tr>
<tr>
<td><strong>Personnel Sub-Total</strong></td>
<td><strong>$4,220</strong></td>
</tr>
</tbody>
</table>

### Direct Operating Expenses

<table>
<thead>
<tr>
<th>Expense</th>
<th>Actual Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speaker Honoraria ($20 per speaker)</td>
<td>$80</td>
</tr>
<tr>
<td>Office Supplies (Binders or folders, pens, binder dividers, etc.)</td>
<td>$150</td>
</tr>
<tr>
<td>Program Supplies/Food</td>
<td>$20</td>
</tr>
<tr>
<td>Printing/Duplication</td>
<td>$50</td>
</tr>
<tr>
<td>Postage</td>
<td>$50</td>
</tr>
<tr>
<td><strong>Direct Operating Expenses Sub-Total</strong></td>
<td><strong>$350</strong></td>
</tr>
</tbody>
</table>

| **TOTAL ESTIMATED COST**                        | **$4,570**  |

If you have experience with programming and budgets, you will certainly recognize that this cost breakdown is modest. For many non-profits, however, it can still be a challenge to fund a program of this size. Often, home health agencies, drug companies, or senior housing facilities are willing to assist you, especially with refreshments. In return, they often ask only that you acknowledge them in your group advertisements or agree to display their materials. Another way to minimize cost is to provide refreshments for the first
session only, then request participants to sign-up and bring refreshments for the remaining sessions. We have instituted a suggested donation of $400 per dyad to help offset the cost of the program as well as strengthen the participants’ commitment to the Memory Club®. However, the inability to pay should not exclude a family from participating and receiving needed support.

2.1.3 Effective Use of Space and Supplies

If possible, hold the Memory Club® meetings around one large table or a set of tables that fit together. This arrangement allows members to see each other and easily access materials such as participant binders or folders, coffee cups, and/or handouts. Ideally, for the breakout groups, when a Large Group breaks into two Small Groups, a circular table is preferred. Members tend to feel more comfortable and safer when seated around a table. For a Large Group discussion, this can be a challenge. Chairs in a circle may be your only option in order to see everyone’s face.

When considering your equipment needs, we recommend providing enough chairs and table space for everyone to gather around. The following list details supplies we try to have on hand for the Club:

- Pens
- Projector and Projector screen
- Dry Erase Board
- Markers for dry erase board
- Supply Box – extra nametags, pens, paper, etc.
- Supply of facial tissues, paper cups, plates, napkins, etc.

On days when you have guest speakers scheduled, you will want to consider how to most efficiently use the space you have. We try to set up our room to
accommodate the speaker’s style and wishes for the presentation. Some speakers are less didactic and prefer to lead a discussion in a circle. Others like to present in a lecture style and have the room set up with rows of chairs. Flexibility is the key. Let the topic, the speaker, and the personality of the group be your guide.

2.1.4 Staffing & Facilitators

The families in your Club will look to the staff for guidance, empathy, and accurate information. The preferred staffing criteria for early stage support and education programs like the Memory Club® would include primary leadership roles and ancillary support roles. Leadership needs to be provided by trained professionals with clinical expertise in ADRD and, if possible, family therapy. Look for someone with ample life and professional experience; someone who demonstrates empathy, has an easy rapport with persons with ADRD, and has facilitated groups.

You will need two facilitators, a lead facilitator and a co-facilitator for the two Small Groups. Co-facilitators can include:

- other trained staff,
- bachelors or masters level interns,
- care partners or persons with the diagnosis,
- volunteers, and
- future Memory Club® facilitators in training.

There is one absolute qualification required for Memory Club® staffing: knowledge of ADRD. In addition, everyone involved should be familiar with the specific issues and needs of individuals with early stage diagnoses and their care partners as their needs differ significantly from those in the later stages of the
disease. Being diagnosed can be devastating for both the person and their care partner. This is the beginning of a difficult yet manageable journey. Those who are in moderate to later stages have usually already dealt with the plethora of feelings, developed coping skills, made plans for the future, etc. It is imperative for facilitators and co-facilitators to understand the difference between early stage and young on-set. Persons with young on-set not only have to deal with this difficult diagnosis but have distinct challenges due to the younger age of on-set. They may have to accept early retirement, are faced with challenges receiving benefits, give up more independence then what is age appropriate, and may still have young children or teens in the home and a spouse who still works full-time.

2.1.5 Marketing to Your Target Audience

There are several ways to market the Memory Club® program to the appropriate audience. Call or send an alert to health care professionals who come into regular contact with clients who could benefit from the service you are offering. Some of the most effective contacts come from established and well-maintained professional relationships with various health care agencies, educational institutions, and physicians – particularly those most likely to be assessing patients with ADRD. They are often eager to have something hopeful to offer patients after having delivered such a difficult diagnosis.

You can also distribute advertising brochures to appropriate agencies, or health care professionals. In addition to referrals from health care agencies, and physicians, you will get referrals from members and/or families involved in previous Memory Club® series.
Hosting educational events to which all interested persons in the community are invited has been an excellent marketing tool. Educational event topics range from the medical aspects to the psychosocial perspective of early stage, and young on-set ADRD. Our best community presentations have included a panel of experts—our own Club members. When well-advertised, these events can easily draw 40 to 80, or more, community members and professionals. Additionally, we are frequently invited to speak at network meetings.

Another avenue for referrals is a Free Memory Screening event. For example, our first partner, CARE, had the capacity to sponsor such an event, and the response was overwhelming. Trained professionals meet, privately and confidentially, with interested/concerned community members to provide a consultation interview that includes implementing an MMSE. After the screening, counseling and appropriate referrals to our early stage programs or other community services are provided.

2.1.6 Space & Location Considerations

We realize that space and location considerations will depend on the resources of your agency. We discuss here what we have found to be the ideal setting. The Memory Club® was conceived to hold concurrently running meetings for its separate member-groups: the PWCl and their care partners. For this, you need at least two private rooms. One room should have enough space for all participants: members of both groups and the facilitators, interns, guest speakers, etc. Care partners typically move to the other room when the groups split into concurrent support sessions allowing PWCl to remain in the initial meeting room.
Support groups take place in a variety of settings from sanctuaries, to classrooms, to lobby areas. Here are some attributes to consider:

- privacy
- quiet environment
- uncluttered space
- space that is not cramped
- adjustable heating and cooling
- accessible parking
- convenient access to restrooms
- barrier-free access to all rooms

2.1.7 Scheduling for Success

Two criteria play an important part in the quality of a Memory Club® series: 1) it is important to consider the age of the participants and how age impacts their circadian rhythm, and 2) the amount of time they can remain comfortable and able to focus at a Club session. For example, as persons age, their body clock or circadian rhythm desynchronizes, causing changes in the body. With ADRD it is very common, as areas of the brain deteriorate, that the circadian rhythm is affected and sleep patterns become abnormal. Most persons diagnosed with ADRD are usually at their best cognitively during the morning hours and early afternoon. Additionally, a very common dementia symptom known as “sundowning” which causes increased agitation late in the afternoon and evenings makes participating in an activity more challenging. Therefore, factoring in these two elements, members will most likely be at their best cognitively in the late morning and/or early afternoon.
Along with the appropriate time of day to hold the sessions, it is also important to keep in mind how long the sessions should last. With ADRD, common symptoms include increased fatigue and shorter attention spans. We have found that the two-hour session seems to be an appropriate timeframe for most of the members. If you feel that members are losing interest during your session, be prepared with alternative activities.

2.1.7.1 Choosing a Meeting Time – Scheduled meeting times will probably depend, to some extent, on the availability of space, staff and the membership. But if you have a choice, we recommend scheduling your groups during the morning hours. Research shows that people with ADRD are sharpest and most focused in the morning. Unfortunately, the most significant barrier to morning support group participation is employment. If you have a large number of working members in your group, you may need to schedule the Club later in the day. We hold our Clubs no earlier than 10 AM and no later than 1 PM.

Evening meetings present fewer opportunities for spontaneous social gatherings. Many of our members like to gather together for lunch after a session. If you have a morning group, make it early enough so that it does not conflict with the lunch hour, and late enough so that members have time to complete their regular morning regimen and allow for travel time to the Club. For the majority of our groups, we open the doors at 9:30 a.m. for an informal half-hour of refreshments and socializing with the entire group, and at 10:00 a.m., the group begins.

2.1.7.2 Choosing a Meeting Length – Because the Memory Club® provides both education and support to its members, it needs to run a little longer than the hour and a half of more traditional support groups. We recommend that you schedule two hours for each session, with time before and after the meetings for
members to congregate and chat. Consider the following when choosing a time and length for your Club:

- Will facilitators and members have enough energy? (i.e., at the end of the day.)
- Are other groups meeting at about the same time? Could this confuse members or congest or compromise the space you have?
- Is the meeting space you are using located near a bus stop? Is parking accessible?

2.1.8 Limiting Group Size for Success

The suggested maximum number of members is eighteen (9 dyads): nine care partners and nine persons with ESADR. A total of more than 18 members makes the Club seem quite crowded. In an effort to respond to demand while maintaining group integrity, anywhere from 12 to 18 members seems to work well. Facilitating becomes more like traffic control if the group is too large. Group process, especially for the persons with ADRD, is most effective when each member has an opportunity to share at least once during each session. This sharing time is very important to our Memory Club® members.

2.2 Recruiting Guest Speakers

To provide interesting and informative programs for individuals with ADRD and their care partners, we recommend inviting health care professionals from the community to speak at some of the Club sessions. (Refer to Chapter 7, “Session Guidelines” to see when and how we use guest speakers effectively.) The right speaker for your audience can prove to be an invaluable asset to the total Club experience; the setting provides a non-threatening forum for speakers and dyad
members to come together to share and learn. When you include programs featuring a guest speaker, you expose your members to experts in the community who can provide answers to asked, as well as unasked, questions.

Look for people who can offer information or support that would not be readily available to this audience under normal circumstances, or people whose expertise will stimulate attitudes of proaction and/or enthusiasm. Above all, consider the needs of your audience; you will find that each group displays a different identity. If your team notices that some dyads in your group are having difficulty negotiating with one another or in stating their needs, invite a speaker to talk about communication issues and strategies. If some Memory Club® members are fighting for their right to continue driving or are angry when their driver’s license has been taken from them, you may want to invite a speaker who can discuss both driving safety issues and the emotional impact of not driving.

2.2.1 Finding Appropriate Speakers

Look for professionals in your community who are involved in clinical or social research or other aspects in the fields of gerontology and/or dementia. Our own members have had access to a wide variety of information and advice provided by professionals in our community. The list includes, but is not limited to, a gero-psychiatrist, an elder law attorney, a geriatric care manager, social workers, researchers, and neuropsychologists.

Programs featuring guest speakers also provide an opportunity for Club participants to invite their friends and family to expand the breadth of knowledge in their support circle. A note of caution is needed here. Guests should be notified ahead of time that they are invited to stay for the speaker’s presentation only. Once the presentation portion of the program is completed,
the privacy of the members requires that all guests be excused. There have been rare occasions when a family guest, i.e., a care partner who lives out of town, has stayed for the support group session. When such a request is made, permission from all group members must be obtained.

2.2.2 Negotiating the Speaking Engagement

Here are some suggestions on how to prepare guest speakers for a successful presentation:

- confirm and prepare the speaker with plenty of lead-time (about a month). Nearer to the time of the group meeting, send a letter summarizing the make-up of the group, its goals and objectives, and a brief composite of the group membership. Include their needs and concerns as well as a plan for the day’s entire meeting, with times for each event (Refer to Section 2.2.3 for a sample letter to a guest speaker.)
- suggest a length of time for the talk – perhaps an hour, so there is time left for a break and a Small Group discussion. Encourage the speaker to leave time for questions and answers
- encourage the speaker to keep the presentation informal, and, if possible, to allow for questions during the talk, as well as afterwards
- encourage the speaker to bring handouts – the less technical the better
- some speakers unintentionally overlook the person with ADRD. Remind the speaker that those who are in your group, while they have ESADRD, are cognizant of their situation and able to express thoughts and concerns.

2.2.3 Sample Invitation Letter/Email to a Guest Speaker
Dear Dr. Smith:

Thank you so much for agreeing to be a speaker for our Memory Club®. The Memory Club® is an intensive information and support program, designed for individuals in the early stages of Alzheimer's disease or a related dementia, and their care partners.

**Your Speaking Date:** Wednesday, October 29th

**Time:** 10:10 AM – 11:15 PM

**Location:** Alzheimer’s Los Angeles
4221 Wilshire Blvd., Suite 400
Los Angeles, CA 90010

**Session Topic:** What You Need to Know About Alzheimer's Disease and Related Disorders: Medical Issues

Some general themes for this topic could include information on how to diagnose dementia, what is the difference between dementia and Alzheimer's disease, current treatments (both pharmacological and non-pharmacological), etc. Please feel free to elaborate on any of these topics in a way that is most meaningful and comfortable for you; we want each of our speakers to have complete creative freedom. If possible, we would like you to build in a 10-15 minute question and answer period. Lastly, please note that half of the group has been diagnosed with a dementia (most often Alzheimer’s disease), so presenting information in “layman’s” terms will be most helpful. We are tentatively expecting 6-10 participants and 6-10 care partners; additional family members have been invited to attend sessions involving a speaker, so there may be a few more people in attendance.

Thank you for your participation in our program. We are looking forward to having you as a speaker and appreciate the time you are taking out of your busy schedule to help us with our program.

Sincerely,

Always M. Gracious, LCSW
Project Manager, Memory Club®
2.3 Preparing the Meeting Room

You will want to give some thought to the appearance of the meeting room. It is a good idea to make sure you begin with enough chairs around the table for everyone to minimize disruptions from members who may show up late. Try to make the environment feel friendly, comfortable, and, above all, safe. Section 1.6, “A Typical Day at the Memory Club®” provides an overview of the chronology around which the Club flows. Refer to this for a general idea of the daily schedule and activities.

We encourage dyads to arrive at any time between 9:30 and 10 AM. A table with coffee and some light snacks is always a welcoming sight. It is also beneficial to have a resource table set up with flyers for up-coming events, pamphlets, and other informational notices. We have, through trial and error, come up with a list of “accessories” we recommend for the meeting room. These are listed in section 2.1.3 in this chapter, under “Effective Use of Space and Supplies.”

2.3.1 Participant Binders/Folders

Each dyad should be provided a Participant Binder/Folder. The binder/folder contains the series schedule, session agendas, supplementary materials that complement each session and will become a place to store all brochures and other information acquired during the program. An example of the participant binder/folder materials is located in Chapter 7, “Session Guidelines.”

2.3.2 Session Materials to Keep on Hand
Here is a checklist of materials that are good to have on hand for every session. We are repeating part of the list provided in Section 2.1.3, “Effective Use of Space and Supplies.”

- Name tags
- Signs to the nearest restroom(s)
- Pens
- Facial tissue
- Water pitchers and disposable cups
- Coffee and tea
- Snacks
- Relevant information: books for sale, upcoming educational events, general information about ADRD issues and agency resources

2.3.3 Avoiding Information Overload

A good idea to keep in mind is to avoid handout overload. Limit the information you hand out to group members during each session and keep them relevant to that day’s topic.

2.3.3 Creating an Information Table

Memory Club® PWCIs and care partners find it helpful to have an information table set up during each session. The literature provided is meant to enhance the experience and give the members something to take with them. Often, they will want to read it later, or share it with family and friends.
CHAPTER 3
Evaluating for Appropriate Membership

In Chapter 1, we introduced the Memory Club® Early Stage Family Intervention Model with its stated purpose—to provide a safe, supportive, educational forum for people with ESADRD and their care partners. We identify “early stage” candidates through a series of filters. The following list shows some of the methods we use for determining Memory Club® eligibility:

- an initial telephone screening call
- the Mini Mental Status Exam (MMSE). We usually look for a score of at least 25 out of a possible 30. However, as we will demonstrate later in this chapter, the individual’s degree of insight is usually a more reliable parameter than the MMSE score
- independence as demonstrated in activities of daily living (ADL)
- personal interviews to assess the candidate’s awareness and willingness to participate in support group discussions
- assessment of each candidate’s ability to contribute to the cohesiveness of the group being formed (i.e., how would candidate “fit in” with the group)

When we interview and evaluate potential candidates for Memory Club® membership, we look for the qualities and skills that we have found to be most important for successful group participation. We look at both the care partner and the person with ADRD to see how well they conform to the group profile. We do not use formulas or rigid criteria during this screening process due to a great deal of variability in symptoms and abilities among individuals with ESADRD, as highlighted in Daniel Kuhn’s symptoms chart
(Chapter 6, Figure 6.1). Within this chapter, you will find additional screening information to help you select members for your Memory Club®.

3.1 How to Identify the Successful Candidate

Ask yourself the following questions as you begin to screen and interview participants for your early stage group:

- Is the person with ADRD seeking membership in a support group only because of the wishes of his/her care partner? Vice versa?
- After explaining the format of the group and its objectives, do both parties seem interested?
- Is the individual with ADRD able to express his/her thoughts and reasons for being interested in a support program?
- Is the person with ADRD able to make connections regarding the diagnosis of ADRD and its symptoms, and relate it to how his/her life may or may not be affected currently?
- Is the person with ADRD concerned about the future, eager to learn more about the disease, how to cope with its symptoms, and adapt to change?

Answers to questions of this type will help to eliminate members of the Memory Club who would be better served by private counseling or another type of support service. We believe both members of the dyad must approach their application as an individual choice. Information obtained from these questions will also help to identify and flag possible barriers to successful membership in an early stage program.

3.2 Barriers to Being a Successful Candidate
Even when both members of a dyad seem to meet the qualifications of the guidelines for membership, other characteristics of either or both members of the dyad may signal that membership is not appropriate and probably would not be successful.

3.2.1 Inconsistent Attendance

The ability to guarantee relatively consistent attendance is critical to successful participation. As you will see in the Chapter 7, “Session Guidelines,” one session of the Memory Club® builds on the previous session. Because the group is small, its success depends on the contributions of all its members during each of the allotted sessions. Without a commitment to attend each session, group safety and intimacy may suffer. Of course, we recognize absences will occur, and missing one session will not be detrimental to the group process. We do, however, recommend that you stress to each dyad the importance of committing to the eight-week series.

3.2.2 Unrealistic Expectations

You will encounter unrealistic expectations regarding the goals and functions of the Memory Club® program. It is important, during the interview, to listen for clues that give you a sense of what the individuals hope to gain, or learn, by participating in the group. You may discover inappropriate reasons for an expressed interest in the Club. Remember that the program is not designed to convince someone who is in denial that they ought to accept a diagnosis of ADRD nor will it reverse or cure memory loss. The Club will also not be able to save marriages or help someone recover his/her revoked driver’s license, and it most certainly will not convince inconsiderate offspring that they are being selfish and should help out more. Although the Memory Club often provides
benefits beyond members’ expectations, its goal is to help dyads explore issues related to ADRD.

### 3.2.3 Divergent Beliefs in the Program’s Value

Occasionally, you will come across a dyad that does not share the same feelings about the value of the Memory Club®. As an example, perhaps the care partner does not agree that the program is something in which he or she needs to be involved. Instead, this care partner believes the Club can only help the family member with ADRD. The Memory Club® works best when everyone is there because they want to be there. When the dyad is divided about whether to join, you have a potentially serious obstacle for successful participation. The Memory Club® is designed to reinforce the dyad. Educating potential families about the objectives of the program can help you to get dyads past these barriers. Expect some resistance as well as nervousness, anxiety, and uncertainty during the interviewing phase.

### 3.2.4 Denial in the Face of Functional Loss

Oftentimes, individuals with ADRD are aware of their diagnosis and are comfortable discussing it but are unable to recognize changes in themselves that are obvious to others. These losses, which in many cases have been documented, include the ability to drive safely, work, function socially, or retain information stored in short-term memory. The problem often arises shortly after an individual has received a formal diagnosis. It is a form of denial and can, at times, be intractable. Here are two examples:

- “I know I have Alzheimer’s, but my memory is fine. Harold thought I was forgetting things and took me to the doctor, but really, I’m fine.”
• “I know Maggie loves me, but she’s nuts; I can drive just fine. The DMV is a malicious, unqualified bunch of degenerates. I’m fine; nothing has changed, Alzheimer’s or not. I’m the same and I can do everything and remember everything I did before.”

3.3 Supporting All Families

We have found either prior to or soon after a diagnosis of ADRD has been made, calling Alzheimer’s LA is often a family’s first attempt to reach out for help. It is often the first place they turn for support and information. Therefore, the role Alzheimer’s LA plays is pivotal, setting the stage for how a family seeks support in the future.

The right guidance and information is even more important for families who do not qualify for membership in the Memory Club®. You can empower a family to take action and look for other solutions with confidence and knowledge, thus preventing feelings of hopelessness, helplessness, disillusionment, and hours of wasted time and energy. You will encounter individuals, particularly care partners, who become disappointed and discouraged after screening reveals Memory Club® ineligibility. These families need the same guidance, information and support as those who do meet the criteria for Club participation. If a dyad does not meet early stage group criteria, be prepared to refer them to other services in your agency or community. This is one of the many reasons to look for opportunities to build relationships with other agencies.

3.3.1 Making Distinctions

In the beginning, particularly if you have had little exposure to people with ADRD, you will be developing a discerning eye that allows you to pick up on
subtle differences among all of the individuals who fall into the category of early stage. We have tried to give you a better understanding of exactly what it means to be in the early stage of ADRD. Here are some subtle distinctions and paradoxes of which you should be aware when you are interviewing your early stage candidates.

- Many individuals with ESADRD are aware of their own symptoms and the disease’s impact on their lives. They are able to articulate concerns and needs, and advocate on behalf of themselves and others.
- Some individuals who have been diagnosed with ADRD and classified – by test scores only – as being in early stage, are not fully aware of their own symptoms, and fail to see any changes in themselves.
- Although everyone with ESADRD experiences changes in short term memory loss, not everyone will experience the same cognitive or behavioral symptoms. The number, degree, and nature of the symptoms experienced by any individual are highly variable (see Daniel Kuhn’s table, Chapter 6, Figure 6-1).
- You will interview individuals with ESADRD who are still driving, working and maintaining an active social life. Often, these are the people who will benefit most from early stage support groups because they are aware of their disease and its consequences.
- Other individuals with ESADRD are retired, have no driver’s license, and may be quite isolated. These people have talked to no one about their concerns and are probably unaware of the manifestations and severity of their condition. They may feel they are the only ones having trouble remembering what day it is.

Remember that not all professionals working with this population understand how to delineate ESADRD from the middle stages of the disease. It is not
uncommon for the term “early stage” to be applied to anyone with ADRD who can still walk, talk, and dress, without assistance. Here are the key criteria for which you will want to look:

- a skilled neuro-psychological evaluation yielding test scores diagnostic for dementia
- awareness of self and others
- orientation to time and place
- high degree of insight
- the ability to perform most ADL’s independently

Even more important than evaluation scores is a candidate’s ability to demonstrate a strong desire to maintain independence, insight into their diagnosis, and willingness to share their story. Most of the people who have attended our Club or sought ESADRD support report a time when they felt they were the only person in the world facing the challenge of ADRD. They will freely admit they felt alone and frightened. You have the power to make a difference in their lives.

3.3.2 The Initial Phone Consultation

The first inquiry or contact you receive is usually a phone call. The caller may be one of the following:

- an individual with ADRD or a care partner calling because of a referral from a health care professional or agency
- an individual with ADRD or a care partner calling after seeing an advertisement, talking to a friend, or attending an educational forum
- a health care professional or agency referring a potential candidate
• self-referrals who have heard about the Club and want to find out if the Memory Club® is right for him/her, a family member, or a friend

3.3.2.1 Communication Techniques — Telephone “cold calls” from self-referrers, care partners, friends, or family members, are the most challenging encounters. Care should be taken to ascertain as many pertinent facts as possible. Additionally, it is advised that you:

• keep your voice reassuring and nonjudgmental
• use gentle questioning to get the information you need
• talk to both members of the dyad
• if you discover during a call that a family is not appropriate for the Memory Club® (i.e., no longer in early stage, dyad in denial about the ADRD, etc.), turn their attention away from joining the Club and give them your full support in seeking out more appropriate resources

3.3.2.2 Agency Referrals — If a referring agency representative or health care professional makes the first contact, your next step is to make phone contact with an appropriate care partner or family member. Much of the pre-screening information you need will not be provided by your referral source unless permission has been obtained from the individuals themselves. Remember to thank the person who provided the referral and follow-up to let them know your plan of care. Additionally, constructive feedback may be necessary to educate the referral source about who is considered appropriate. Anything you do to promote continuity of care will help the family in the long run.

If your referral comes from a partner agency, clinic, or other health care professional familiar with the Club membership criteria, the candidate is almost always an appropriate one. Referrals can save time when recruiting prospective
members. You will still need to establish phone contact with one or both members of the dyad in order to establish a relationship with them. The success rate of your referrals depends on your professional relationships, and the availability of complementary agencies in your community. Nevertheless, it is by far the most efficient and productive way of securing Club membership, particularly referrals from geriatric clinics. Once your program is established, you will find that referrals are coming from members and/or families who were involved in previous Memory Clubs.

3.3.2.3 Screening Techniques — We recommend establishing a screening protocol for initial phone calls. In an effective phone screening session, there will be two primary elements: the information you obtain, and the information you provide. Each of these is important.

Information You Want to Obtain

The information you will need to obtain from the caller during a pre-consultation call is listed below. Remember, the person with ADRD, their care partner or a close family member may make the initial contact.

- Name of the person with ADRD and the care partner
- Relationship of the person with ADRD to the care partner
- Home address and phone number
- Diagnostic information, i.e., What is the diagnosis? Who made diagnosis? When? What type of testing was done? Symptoms experienced?
- MMSE score, if available. You’ll be looking for at least 24 out of a possible 30; typically our group members have been averaging around 25. (See also Chapter 1, section 1.2.2.1.)
- Referral source
Information You Want to Provide

The information you will need to provide the caller regarding benefits of participating in the Memory Club® and what is involved in Club membership is listed below:

- Club’s group process is designed for dyad participation: the person with ADRD and their care partner
- Limits of confidentiality
- Membership criteria (See Section 3.1)
- Importance of making a commitment to attend every meeting
- Ability to attend a meeting of two-hour durations
- Cost or recommended donation, if any
- In-person interview of both members of the dyad to determine appropriateness for the Club is required
- Identification of the purpose of the interview and the fact that enrollment is not guaranteed

3.3.3 In-office Family Consultations

An in-person interview should be scheduled for all referrals, no earlier than one month prior to the anticipated start date of the Club. As is the nature of ADRD, a lot can change in a month. Therefore, we recommend that you keep the time between screening interviews and Club attendance as short as possible. You will minimize last minute cancellations and maximize the limited number of slots you have for the Club. Of course, families that do not qualify for Club participation should be scheduled for a care consultation appointment, to help them find programs and resources that better meet their needs.
3.3.3.1 The Pre-enrollment Interview — During the pre-enrollment interview, one, or at most, two, Club facilitators meet simultaneously with the dyad. At that time, you will want to talk about the interests each member of the dyad has in the Club, hear their stories and needs, answer questions and provide them with detailed information about the Club and its mission. During this time, you will also have an opportunity to use your observational skills to watch body language and relationship cues (within the dyad), along with the degree of independence, and ability to focus for the person with ADRD. The primary purpose of this interview, of course, is to help you reach a decision about this dyad’s appropriateness for Club membership, and to assess their immediate needs. A sample pre-enrollment assessment interview and client folder is located in the “Sample Forms” section of this manual.

3.3.3.2 Interview Content — In order to avoid overwhelming prospective members during the interview, try to limit the number of facilitators to no more than two; one is usually sufficient. You can expect each interview to take from 1 to 1½ hours. You will be discussing with them what you are looking for in potential members, asking questions, and providing education, while picking up cues to help you with your decision. In addition, the dyad will certainly have questions and concerns to be addressed.

Remember, you are looking for candidates who are most likely to benefit from Club membership. These are the guidelines we use to help identify persons with ADRD who can be successful in a group setting:

- diagnosis of ADRD in the early stage
- awareness that the diagnosis is impacting their lives
• willingness to participate in a support group and welcome the social experience
• willingness to express thoughts and feelings
• ability to sit for up to two hours without restlessness or disruptive behaviors
• hearing sufficient to participate in and understand group discussion
• absence of significant psychiatric symptoms that would impede participation in the group (i.e., acute paranoia, depression, delusions/hallucinations or substance abuse)

3.3.3.3 Materials to Distribute During the Interview — At the time of the interview, prospective members should receive any materials that give them a clearer idea of the program. Also, try to provide any information you have about ESADRD that can help to alleviate their immediate concerns, and answer questions. The following are suggestions based on the literature and handouts we have generated for our Memory Club®.

• Program description
• Series calendar and session topics
• Agreement, Guidelines & Informed Consent
• Parking information for meeting site

3.3.3.4 Membership Decisions — At times, you will be able to decide within the first five minutes of a conversation whether or not a couple is appropriate for the Club. If you decide quickly to accept the couple, the group really starts on this first contact as you get to know them and they get to know you. Spend the additional time sounding them out and providing feedback, answers and encouragement.
Other times, you will not be able to make an immediate decision. You may need to delay your decision and follow-up with prospective members later. You may eventually decide to bring them on board for the Club, or, you may decide to share with them your concerns—why you feel another program or service may better meet their needs. Your ultimate decision will be based on many factors— but primarily, on their needs as well as other critical aspects such as anticipated group dynamics and group size.

3.4 Final Check-in

Once you have made your decision about potential members and received confirmations, we recommend that you schedule a “check-in” telephone appointment with the newly enrolled members, just prior to the group’s start date. New questions will undoubtedly have arisen as they anticipated the first Club meeting. Addressing their concerns and using this time to finalize details with families saves time later.
CHAPTER 4
Thematic Guidelines for Early Stage Programming

This section identifies and explores the needs of families living and coping with ESADRD. These needs have been translated into themes that resonate with our Memory Club members as they meet the challenges of ADRD. We have carefully woven these themes—or focus areas—into our Memory Club® series.

The themes frequently overlap within the series structure. They build on one another in an effort to cover the breadth of the challenges that must be faced. They play a primary role in meeting the goals defined by the Club’s mission. Of course, these themes cannot capture all the needs and concerns individuals and families face. Nevertheless, we have found that most issues explored by dyads in our Memory Club® series fall into one of the thematic categories in Section 4.1.

4.1 Themes

We have identified and developed the following themes to provide a framework around which to organize the Memory Club®:

A. Understanding the Disease Process
B. Common Emotional and Psychological Reactions to the Diagnosis
C. Facilitating Effective Communication
D. Family Dynamics
E. Role Transformation and Task Sharing
F. Honoring Independence vs. Taking Over
G. Safety Concerns
H. Practical Planning for the Future
I. Coping Strategies and Harbors of Strength

Recurring themes establish a thread of continuity and form the very foundation of the Memory Club, providing its primary focus, topics and objectives. The themes used for a particular session are included in the session descriptions contained in Chapter 7, “Session Guidelines.”

4.1.1 Using Focus Area Themes

In Chapter 7, “Session Guidelines,” you will find a detailed description of the agenda and content, plus resource suggestions, for each of the sessions that make up our eight-week version of the Memory Club®. You can use this programming plan as a guideline for your own efforts to establish a Memory Club®. Note that each session has its own topic in which are embedded threads of one or more of the early stage themes.

If you are planning to start your own Memory Club®, you may decide to explore some of these themes in greater detail than we provide. For that reason, we have provided additional resources to complement the manual. We strongly encourage you to read and explore them before creating your own Club.

4.1.2 Relating Themes to Both Members of the Dyad

Remember, both the care partner and the person with ESADRD are considered to be members of the Club. The care partner in the dyad may be a spouse, partner, parent, adult child, sibling, or even a friend. During a session, care partners and persons with ADRD deal with the same focus areas featured in the current topic, but from within their own support group. Although their perspectives are different, they share a common thread in every theme. As you
begin to facilitate group meetings, you will learn the importance of approaching a theme with consideration and empathy for each part of the dyad. In becoming familiar with recurrent themes that pervade ESADRD, you will gain a greater perspective and deeper understanding as you assist all the members of the Memory Club®.

Whether they are meeting separately or together, you will discover a unique opportunity to learn from both members of a dyad. Each member of the group will have his/her own strengths and weaknesses in coping with this disease. Both as a dyad, and as individuals, their coping styles will vary in how well they communicate and how much they are willing to share with the group. You will find an eight-week series is not a long time; nevertheless, most of our participants report significant growth during their time in the Club. As a valuable bonus, many of them maintain meaningful friendships with the other participants beyond the life of the Club series.

4.2 Focus Area Theme Descriptions

The nine focus area themes listed in Section 4.1 resonate within all of the programming for Memory Club® group sessions. In order to be an effective group facilitator, it is important to understand these themes and their ramifications for people with ESADRD as well as for their care partners. See Chapter 7 for both a schedule and description of each session’s program. Within each session’s program, you will find one or more of these themes. In this chapter, we have expanded on each theme.

Themes

A. Understanding the Disease Process
We have received a great deal of feedback from our families about the way in which they were given a diagnosis of ADRD. The majority tended to agree that the physician who gave the diagnosis provided insufficient information about the disease. Additionally, not enough time was allotted to discuss the diagnosis with the physician. Consequently, their need to understand the disease process is twofold:

- What is this disease?
- How will it affect my/our life?

We have also learned that the dyad’s primary concerns often differ. The person with ADRD is asking the difficult question, “Who am I now?” The care partner’s main concern is often centered on his/her role as a supporter and as the primary resource gatherer. Additionally, the question he/she is asking is, “What do I do now?”

Understanding the disease process is a topic we spend a lot of time discussing in the Memory Club®. We arrange for a geriatrician, neurologist, or geriatric psychiatrist to address these concerns and dispel myths. One consistent finding among participants is the need for reassurance:

- They are not alone!
- It is not their fault; what they are experiencing is a disease.
- They are not going crazy; their symptoms are real, and others are experiencing similar symptoms resulting in major life changes and challenges.
• There are resources and services that can offer real help in coping with changes, planning for the future, and providing guidance through a confusing web of information.

• There are treatment options – both medical and non-medical.

B. Common Emotional and Psychological Reactions to the Diagnosis

The way a person responds to a diagnosis of ADRD depends on several factors including: the individual’s personality, support system, coping skills, and worldview. Each person reacts differently, with different approaches to the challenges of ADRD. His/her pre-existing knowledge about ADRD may also affect his/her reaction. People often make a comparison between receiving a diagnosis of any fatal disease and receiving a diagnosis of ADRD. It is important to respect the variety of reactions one can have upon receiving this diagnosis. Do your best to provide Club members with a safe place to express their feelings.

The months or even years that may have passed since receiving a diagnosis will vary within Club membership. Nevertheless, you will find that many have clear recollections about the period of time immediately following their diagnosis. Some speak of a period of denial or darkness. When asked what brought them out of this darkness, Club members shared the following responses:

Responses from Persons with ADRD

• Knowing that I wasn’t alone.

• My grandchildren.

• Realizing that I had a choice about how I wanted to spend the rest of my life, and I didn’t want to spend it being worried, scared or depressed.

• My faith there is a reason for everything.
• Knowing that nobody gets out of this world alive... why should I be any different?
• Believing in living for today – living for the moment.
• Having my family, my friends and, now, even making new friends, so I’m OK.

Responses from Care Partners
• Knowing we still have each other.
• Believing there are people out there to help us and I shouldn’t be afraid to ask.
• We started talking about it and made plans. It has helped me to eliminate all the unnecessary worry and instead focus on enjoying the time we have together.
• I have more information now. I know what we’re dealing with, and I feel confident about anticipating the changes. This helps me feel prepared.
• She needs me. For years she was there for me, now it’s my turn to be there for her.

For some, receiving a diagnosis was an epiphany because, finally, the changes they were experiencing made sense and had a name. For others, it began as a gradual process that eventually brought them to center again. When the feelings of both members of the dyad are validated and they receive the gift of a safe place to explore and discuss their concerns, you have helped them gain acceptance. These profound changes in their lives will give each of them a sense of control. They can spend this precious time enjoying each other and other relationships.

C. Facilitating Effective Communication
It is surprising how many dyads, and other family members, avoid talking about the changes they are experiencing once the diagnosis is made. Many talk about it only when a problem arises, such as a forgotten appointment, or the onset of problems associated with continuing to drive. When these symptoms arise, powerful dynamics of communication within a family system continue to persist. We try to emphasize to families that learning a new language is required. Effective communication is critically important to families living with ADRD. Strong communication skills help to maximize the safety and well-being of the entire family.

When changes and concerns are not addressed within the family, tension, grief, misunderstandings, and accidents may occur, which may contribute to depression, isolation, and increased memory difficulty. This is particularly difficult for the person with ADRD who struggles with feelings of being disconnected, alienated, and often feels a need to cover memory and judgment lapses. Knowing that you can express your feelings to the important people in your life and receive empathy from them makes all the difference in the world.

It is important to help the person with ADRD communicate with friends, colleagues and other people in his/her life in ways that are comfortable for them. Some of our participants are quite candid when it comes to telling others of their diagnosis, and very clear about what their friends and family can do to help or support them best. For others, it is just too embarrassing or too difficult to reveal what they consider to be a very personal and challenging struggle with the disease.

Being the care partner of someone with ADRD can be terrifying. Both members of a dyad will benefit from hearing success stories and strategies. They will enjoy getting ideas from others who are in a situation that is similar to theirs. Whether or
not it is confronted head-on, ADRD will affect the entire family and loved ones. How they choose to tell others, share their story, and seek support, is within the control of the person with ADRD and the care partner. There are no right answers, but we can provide smoother paths for coping with the disease.

D. Family Dynamics

Families are complicated. Their dynamics take years to develop and we do not delude ourselves into believing that a series with us will change them. However, it is important to address how family dynamics impact the wellness of each member of the dyad. Each member of a family plays one or more roles within that family. All family members have a unique way of expressing themselves. Finally, all members experience the family in different ways. Some families consider themselves as close, others as distant, dramatic, or dysfunctional.

Our focus is not to judge or change these dynamics, but rather to highlight them in a general sense, and give participants an opportunity to reflect on the nature and idiosyncrasies of their family. Family dynamics are described by the following parameters:

- How they define the quality of their relationships.
- How well informed is each family member.
- Their different coping styles, needs, and priorities.

Many report a belief that their families have grown closer since they received the diagnosis. This does not happen overnight; something has to change within the family structure. Whatever families do with the information is their decision but highlighting the common and universal impact of family dynamics when coping with ADRD and planning for the future, may help them reframe the way
their family functions and perceives the situation. For example, imagine the
typical American family of today: one child on the West Coast, another on the
East Coast, maybe one living a mile away, or one living in the basement. The
number of people in a family and the quality of their relationships should be
considered when making decisions. We have witnessed many a “mess” when
families scramble together during a crisis. Making plans in advance and
including or informing family members about these decisions is essential. Aside
from family dynamics, the biggest messes come about when key people in the
family are in a position to make a decision without having the necessary
information. We address this issue when discussing legal, financial and medical
plans. In an effort to make all necessary information available to everyone in the
care team, we invite other friends and family members to attend the sessions
with guest speakers.

E. Role Transformation and Task Sharing

As discussed previously, ADRD challenges families in multiple ways. It places
added stress on marriages, friendships, social interactions, and the way
members of the dyad function in their worlds. Roles and responsibilities, once
assumed, must gradually undergo profound changes because of the changing
nature of the disease and its impact on memory, executive functioning and
behavior. How these changes affect the person with ADRD and his/her care
partner will vary over time. Acknowledging role transformations and the need
for task sharing can help families identify how change translates into real life
within the context of their relationships. Figure 4-1 shows some examples of role
changes and instances where task sharing is necessary and can contribute to
additional stress within the relationship.
Figure 4-1

<table>
<thead>
<tr>
<th>Person with ADRD</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of certain responsibilities:</td>
<td>Gain of new responsibilities:</td>
</tr>
<tr>
<td>- No drivers license</td>
<td>- Arrange or provide transportation</td>
</tr>
<tr>
<td>- Early or forced retirement</td>
<td>- Stay in or rejoin workforce</td>
</tr>
<tr>
<td>- Increased challenge in organizing day</td>
<td>- Spend time arranging calendar</td>
</tr>
<tr>
<td>- Increased difficulty arranging social activities</td>
<td>- Spend time planning, arranging activities</td>
</tr>
<tr>
<td>- Increased difficulty with calculations</td>
<td>- Pay bills, manage checkbook</td>
</tr>
<tr>
<td>- Changes in libido</td>
<td>- Decrease in sexual intimacy</td>
</tr>
</tbody>
</table>

After reviewing Figure 4-1, you can begin to appreciate the changes in roles and responsibilities. These exchanges are often subtle and not discussed or considered in advance. In fact, many families report the invisibility of this process and the struggle that often ensues. It is important to remember that, in most cases, individuals with ESADRD are well aware of these losses. They are often mindful, as well, of the additional pressure their loss of function places on their care partner. These losses—a sense of independence, autonomy, and control—come as a real blow to those accustomed to functioning independently. Helping families to talk about these changes and develop strategies for coping with them in the future is invaluable.

**F. Honoring Independence vs. Taking Over**

Even though there are responsibilities and tasks that need to be shared or exchanged, how this gets carried out can be the real issue. We feel strongly about the inclusion and consideration of individuals with ESADRD in all decisions that will affect their lives. We encourage care partners to think of ways—
creative ways—to find a solution on the spectrum between, “I will take over this task” and, “they will do this independently.” In other words, there is usually a way to evaluate a current need (i.e., balance the checkbook) and find the matching level of appropriate assistance (i.e., sit with them when they balance the checkbook, double-check it and co-sign all checks, etc.).

It is the roles we play in our lives – the jobs we embrace as adults, the responsibilities that link us to a sense of self, identity and autonomy – that are so very hard to lose. Individuals with ESADRD struggle greatly with their losses, and mourn them for a long time. Some, you may find, become fixated or obsessed with a lost responsibility that was particularly meaningful to them. This often happens with driving as well as with finances. We, as group facilitators, must be careful not to diminish the impact these losses have on our members. But we must focus on the task or role that needs to be filled rather than the feelings of the person who is unable to accomplish that task or fill that role independently. Adjusting expectations and accepting these changes can be addressed through support and counseling.

Daniel Kuhn wrote the following poignant words that we share with our members: “Acceptance finally takes place when the difficult task of letting go is complete. You no longer wish to return to the past and are able to take each day at a time. Though you may not understand why this disease has come into your life, you accept it as part of your unfolding story. Acceptance does not mean defeat, but it means taking life on its own term.” Mr. Kuhn goes on to say the grief experienced by individuals with ADRD and their care partners occurs over time and is “resolved gradually, sometimes in fits and starts.” We have found this to be true and do what we can to support our members in their grief and assist them in adjusting to the inevitable changes—within themselves and their relationships.
G. Safety Concerns

The issue of safety should always be emphasized as a concern for families living with ADRD. Imagine the following scenarios as though you were the one with ADRD:

- You step out of your front door to get the mail; when you try to go back inside, you discover you are locked out. You do not have your cell phone, it is 90 degrees outside, and you know your wife will not be home for several hours. You believe your only choice is to wait on the porch step for her return. What would have helped you, if only you had known? The back door is unlocked, your neighbors are home and they have an extra key.

- You are in Rome on a tour with 30 other couples. Your husband goes in one store and you go in another. Time passes, and when you leave the store you do not see anyone you recognize from your tour group. You start walking until you grow tired; then you take a rest on a bench, and end up taking a four-hour nap. What would have helped you, if only you had known? Your husband is only a block away, in the opposite direction.

- You are with your brother in the local mall. The two of you agree to meet up at a certain time, by the drinking fountain. When the time comes to meet, you wait at the water fountain in the middle of the mall. You wait there for half an hour. When he does not come, you decide to check the car. You find the car and drive home. What would have helped, if only you had known? You and your brother decided to meet at the drinking fountain, not the water fountain in the middle of the mall.
• You have an appointment at 10 AM. You decide to leave early and pick up a cup of coffee along the way. At the coffee shop you see your good buddy Joe and decide you have time to sit and chat. After a few hours you and Joe walk home together. What happened?
  You missed your 10 AM appointment and left your car at the coffee shop.

The examples are from real situations that have confronted our clients. They are seemingly harmless lapses in judgment, reasoning, and memory. In some cases, the situations are not this mild, but can actually become life threatening. Giving Memory Club members an opportunity to discuss and plan for potentially dangerous situations can help minimize these occurrences in the future.

WANDERING

We hear the words “wandering” or “getting lost” frequently working in the field of dementia care. In the early stages of the disease, such words may seem misleading, and can put the person with ADRD on the defensive. Nevertheless, these incidents can happen. The people described in these scenarios are by no means incompetent and would take offense if you suggested they are. Wandering is a sensitive subject, but you can normalize the subject for individuals with ESADR and their care partners. Discussing safety in a peer group setting helps to diffuse possible tension and defensiveness by re-framing potential safety issues. Families can then begin a dialogue that will shed light on the gravity of these issues, recognizing them as indicators that the issues need to be addressed as a person with ADRD begins to segue into a slightly altered level of competency.

Alzheimer’s LA recommends that all our Club members register for “MedicAlert Found CA.” This is a nationwide safety program that identifies, locates and
returns wanderers. While wandering is often associated more with moderate cases of ADRD, but as we have learned, individuals in the early stages are also vulnerable.

The Memory Club has been successful in creating a social and lighthearted MedicAlert Found CA registration event as one of our interventions during a program series. Registering as a group serves to normalize a potentially uncomfortable situation in which the person with ADRD is apt to feel singled out. It is not surprising that some folks get defensive and resistant to an activity, which, on the surface, has the appearance of “labeling” them as inept when they already feel quite victimized.

We discuss, as a group, the advantages of the MedicAlert program. We highlight incidents reported by our clients, especially previous Memory Club® and current Graduation Club members. Some of these clients have reported that a bracelet (person with ADRD bracelet and care partner bracelet) may have saved their life; some describe incidents during which they wished they had one. Usually, there is at least one member who has already registered; we praise them for their courage and foresight. These members, all of whom have been willing to share with the group, tell their stories and motivate others to register and wear a bracelet too. When the recommendation occurs between peers, the likelihood of acceptance is greater. The stigma is removed and the message gets to the heart of why a person with ADRD and his/her care partner should wear a MedicAlert bracelet. In addition, they are reinforcing adult choice, individual autonomy, the importance of family cohesiveness and, most of all, security.
TO DRIVE OR NOT TO DRIVE

The scenarios related above are called key stories; you will want to pay close attention to them. The role of key stories as markers for revelation or acceptance in a person with ADRD or care partner’s life is discussed in more detail in Chapter 5, Section 5.5.

One of the key stories we hear and address most often in the Memory Club® is this issue: to drive or not to drive. The subject of driving privileges is a heated topic and rightly so. For many, the car serves as a lifeline to the community, a symbol of independence, freedom and control. It is a luxury and, in some cases, a necessity (for example, consider someone with young onset ADRD who is employed and has young children living at home). We handle this topic by spending group time discussing:

- reporting laws in our state as they relate to ADRD
- cognitive symptoms and neurological changes that impact safe driving
- emotional aspects of driving
- alternatives to driving
- local transportation resources

Safety challenges or incidents will not be an issue for some families during the series and may be difficult for them to imagine. You can, however, discuss the warning signs and help families anticipate potentially dangerous situations. Safety will be a concern at some point in the future and they need to prepare for this. Discussing these issues in a group setting is much less threatening than in a one-on-one exchange. Removing the potential for early stage members to feel they are being personally attacked, or unfairly judged, will allow all participants to focus on the real issue at hand, driving.
H. Practical Planning for the Future

We simply cannot emphasize enough the importance of making plans, not only for peace of mind, but for the financial and/or legal implications that can arise if decisions are not made. As we mentioned in the previous section on safety, having a plan, and a back-up plan, will assist families in making difficult decisions in the future. Additionally, having plans and making them together builds on the resilience and strength of each dyad, in addition to including the person with ADRD in decisions made about his/her life.

Given that this is a very personal process that necessitates the guidance of someone with expertise in these issues, we invite an elder law attorney to lead the discussion. He or she provides information about decisions they should be making, as well as additional information for the population with ADRD. Topics include but are not limited to:

- Advance Directives
- Durable Power of Attorney (Medical & Financial)
- Conservatorship
- Long Term Care Insurance
- Medi-Cal Planning
- Estate Planning, Trusts, and Wills
- Explanation of confusing legal terminology

There are countless, unfortunate situations that can result from not making long-term-care plans in advance. Too many families operate in what we call crisis mode, always having to react to a problem and come up with a plan of action on the spot, leading to frustration, stress, and anger. Coping with ADRD is more
than enough for any family. Helping families understand the consequences of not planning, and therefore running the risk of unfortunate and unnecessary crises is the responsibility of the professional working with the dyad. On the other hand, helping families and the members of the dyads understand the benefits of planning ahead and knowing where to turn to make sure their wishes for the future are secure is also the responsibility of those professionals.

I. Coping Strategies and Harbors of Strength

Every person has the capacity to draw from within themselves or the world around them to help cultivate strength and cope with the many challenges life throws his/her way. How we do this, and how often, make a big difference in our overall functioning. We can all benefit from a little reminder as well as the opportunity to hear how others attempt to maintain emotional, spiritual, mental, and physical wellness. We try, in the group setting, to assist our members in identifying what helps each of them, both persons with ADRD and their care partners, to find peace and joy in their lives. This sharing of resources can be the encouragement they need to meet their personal challenges, try new approaches and honor each other’s differences and needs.

It is important for both members of the dyad to understand and appreciate what helps the other person in their partnership. Together, they can work out how to maximize their peaceful moments and the meaningful activities in their lives. Some members will have experienced changes in their social life and personal relationships. Some will miss activities they once enjoyed but can no longer participate in without assistance (golf, dancing, tennis, acting, etc.). Finding new avenues of self-expression, entertainment and friendship may be necessary.
Many couples in our group develop friendships. They go out together as well as arrange group get-togethers and outings. Spending time together with individuals who understand helps ease tension, nerves or even embarrassment. Persons with ADRD often express feelings of frustration and social anxiety. They may no longer feel completely comfortable in former social circles or in meeting new people. Exploring ways to cope with these anxieties and fears can be very helpful to your members. Developing strategies for coping with ADRD and the stress it places on persons with ADRD and their care partners is a wonderful use of group time. Not only will this help each of your members cope with an unpredictable future, it will help them enjoy life in the moment, day by day.
CHAPTER 5
Group Facilitation

As you would assume, the type of support available in a Memory Club® usually depends on the Small Group with whom you are working. While the focus themes for each programming day are the same for both groups (see Chapter 4, “Thematic Guidelines for Early Stage Programming”), the nature of the support needed varies widely between the two groups.

Each group has at least one facilitator who remains the facilitator for that group for the duration of the sessions. At the beginning of each session, the two groups usually meet together briefly. However, if a speaker is scheduled, both groups stay together for that part of the program. The room set-up naturally changes (see Chapter 2, Section 2.1.3) and we encourage our members to invite family and/or friends to come as guests, with all attendees seated in an audience format, perhaps in a larger room if necessary.

On non-speaker days, after meeting together for a brief time to connect, the Small Groups separate for about two hours, meeting with their peers and facilitator. In our Memory Club®, the care partners go to a separate room where they can meet privately. The persons with ESADRD remain in the Large Group room, which is both private and familiar to them. If space prevails, you might have them move to some other private meeting area. The idea is to provide privacy for both groups and consistency for those with ESADRD.

5.1 The Care Partner's Memory Club® Group

Who are the care partners? As mentioned previously, care partners are not only
spouses. Care partners are anyone who is willing, and available, to be there for
the person diagnosed with ADRD. Ideally it will be a family member, or a close
friend or neighbor and not a paid caregiver. The facilitator will quickly realize
that each care partner comes to the Memory Club® with his/her own unique
personality, concerns and ways of coping. Some may be very concrete,
overwhelmed and focused on solving specific problems. Some care partners
may be very emotional and may need to use the group to deal with feelings of
grief and loss. They may need a place to cry and share feelings of sadness,
anger, guilt and frustration. Some care partners may be working or have
teenagers at home. Others may have retired and imagined their retirement
years would be filled of travel and leisure. Some care partners may want to talk
about what the future might bring, so they can plan. Most care partners will
want to concentrate on the present and tread lightly toward the future.

It is the job of the facilitator to be flexible and accepting, and to help care
partners maintain perspective and hope. Many times, humor is an essential
coping skill. As an experienced facilitator, you will probably intuitively do the
following:

- Meet care partners where they are as they begin their journey in the
group.
- Balance education with emotional support.
- Provide accurate information about the disease, specifically, what to
  expect and how to prepare for the future.
- Care partners will ask about new ways of responding to specific problems.
  Suggestions are beneficial, yet it also helps to explore the care partners’
  feelings about the behavior. Many times this exploration will be what
  allows them to try out the suggestions.
Care partners are entering the ADRD journey in the context of a relationship full of its own wonders and challenges. Respect their prior relationship dynamics and pay attention to the ways in which they are affecting their transition into the role of care partner. Encourage care partner empathy for both the person with ESADRD and him/her self. Explore care partner needs and try to find solutions and resolutions when care partner and person with ESADRD needs conflict. Be empathic. Through your empathy, you will increase the empathy of the care partner for himself/herself and for the person with ESADRD. Validate the care partner’s need to maintain a separate life, even in the face of increasing dependency of the person with ADRD. Gently confront and work through denial when it interferes with the safety of the person with ADRD.

5.2 The Persons with ADRD Memory Club® Group

The blessing of any support group is the ready access to peer support and understanding. In most cases, for every person who shares a struggle, there will be at least one other person who can relate to their experience, another who can share their story, and another who can provide guidance, support, even hope and motivation. Facilitators for the persons with ESADRD Memory Club® Group should not be doing all the work. A good facilitator working with individuals who have ESADRD will help shape the group experience by providing cues and weaving the pictures. He/she will work to:

- link members by pointing out what they have in common
- assist in the building of friendships and bonds
- provide a safe and “level-playing-field” they can trust

Let us take a look at how you can begin to weave these pictures, starting on the very first meeting day. Here are some tips, based on lessons we have learned.
They may be helpful as you contemplate how you will facilitate your group. You will see that some of these ideas can be appropriate for both care partners and persons with ADRD, while some will apply more specifically to those with the ADRD. This advice is based on the assumption that you will facilitate your group by concentrating on group characteristics that are observable, as well as roles you can take on in order to be adaptive to the needs of the group.

5.2.1 What You Can Learn by Actively Observing

What is the group makeup? Here are some examples:

- The Not-So-Obvious: Does the majority tend to share emotions easily? Are they more or less flexible, adaptable, resilient? Do they expect concrete solutions to the challenges raised by ADRD? Do they demonstrate creativity and problem-solving skills? How are they at relating to each other as observed from session to session? How well is empathy expressed? Are bonds being developed? Do group members easily talk amongst themselves or do they require a lot of prompting?
- What are their needs, both individually and collectively?
- Similarities and differences, i.e., age, backgrounds, coping skills, present situations?
- Strengths and weaknesses?

5.2.2 Playing Different Roles to Meet Their Needs

Assumption of various roles by the facilitator often works effectively in setting or changing a mood, redirecting the conversation when a problem occurs, and
giving the best information and/or guidance, either for the group, or for a specific member. Here are some helpful roles you might want to assume during group sessions:

- **Reframer:** Re-framing or presenting alternative perspectives to the same problem or issue.
- **Restater:** Carefully restating or assisting a member when they have trouble expressing a thought or feeling.
- **Narrator/Storyteller:** Connecting their stories by building a group composite to which everyone can relate, despite their differences, highlighting what they have in common.
- **Validator:** Validating their individual experiences and collective struggles.
- **Good Manager:** Utilizing the internal experts; looking to group members to provide support and guidance to their peers, i.e., “Joe, you’ve been through something very similar lately. Do you mind sharing with Mary and the rest of us how you dealt with that issue?”
- **Cheerleader:** Praising their risks for sharing, for trying new things outside of group, for confronting a problem.
- **Respecter:** Honoring their limits of what they choose to share and not to share, what they are ready to confront, as well as what they may not be able or ready to confront.
- **Educator:** Providing valuable knowledge about the disease and its symptoms, as it relates to group members’ experiences.
- **Good Host/Hostess:** Inviting and including are two excellent techniques on which to call. Drawing from everyone in the group, acknowledging and inviting everyone to share, especially those who are less verbal, preferring to be listeners. You are simply providing them with an opportunity and acknowledging their important role – whether they choose to share or not. You can show them that, share or not, they will still be valued as a group member and will not become isolated. Recognize
and acknowledge body language, “It looks like you’re not alone Bob, I see Cheryl nodding, smiling, shaking her head.”

- **Friendly Know-it-All**: As a facilitator you will become quite familiar with everyone’s key stories, and they will come up over and over again, almost becoming metaphors. As the weaver of their stories, you can help provide bits of information when a group member has difficulty keeping all of the facts together as they try to communicate. It can be as simple as a mix-up of a name or place, or as complex as personal details about their work, history, family of origin, hobbies and the like.

### 5.3 Getting Started

We treat the first day of each Memory Club® series primarily as a day for getting acquainted and getting comfortable with one another. The members may understandably be nervous, as we all are when starting something new. For that reason, we place a certain amount of emphasis on establishing a strong comfort level for everyone in order to get off on the right foot.

You have done your best to prepare your new Memory Club® members and given them information handouts (see Chapter 3, Section 3.3.3). You have had the final check-in meeting to answer last-minute questions and confirm their readiness for the Club. All your hard work and preparation are now ready to be put into action. The screening processes and interview hours will have prepared you well; you know each member of the group, and you believe they will make a cohesive, compatible group. But what about the members themselves, who are, at this moment getting dressed and ready to travel to the meeting site? How are they feeling? Nervous? Anxious? Afraid? Worried? Excited? Try to put yourself in their shoes.
5.3.1 First Day Jitters

In our experience at the start of a Memory Club® series, most members arrive at once relieved and anxious—relieved that the day is finally here and anxious about how they will fit in. The whole concept is so new to them – as is, for some, their diagnosis of ADRD. They have many questions. Sometimes they are afraid to ask the more personally revealing questions, such as, “Will I be safe?” “Will I feel embarrassed?” and “Will I be different from everyone else?” They wonder what the next eight weeks will bring. Most likely, they have a perfectly healthy case of first-day jitters. By using your energy and enthusiasm, you can usually put your new group at ease as you welcome them to Session One.

5.3.2 Session One Agenda - A Format

Every session in Chapter 7, “Session Guidelines,” contains an agenda like the sample in Figure 5-1, which we distribute to our members to help them follow along. Again, in Chapter 7, you will find more detailed agendas, complete with themes, goals, actual program content and resources, as well as a discussion of how to present that program.

Figure 5.1 (Sample)

-------------------------------
• 10:00 – 10:30 Welcome, group structure and guidelines discussion, review logistics
• 10:30 – 11:10 Large Group introductions
• 11:10 – 11:20 Break, followed by members separating into respective groups
• 11:20 – Noon Small Group discussion

-------------------------------
Your discussion ideas for Session 1 would include the following:

- Introduction to the Group
- Q & A about the Club
- Introductions of each member
- Small Group introductions and sharing

### 5.3.3 The Facilitator as a Weaver

As a group facilitator, you will have learned a lot during the private family consultation screening assessment. There will be similarities among the group members that you can anticipate and be ready to share as you begin to weave the group together. You are the weaver, responsible for keeping track of the threads of information shared. It will be your responsibility to help the group members grasp the ties that bind them together. Their experiences together will become building blocks for relationships they will create with others, outside of the group experience. This is one of the many great joys of the Club—the lasting friendships that are created.

### 5.3.4 Communication Between the Two Groups

Although we provide, in Chapter 7, a program to use for each meeting session, it is up to you to decide how much time you want your members to spend in their Large Group and Small Group formats. In our experience, it has been helpful for the dyads to meet collectively, as a Large Group, at the beginning and end of a session, even if it is just for ten minutes.
A person with ADRD may feel uncomfortable being separated from their care partners; the reverse is also occasionally true. What we have found is that some members are extremely curious about what is happening in the “other” group. It is important to acknowledge this reaction and allow some amount of Large Group sharing. We make a serious effort to deemphasize the atmosphere of “our group” and “their group,” and to promote togetherness, even though the dyads do regularly spend time apart.

The overall goal of the Memory Club® is to strengthen the dyad by promoting greater trust and more open communication. Many of our participants with ADRD are already feeling uninformed and left out within their social and family circles. A repetition of that dynamic within their Memory Club® experience could potentially increase anxiety and exacerbate a lack of self worth. Such an experience would certainly be counterproductive for everyone. As you will come to understand, it is imperative that you make every effort to address the different needs of the Small Group members.

5.4 Getting to Know You

During Small Group meetings, take notes on the details being shared. Later, you can weave these stories or observations together into binding statements that unite your members and give the group a feeling of integration and commonality. Notice the themes that are being raised by their contributions and call them to the group’s attention. Validate that what they have to say is interesting and important. Finally, thank them for sharing their experiences and ask if they have any final comments before they go.

5.5 Key Stories
Key stories are events that do not go unnoticed. They represent a turning point or behavioral segue that stimulates an individual to seek a diagnosis perhaps, or, possibly, make a decision about division of tasks and responsibilities. Key stories are situations that startle, amaze or challenge, and eventually change the status quo within a family system.

Most of our members have a key story. These are usually the defining moments or events in the mind of a person with ESADRD or a care partner that stand out as their time of revelation, as their time of realization, or acceptance, that they or someone they care about is, indeed, coping with a possible diagnosis of ADRD. These stories live in their minds for a long time, like a key to a door, or a marker in time – their moment of truth. They are so important that they bear much repetition.

Taking the time to learn key stories during the sessions will help you sculpt the program to the individual needs of your group, which is far more interesting and personalized than following our outline point-for-point. When you use these key stories as examples and references to feelings and session topics, you will also be helping members relate to one another. You will be saying that they are not alone, that they share many of the same feelings, frustrations and concerns.

Each member in each group will have a different key story. You can learn much more about the person with ADRD/care partner by focusing on his/her key stories and concerns related to the diagnosis. Here are a few examples – true statements taken from members of past Memory Clubs.

- “I can’t believe I lost my license. I’m so furious! I’m really feeling discouraged.”
• “My kids don’t think I should live alone anymore. I’m just afraid I’ll lose my house.”
• “Mom and I have been fighting a lot more lately. Every time I see or talk to her on the phone, I can just feel my blood pressure rising.”
• “I haven’t told my boss about my diagnosis yet. I’m not sure when or how to do that.”

5.6 Keeping Notes in Small Group

In your role as a facilitator, we encourage you to take a few minutes after each session to record your own thoughts and impressions. Over the course of the sessions, you will be able to track personal growth (theirs and yours) and potential barriers for each dyad and family system. This information will also be helpful during the Exit Interviews and Graduation Clubs. Keeping a journal and encouraging the members to keep their own journals is another idea. A journal is helpful for persons with ADRD because it allows them to track their feelings and thoughts throughout the week and share them during Small Group. It is concrete, simple and takes the pressure off them when they are trying to remember experiences and feelings.

5.7 Final Thoughts on Facilitating

Certainly, the needs of people with ESADRD are unique. That doesn’t surprise anyone. On the other hand, their abilities – in the areas of self-expression, judgment, bonding with other members of the group, and, above all, their sense of humor – surprise many. Nevertheless, this group must be carefully nurtured, even protected, to avoid pitfalls such as embarrassment over memory lapses, lack of awareness of the needs of others, and an occasional inability to know how much sharing is too much sharing.
A high priority for anyone struggling through the uncertainty of ESADR is the opportunity to have their ideas or stories (their key stories) validated, linked to the key stories of others in their group, and reinforced at regular intervals. As important as key stories are, we try always to avoid making them feel any pressure to contribute when they are uncomfortable opening up to the group, especially to talk about feelings. Some of our members need more time than others to adjust to a new group.
CHAPTER 6
Characteristics of Alzheimer’s Disease & Related Disorders

Each person with ESADRD experiences a unique set of feelings and needs based on their emotional make-up. Any individual who experiencing the early symptoms of ADRD has the potential of becoming a trail-blazing pioneer. Once a diagnosis is received, the person with ADRD can move in one of two directions. One person with ADRD may stop in place without awareness of or acknowledgment of the changes that are occurring, feeling alone, shut out, afraid, and unaware. Other individuals are able to move toward the future, clear about the ramifications of ESADRD, unashamed, unafraid, and able to appreciate—even savor—life, love, family and friendship. In order for persons in the early stage of ADRD to move forward, we must provide them with an opportunity to share openly with their peers. Experts and specialists in the field of ADRD have made great efforts to help illuminate this journey by identifying the clues and early symptoms and exploring the possibilities for maximizing the journey.

6.1 Identifying Early Stage Alzheimer’s Disease & Related Dementias

There seems to be significant confusion regarding what we mean when we use the term ESADRD. Confusion persists because the distinctions between stages of ADRD are challenging to differentiate. Every human who walks the earth is unique; a diagnosis of ADRD does not change this. From personality to life history and medical history, we remain unique and distinct in our differences. Thus, the ways in which any person experiences and expresses ADRD is unique to that individual. Of course, the same principle applies to each care partner and how he/she responds to the stresses of performing the task of providing care.
6.1.1 Symptoms of Early Stage Alzheimer’s Disease & Related Dementias

Early symptoms of ADRD can be subtle enough to go unnoticed in social settings or superficial exchanges. Persons with ADRD are able to refine and adapt their intellectual and social skills to mask lapses in memory, difficulty with word finding, or even orientation. Through advances in medical and social science, symptoms common to the early stages of ADRD are now well documented. However, not all symptoms will be seen in all people.

The symptoms listed in Figure 6.1 represent the first observable changes that may be found in a person with early stage Alzheimer’s disease.

**Figure 6.1**
*Symptoms in the Early Stages of Alzheimer’s Disease*

<table>
<thead>
<tr>
<th>Always Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impairment of recent memory</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>One or more sometimes present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty with reasoning</td>
</tr>
<tr>
<td>Disorientation</td>
</tr>
<tr>
<td>Difficulty with language</td>
</tr>
<tr>
<td>Poor concentration</td>
</tr>
<tr>
<td>Difficulty with spatial relations</td>
</tr>
<tr>
<td>Poor judgment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-cognitive or behavioral changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality changes</td>
</tr>
<tr>
<td>Delusional thinking</td>
</tr>
<tr>
<td>Changes in sexuality</td>
</tr>
<tr>
<td>Diminished coordination</td>
</tr>
<tr>
<td>Diminished or lost sense of smell</td>
</tr>
</tbody>
</table>

[Daniel Kuhn, 2003]
The information in Figure 6.1 helps to illustrate the symptoms that separate someone with ESADRD from someone who has progressed to moderate to severe stages. Pinpointing the precise onset of the disease is far more difficult. As Kuhn suggests, the brain has been undergoing changes for many years before observable symptoms of even the earliest stage of dementia appears.

6.1.2 Why Diagnosis is Important in ESADRD

The brain experiences and manifests ADRD in many ways. As we learned in Figure 6.1, memory loss is the most universal early symptom. However, it is extremely important to determine its cause and nature as soon as possible for the reasons listed in Figure 6.2.

Figure 6.2

Reasons for Obtaining an Early Diagnosis

- To rule out reversible forms of dementia
- To rule out a context and explanation for symptoms
- To obtain appropriate medical treatment
- To let you decide whether or not to enroll in research studies
- To help you understand your changing roles and responsibilities
- To ease communication among all concerned
- To plan for the future

[Daniel Kuhn 2000]

Understanding the symptoms and recognizing them as a possible indication of ESADRD is an important factor in guiding families toward dementia screening, examination, and treatment. An early diagnosis of ADRD takes the heat off the
person with ADRD to cover or hide symptoms and allows family members to come to terms with the diagnosis at their own pace. A diagnosis opens up access to treatment and support options that can ease the journey for everyone. The time spent in the early stages of ADRD can provide opportunities to communicate feelings, fears and frustrations. Finally, the emotional well-being of the individual with ESADRD and the family is protected from the need to make decisions in crisis. Involving the person with ADRD in planning for the future is not only possible but should be encouraged.

6.1.3 Using Early Stage Time Productively

Early diagnosis affords individuals with ADRD and their families many opportunities to prepare for, and focus on, issues of the heart and human experience, such as soul searching, introspection, spiritual communication, and expression of deeply felt emotions. People with ADRD are often interested in becoming involved in care decisions. Some take advantage of the opportunity to re-evaluate their lives and to do the things they have put off. For example:

- expedite plans for travel
- participate in a special event or activity
- seize the chance to express creativity through art or photography
- write books, poems, or journals
- organize reunions and spend more time with family and friends

Whatever an individual or family decides to do is up to them. The important point to emphasize is that they have the time and support to do it.

6.2 Depression in Early Stage Alzheimer’s Disease & Related Dementias
The Memory Club® facilitator will quickly realize that it is common for people with ESADRD to feel sad. Depression and behavioral symptoms can be the first signs of an emerging ADRD diagnosis and may even precede dementia symptoms. Knowledge about depression will help the facilitator determine the best direction for intervention during the Club.

The awareness that something is wrong can understandably lead to feelings of loss and sadness. It is important to talk about these feelings so that people feel less alone. The other side of awareness is that it can enhance the capacity for insight, coping, and problem solving necessary to decrease depression. Additional facts about depression that may prove useful during the Memory Club® include:

- Depression is treatable.
- Feelings of sadness, frustration, and anxiety can often magnify cognitive problems. This is another reason why it is important to recognize these feelings, and deal with them.
- Although depression is different from apathy, both can result in difficulty initiating and maintaining meaningful activities.
- Depression is common in care partners.

We realize that ADRD affects both the individual and the family, and can have devastating personal implications for both. Depression may occur because of feelings of helplessness and guilt about how to deal with disease-related changes in the self, in life, and in interpersonal relationships. Participation in the Memory Club® can be empowering and might also reduce depression through providing education, support, meaning, and decreasing isolation. Finally, the facilitator can help the individual and the family work to maintain a sense of self.
outside of the ADRD diagnosis which will serve to help both of them weather some of the devastating emotional effects of this disease.
CHAPTER 7
Session Guidelines: Step-by-Step Approaches

In this Chapter, we have provided a step-by-step guide for an eight-week Memory Club® series. We have found that an eight-week model tends to be the most successful for the group to establish bonds, while allowing enough time to cover the vast subject matter and themes, which were referred to in Chapter 4, “Thematic Guidelines.”

Session 1: Welcome to the Club!

In Session 1, you will want to cultivate a relaxed and easy-going atmosphere. Nevertheless, it should have structure—a structure provided by you, the facilitator(s). The goal is to set the stage for the Clubs’ experience by introducing yourselves, explaining the group guidelines, highlighting the day’s schedule, and reviewing the contents of their participant binder/folders. The participant binder/folder include the day’s agenda as well as supplementary literature that compliments the day’s session. (At the end of this chapter, please find examples of suggested participant binder/folder materials.)

Session 1 Agenda – A Suggested Format

Initially, the two groups meet together as a Large Group. Then, for approximately one hour, the Small Groups meet separately with their peers and a facilitator. Use the contents of the participant binders/folders drawing the group’s attention to the agenda for Session 1, “Welcome to the Club.” Your session agenda might look something like the following:
• 10:00 – 10:30  Welcome, discussion of group structure and guidelines, and review of logistics
• 10:30 – 11:15  Large Group introductions
• 11:15 – 11:25  Break, followed by members separating into respective groups
• 11:25 – Noon  Small Group discussion

Discussion ideas for Session 1 include the following:

- Introduction to the group
- Q & A about the Club
- Introductions of each member
- Small Group introductions and sharing

**Introductions and Group Sharing**

We have found that brief introductions, review of group structure and confidentiality and Small Group sharing are enough disclosure for the first session. During introductions try to limit each member’s comments from about two to five minutes, give prompts only if necessary, and never press too much so early in the Club. Remember, it takes some members longer than others to recognize the Club is a safe place for sharing.

**The Video – Letting the Members Do the Talking**

Utilizing an early stage video gives Club members a good “jumping-off” place from which to begin sharing their own experiences or key stories. (Key stories are discussed in Chapter 5, Section 5.5) Key stories are the defining moments or events in the mind of a PWCI or care partner, which stand out as their time of
revelation, realization, or acceptance: that they or someone they care about is indeed experiencing a problem with his/her memory. These stories live in their minds for a long time, like a key to a door or a marker in time – their moment of truth. The early stage videos and/or video clips we recommend showing are:

- “Alzheimer's Disease: Inside Looking Out”
- “The HBO Alzheimer’s Project – The Memory Loss Tapes

The individual stories within these videos and YouTube video clips are varied enough to give each member something to which they can relate. The follow-up discussion after the video provides an opportunity for members of the Large Group to share their reactions. We have found that this discussion can be fairly intense. Many “ah-ha!” moments are shared. Be sure and make a note of these reactions and revelations and set them aside for subsequent Group discussions.

**Small Groups**

When breaking into Small Groups in the first session, begin with another round of member introductions. Follow the introductions by asking the members to share their key stories. Use sensitive, probing questions to encourage participation of each member. If you notice that one or two members are particularly reticent, do not push them to participate. Deeply personal revelations by every member should not be expected, especially on this first day, in a new environment. You might open the Small Group session by saying, “Mary, tell us something about your ADRD diagnosis.” Another technique that works well is to encourage one member to explain his/her story to the member who just spoke, pointing out a similarity in themes.
Remember, your goal as a facilitator is to get the members talking to each other, not just to you. When a member is sharing, try to maintain eye contact with all group members while keeping your main focus on the speaker. By glancing at other members from time to time, you send a message of connection to both the speaker and the group. As a facilitator, you can model group cohesion by encouraging group sharing. You can encourage and cue group members to talk to each other through your body language. During this first meeting, you are setting the stage for a sharing experience; the last thing you want is for them to talk only to you.

**Taking Notes in Small Group**

During this Small Group meetings, take notes on the details being shared. Look for opportunities to link these stories or observations together into binding statements that unite your members and give the group a feeling of integration and commonality. Notice the themes that are being raised during member’s contributions and call them to the group’s attention. In this role, you are reinforcing what they have to say is interesting and important.

**Parting Words**

Before a Memory Club® session draws to an end, discuss the topic for the next session. This is particularly important when a guest speaker is on the agenda since we encourage our members to invite anyone in their close circle of friends and family to come and hear the speaker. In anticipation of any speaker, it’s helpful to generate a list of questions Club members would like addressed by the speaker and forward those question to the speaker. We have found that we greatly add to our members’ peace of mind by making sure that accurate
information about dementia is readily available to them. The next meeting, Session 2, features a speaker who will address the medical aspects of ADRD, hopefully dispelling myths and some degree of confusion. We encourage members to arrive early on “speaker days” to have an opportunity to talk among themselves and discuss old or new business. Finally, thank them for sharing experiences, and ask if they have any final comments before they go.

Session 2: What You Need to Know about Alzheimer’s Disease & Related Disorders in the Early Stage, Medical Information

The goal for this session is to clear up myths and misconceptions about ADRD, giving participants the opportunity to have an expert answer their questions about the diagnostic process, living with ADRD, treatment options and research. For this session, we invite a speaker – usually a clinical specialist – who can provide a medical overview of the physical manifestations of ADRD as well as address questions from the group.

Session 2 Agenda – A Suggested Format

Since today’s program features a guest speaker, you will want to arrange the room to accommodate a larger audience since members’ guests are invited. In the contents of their participant binders/folders draw the members’ attention to the agenda for Session #2, “What You Need to Know About Alzheimer’s Disease and Related Disorders in the Early Stage, Medical Information,” as well as to the materials that enhance the session. Remind guests that the Memory Club Small Group meetings will take place immediately following the speaker’s departure, and, therefore, any guests will need to depart due to the confidentiality of the group process.
This session features a guest speaker. The following is a suggested session agenda:

- 9:30 – 10:00  Families begin arriving
- 10:00 – 10:10  Brief check-in, announcements, review current agenda, and introductions, if necessary
- 10:10 – 11:15  Guest speaker name and title
- 11:15 – 11:25  Break (at which time guests take their leave)
- 11:25 – Noon  Small Group discussion

The themes you will be covering in Session 2 include the following:

- Understanding the Disease Process
- Common Emotional and Psychological Reactions to the Diagnosis
- Coping Strategies and Harbors of Strength

**Getting Real**

We have found this session to be extremely reassuring and informative for our members. They have spent countless hours jumping through hoops in doctors’ offices and testing facilities to ascertain whether or not they have a diagnosis.

**Session Goal**

The goal for this session is to provide factual information about ADRD in an effort to help families begin a dialogue about symptoms and their impact in the context of individual and family life. Session 2 ensures that all members have the same information so that they can move beyond the clinical questions of ADRD.
to the challenges the disease presents to living life. Ultimately, the Club plays an instrumental role in helping individuals with ADRD and their care partners reconstruct their sense of self, their future, and their expectations. Your job as a facilitator is to help them advocate for their own needs and reach out to others dealing with similar challenges. The group may last only eight weeks, but we have seen how it can provide opportunities to build lifetime friendships. We have watched our members continue to stay in touch beyond the Memory and Graduation Clubs. Additionally, knowing the facts actually helps them grow closer, and allows them to move forward in their own growth and in their new relationships.

**Speaker Do’s and Don’ts**

In securing your speaker for this session, it is important to let him/her know who the audience is as well as their key stories and questions. Speakers appreciate a letter that includes a list of questions and general information about the Club’s membership and the meeting schedule. Refer to the sample letter in Chapter 2, Section 2.2.3.

With Memory Club families and friends as the audience, the most effective presentation is informal and audience-guided. Encourage speakers to avoid academic presentations with lots of overheads, power-point slides and lengthy handouts. This audience needs:

- a listening ear
- thoughtful answers to their questions
- expertise in ADRD
• a medical professional who has experience working in the field of dementia and can pick up on implied (but perhaps not expressed) concerns

Our guest speakers have often expressed feelings of frustration over how little time they have in their clinics to meet with patients. It is often a welcome opportunity for everyone to have the luxury of an hour to discuss the facts of ADRD and to ask the questions that arise after a diagnosis is received.

**Facilitator Do’s and Don’ts**

As facilitators, we take a step back – in fact, quite literally we make sure we sit in the back of the room. Occasionally, we ask questions we feel are important. At times, we raise a concern mentioned by a family who is not comfortable speaking in front of the group. This session is our chance to listen, watch and learn.

Even though the discussion is casual and only about an hour long, a lot of information is covered in a short amount of time. It is important for the facilitator to resume the role as time monitor. Additionally, the facilitator needs to be ready to manage families that may try monopolizing the session by asking lots of questions specific to themselves and their issues. The facilitator may need to intercede to stop the monopolizing, while assuring that their questions will be addressed later or individually. The facilitators should also be taking notes about questions asked and concerns raised. We have found these notes or “memory joggers” are helpful to our members with diagnoses during the later discussion in their Small Groups. Members have expressed appreciation at being able to revisit topics covered during the speaker-led discussion since their main concern
is often making sure they remember all the information. Giving members the opportunity to process with each other helps them to bond and share what they know—often for the first time in the group. Although they are there for themselves and their families, they also benefit by helping others—which is the point of a support group and shared experiences.

**Session 3: Do I Have to Talk About My Feelings?**

In Session 2, we covered material that is fairly powerful, providing the facts about the nature of ADRD, covering concerns and answering questions that speak directly to the realities of life with ADRD. Session 3 is designed specifically to encourage the ongoing expression and exploration of feelings for those who are able, while paying particular attention to those who are still reluctant to express their feelings. In this session, we examine emotional reactions, feelings, and the implications of this disease for each member—PWC and care partner alike.

**Session 3 Agenda - A Suggested Format**

The following is a suggested session agenda:

- 9:30 – 10:00  Families arrive
- 10:00 – 10:10  Brief check-in, announcements, go over day’s agenda
- 10:10 – 11:00  Large Group discussion and support
- 11:00 – 11:15  Break
- 11:15 – Noon  Small Group discussion

The themes you will be covering in Session 3 include the following:
**Session Goal**

The goal for Session 3 is to provide a safe and supportive environment in which members can examine and discuss their feelings as they relate to their diagnosis and the impact of ADRD on their sense of self, their family, and their friendships. At this time, it is imperative that we validate the challenges ADRD has created for them: daily, as they live within their family environment; socially, as they strive to maintain important relationships outside the family; and physically and spiritually, as they look to the importance of their overall sense of well-being.

**Session Notes**

We think of Session 3 as an invitation we extend to each member. We begin by setting guidelines that suggest how members might begin to think about their feelings, searching for ways to make them more open to their feelings. It is the facilitator’s task to reframe expressed thoughts, questions, and comments in a way that will eventually allow each member to connect to a feeling. For some members this will be easy, while others will need help, support, and perhaps even cues to connect their feelings to something concrete.

It is likely that most members’ lives have become so focused on tasks (i.e., keeping track of and going to medical appointments, doing chores, etc.), that they may have had little time or desire to process the impact of the ADRD...
diagnosis. Very seldom do they take the time to acknowledge what they are feeling. Additionally, shock and denial may be blocking their feelings.

Being in a group, especially a group of peers, assists with the process of opening up to one’s emotions. Within the safe environment of the Memory Club, those who struggle with expression of their feelings have immediate reassurance and validation from the other members. Here, within this group, they experience empathy, trust and safety in the faces seated around the table with them. This session is for them. If you and others in the group are able to draw them out, you will greatly increase the value of the entire program for everyone. This session is pivotal in many ways. The majority of our members cite this as one of the most helpful and meaningful sessions. More importantly, this session helps them to understand and appreciate the experiences and feelings of their partner, be it a spouse, parent or significant other.

**Session 4: Getting the Facts Straight - Legal and Financial Issues**

Members have now attended three Memory Club® sessions. Each dyad should now be better equipped to absorb and evaluate information on long-term-care issues. For this session, we invite an elder law attorney to address the very important topic of long-term care planning. Due to time constraints, this is not meant to be an exhaustive tutorial but rather a general overview.

**Session 4 Agenda - A Suggested Format**

This session features a guest speaker. Here is a suggested agenda:

- 9:30 – 10:00  Families begin arriving
The themes you will be covering in Session 4 include the following:

- Practical Planning for the Future: Health Care, Legal Issues and Financial Planning
- Medicare/Medi-Cal - Clearing up Misconceptions

**Session Goals**

In Session 4, we provide our members with information on the importance of planning for the future to assist them in making informed decisions. We also discuss and explore members’ concerns and feelings related to anticipating the future. We have had enormous success with local elder law attorneys who have provided invaluable, timesaving, and money-saving information to our members.

**Session 5: “I Get By with a Little Help from My Friends…”**

ADRD interrupts and complicates the balance of giving and receiving that lends stability to our lives. People diagnosed with ADRD begin to realize that they are obliged to receive more help with ordinary life tasks – more take and less give – often feeling less comfortable with the
imbalance. The care partners, on the other hand, are required to lend assistance in new and possibly unfamiliar ways. Care partners often find it necessary to perform tasks and take responsibility for household jobs that used to be their partner’s responsibility.

Selecting a Speaker

Find a professional in the field of gerontology and/or dementia, such as a clinical social worker, MFT, or psychologist, experienced in working with PWCI and families who can discuss the changes experienced in the relationship as well as community resources that provide respite for the care partner and appropriate stimulation for PWCI.

Session 5 Agenda - A Suggested Format

This session features a guest speaker. Here is a suggested agenda:

- 9:30 – 10:00 Families begin arriving
- 10:00 – 10:10 Brief check-in, announcements, go over day’s agenda
- 10:10 – 11:15 Guest speaker name and title
- 11:15 – 11:30 Break (at which time guests take their leave)
- 11:30 – Noon Small Group discussion

The themes you will be covering in Session 5 include the following:

- Facilitating Effective Communication
- Trusting each other
- Role Transformation and Task Sharing
- Honoring Independence vs. Taking Over
Session Notes

Nobody gets through this life without help. There is the help we take for granted such as receiving directions to the location of the restroom in a strange building. Most likely, we would feel comfortable giving or receiving such help. Then there are other kinds of assistance that, if needed, would perhaps make us feel uncomfortable, embarrassed, needy or even ashamed. Think how you would feel if you suddenly discovered you needed help writing a check or using the self-serve pump at the gas station because you suddenly realized you had forgotten how to do these things.

Reluctance to give and get help can be cultural; in some cases, it is just a natural part of being independent, an adult accustomed to doing things a certain way. From the perspective of the person with ADRD, needing additional help can be quite distressing. Many of our members have shared feelings of guilt, shame and frustration, believing they are no longer “pulling their share of the load,” or contributing to the family as much as they should. They feel helpless, useless, a burden, etc.

Conversely, the care partners tend to communicate feelings of frustration and a sense of being overwhelmed. They are caught in a cycle of deciding which responsibilities they need to assume, when, as well as how. They are constantly monitoring their partner’s capabilities. They must decide when help is needed, then offer it tactfully. They often feel guilty, frustrated, and sad to have been placed in such an uncomfortable position. As many of our members have shared, nobody wants to be the “bad guy.” As mentioned in the Chapter 4, Theme 6, “Honoring Independence vs. Taking Over,” respecting independence
while anticipating role changes and responsibilities is a daunting challenge and one that needs to be discussed and normalized for dyads.

Session Goals

In Session 5, we provide our members with information that will hopefully help them accept the changes in their lives. We focus on role changes, loss of independence and the importance of working together as a team sharing daily responsibilities. We also stress the importance of not being embarrassed to ask for help.

Session 6: Taking Care of Yourself & Each Other

Chapter 4, Theme I, “Coping Strategies and Harbors of Strengths,” emphasizes that all people have the capacity to draw from within themselves, or from the world around them, to cultivate strength and cope with the many challenges life throws their way. Often, in times of stress, having a diagnosis like ADRD causes the PWCI to fixate on lost skills, privileges, abilities and relationships. That is when it is important to work with them, helping them maintain and foster the things they can do and enjoy doing. Both the person with ADRD and care partners will need to harness their strengths to prepare for difficult challenges. Emphasize that their lives may be changing but there is much they can still do. In addition, stress that individuals with ESADRD and their care partners can continue to lead happy, meaningful lives, but it takes forethought, planning and flexibility. The challenges are significant and finding balance, while not easy, is achievable. It is balance that provides resilience, peace of mind and a sense of togetherness.

Session 6 Agenda - A Suggested Format
The following is a suggested session agenda:

- 9:30 – 10:00  Families begin arriving
- 10:00 – 10:10  Brief check-in, announcements, go over day’s agenda
- 10:10 – 11:00  Large Group discussion
- 11:00 – 11:10  Break
- 11:10 – Noon  Small Group discussion

The themes you will be covering in Session 6 include the following:

- Facilitating Effective Communication
- Family Dynamics
- Role Transformation and Task Sharing
- Honoring Independence vs. Taking Over
- Coping Strategies and Harbors of Strength
- Quality of Life Issues
- Taking care of yourself—physically, emotionally, mentally, and spiritually

**Session Goals**

Explore ways in which members find comfort, peace and strength. Discuss various coping strategies and the impact of mood and attitude on overall wellness. Discuss the benefits of taking care of yourself (physically, emotionally, mentally, and spiritually) and what it means in relation to each member’s values and goals. Additionally, you will want to build in time in this session to discuss
and begin preparing members for graduation from the Club. Introduce the Graduation Club and plan for on-going contact and support.

**Session 7: Where Do We Go from Here? Applying New Knowledge and Information to Your Life - Clinical Trials and Research**

Session 7 has two components. In the first hour, a researcher will be facilitating a presentation on the latest ADRD research. The second hour is focused on safety awareness. We discuss the issues of driving and wandering, as well as the importance of disaster planning.

**Session 7 Agenda - A Suggested Format**

Here is a suggested meeting agenda for Session 7:

- 9:30 – 10:00 Families begin arriving
- 10:00 – 10:10 Brief check-in, announcements, go over day’s agenda
- 10:10 – 11:00 Guest speaker name and title
- 11:00 – 11:10 Break
- 11:10 – Noon Small Group discussion

The themes you will be covering in Session 7 include the following:

- What are Clinical Trials?
- What is the Value of Participating in clinical trials?
- Current clinical trials?
- Safety
Session Goals

In Session 7, members will learn about current research and clinical trials. The Small Group conversations will focus on safety issues such as continuing to drive, wandering and other ways they can provide themselves with a safe environment both in their homes as well as when they are out in the community.

Session 8: New Outlooks, Graduation Celebration

Congratulations! It always seems hard to believe that you have reached the eighth session. By this time, your members will know each other well and are, hopefully, reaching out to one another beyond the time spent in the Club. At this juncture, you will now have met one-on-one with each dyad, so issues and concerns about the future will have been addressed. In most cases, there will be couples that do not continue on into the Graduation Club (see Chapter 8, section 8.1.2). This may be something you want to address in your Large Group discussion so that everyone within the group is prepared for these changes.

Session 8 Agenda – A Suggested Format

Here is a suggested meeting agenda for Session 8:

- 9:30 – 10:00 Families begin arriving
- 10:00 – 10:10 Brief check-in, announcements, go over day’s agenda
- 10:10 – 11:00 Large Group discussion and celebration, evaluations
- 11:00 – 11:10 Break
- 11:10 – Noon Small Group discussions
The themes you will be covering in Session 8 include the following:

- Reviewing the Memory Club® experience, its accomplishments, growth, and challenges
- Discuss feelings about graduation
- Understanding the changing nature of the disease, and the need for on-going or intermittent guidance

**Session Goals**

The goals for this session are to recognize the completion of the program, the members’ contributions, personal growth, challenges, as well as their willingness to participate and share. We are evaluating member satisfaction with the group process and overall impact on the individual as well as the dyad. In this session, we review information covered in previous sessions and discuss implications for the future, the changing nature of the disease, and the need for on-going support or intermittent guidance.

At the end of each of our Memory Club® Series, we organize a luncheon at a nearby restaurant or plan a potluck lunch. This is, of course, optional, but we have never had a member not attend. Rituals and celebrations are important. Having a meal together and time to socialize is a wonderful way to conclude the Club. You can also use this time to hand out certificates of completion, take pictures, make a final toast or just talk.

**Sample 8-Week Memory Club® Session List**
• Session One: Welcome to the Club!

• Session Two: What You Need to Know about Alzheimer’s Disease and Related Disorders in the Early Stage, Medical Information
  Guest Speaker: Neurologist, Geriatrician, or Geriatric Psychiatrist

• Session Three: Do I Have to Talk About My Feelings?

• Session Four: Getting the Facts Straight – Legal and Financial Issues
  Guest Speaker: Elder Law Attorney

• Session Five: I Get By with a Little Help from My Friends...
  Guest Speaker: Clinical Social Worker or Psychologist or representative of community agencies

• Session Six: Taking Care of Yourself and Each Other

• Session Seven: Where Do We Go from Here? Applying New Knowledge and Information to Your Life
  Guest Speaker: ADRD Researcher

• Session Eight: New Outlooks, Graduation Celebration

**Suggested Participant Binder/Folder Materials**

It is recommended that each dyad be provided a participant binder/folder. The binder/folder contains the series schedule, session agendas, supplementary materials that complement and enhance each session. In addition, hopefully,
the binders/folders will become a place for the members to store all brochures and other information acquired during the program.

Ordering materials:

- You can pick up, we can deliver or mail the materials generated in-house. In-house generated materials include, The Alzheimer's LA Resource Directory for LA County 2018-19, topic sheets: “What are the first signs of Alzheimer’s Disease?” “Alzheimer’s Disease and other Dementias”, “Alzheimer’s Disease Medications” “Legal and Financial Planning”, “Meeting with an Elder Law Attorney”, “Early Stage of Dementia”

- You will need to contact the companies that generate the MedicAlert brochures as well as the driving booklets, “At the Crossroads” and “We Need to Talk.”

Please find attached binder/folder materials for each session.

- Caregiver Bill of Rights
- PWD Bill of Rights
- Memory Club® Agreement and Appreciation
CHAPTER 8
Transitions

Making transitions — moving from one stage of care to another because of changes in cognitive abilities — are difficult but necessary steps in the course of ADRD. The point at which transitions are needed varies, depending on the kind of program you develop. For our Club, there are two times when transitions must be considered: before the end of the Memory Club® series, and at some point during the course of the Graduation Club (See Section 8.3 for comprehensive discussion of the Graduation Club).

8.1 Transitioning Club Members to Other Programs

Planning for and making transitions is perhaps the most difficult part of group facilitation. Aside from having to watch group members decline in cognitive ability, the reality is that from the moment a person with ESADRD enters the program, he/she will eventually begin to decline. If that person with ADRD is in your program(s), he/she will need your help in transitioning to a more appropriate type of care and support environment. It will be your job as facilitator to make transitions as smooth as possible. The topic of transitioning continues to be a delicate and complex issue in the training we offer to support group leaders.

8.1.1 Preparing the Families

The keys to successful transitions are on-going communication, constant feedback and regular family consultations. It is paramount that families understand that the Memory Club® has an eligibility requirement and is time-
limited. Keep Memory Club® participants informed early on and throughout the
group process about other community resources. By preparing them for
eventual (or immediate) departure, you keep anxiety at a minimum and give
families time to adjust to the idea of transitioning, so they can make appropriate
plans. The reins for transition should be in their hands, as much as possible, to
facilitate a sense of control during a period of constant change. Regular
consultations help each family illuminate critical needs, and process concerns.
Family consultations also help the primary care partner with her/his objectivity by
providing an opportunity to discuss, in a non-threatening context, examples of
their loved one’s behavioral changes, increasing needs, declines in functioning
and other points of concern that inevitably present themselves during a group
session. Without this foundation—a solid relationship built between participant
and facilitator—families can be left feeling unprepared and unsupported.

8.1.2 Facilitating Supportive Transitions

The progress of ADRD is painful to observe and extremely disheartening for
everyone involved. We can avoid adding insult to injury by assisting each
family’s adjustment to these inevitable changes. Much can be accomplished
within the group, but spending time with each family, in private consultations,
can make an even greater difference to them. Make sure, when the need
arises, to discuss a transition so that the person with ADRD and his/her care
partner do not feel “demoted.” Emphasize to them this is the best match of
needs. Begin early on educating members about other kinds of support services
that are available. Help families develop their own individualized care plan.
Focus on needs—individual and family—and on which community resources will
best fit their needs. Help each person with ADRD and his/her care partner to
conceptualize all of their options and to maintain realistic expectations.
8.1.2 Transitioning from the Memory Club

As you approach the end of the Memory Club® series, you will need to begin thinking about, and preparing for, the immediate future of these members who are now facing an important transition. We tend to treat the last session as a graduation, which implies, as it does with all graduations, change; a successful completion of tasks, new possibilities, and, of course, some degree of sadness associated with change. You will note in Chapter 7, “Session Guidelines,” the last session of the Club is structured to be a graduation ceremony with a celebratory focus as well as recognition of contributions and personal growth. Before the final session of the series, you will need to schedule Exit Interviews. Exit Interviews are meetings with each dyad to individually evaluate and discuss the positives and negatives of their group experience, and offer guidance in identifying appropriate community resources. This may include continuing on with the Graduation Club if appropriate.

8.2 Family Consultations and Exit Interviews

Family consultations are approximately ½ to 1½ hours in length. Be sure to schedule consultations so that each family gets as much time as they need. You will need to decide which facilitators should attend. By this time, the dyads should know their primary facilitators well. They may only feel comfortable with the two primary facilitators in the room.

8.2.1 Preparing for the Consultation

Before a consultation, it is vital that all involved staff has had the opportunity to provide input on participants and a consensus has been reached regarding
recommendations for each dyad’s graduation plan. During the exit interview, families need to know on whom they can rely in the future for support, guidance and resources. Additionally, be very clear about which services you can offer and which services you do not provide. Be prepared to make referrals to other agencies/professionals when appropriate and available.

8.2.2 Maximizing the Consultation’s Usefulness

When meeting with individual families prior to “graduation day,” there is much you can learn that will allow you to provide the most appropriate support and follow-up care options. By talking privately to the persons with ADRD and their care partners, probing for the roots of their questions and concerns and opinions, you are in the best possible position to assess their needs and make recommendations that are realistic and feasible for them:

- Provide private time for graduating members to ask questions, express their concerns, and discuss feelings about the Club experience, graduation and the future.
- Focus on making these assessments:
  - How is each member of the dyad doing emotionally?
  - Is each member of the dyad prepared for graduating from Memory Club?
  - Is the dyad appropriate to transition into the Graduation Club?
  - Should the dyad, based on the functioning of the person with ADRD, be directed to other services?
- Provide information about community resources and any additional support the dyad may need based on your assessment and their expressed concerns.
• After consulting with other facilitators, make a decision about whether or not the dyad is appropriate to participate in the Graduation Club.
• Assist all graduating families in developing a care plan, both for individuals with ADRD and care partners.

8.3 **Graduation Club**

One of the more gratifying rewards for our efforts with the Memory Club® has been the demand for an offshoot program that would continue the early stage group model well beyond its original eight-week series. From each of our Memory Club® groups, a handful of graduates—those still appropriate to participate in support group dynamics along with their care partners—have indicated a desire to continue taking part in a support group program. We call the continuing group the Graduation Club. Following the completion of each Memory Club® series, appropriate dyads transition to the Graduation Club. Graduation Club ADRD members meet approximately twice each month with their care partners to continue connecting with peers. The Graduation Club remains an integral part of their lives for as long as they are able to share appropriately and benefit from the group process.

8.3.1 **Filling the Gap**

The Graduation Club was conceived to support individuals who are not yet appropriate for other kinds of support services offered in the community such as generalized ADRD caregiver support groups or adult day care programs because of their early diagnosis and mild symptoms. We recognize a gap in which ADRD services are not providing early stage families with support that matches their needs. One client shared this thought: “I have to wait until I get worse to attend an activity program. There’s no one there for me to relate to,
and it’s scary to think about the time I am wasting doing nothing, sitting by and talking to myself.”

There are many options to consider if you want to design a group for participants who have completed the Memory Club® series. Your decision(s) should focus on the unmet needs of this population in your community in conjunction with the resources available to you.

### 8.3.2 Screening Criteria for the Graduation Club

In our community, the best solution for Memory Club® graduates who are not ready to go to a more structured activity program seemed to be a Graduation Club made up of Memory Club® graduates. We decided early on to make the Club available only to those who were still appropriate for an early stage support group setting. The Graduation Club uses the same membership criteria used in the Memory Club® screening process. The difference is the facilitator has had the opportunity during the Memory Club® series to observe and evaluate the members’ cognitive function and will have some idea of the type of transition each member should make. Ask yourself the following questions before you decide who is appropriate for the Graduation Club:

- How did they function in the Memory Club®?
- What did they contribute?
- How self-aware are they in comparison to when they started the Memory Club®?
- Have there been any changes in cognition or functioning that may hinder their participation in the Graduation Club?
- How in touch are they with their emotions?
- Do they have insight into how their diagnosis impacts their life?
• Are they free from behavioral symptoms that would disrupt the group process?
• Are there issues or concerns in their life that they want to work on?
• How well do they relate to others?

Club membership in this program tends, of necessity, to remain in a state of flux as mental, verbal, and social acuity declines. Group membership consists of graduates from the most recent Memory Club® series, and a core of previous Memory Club® graduates, who are still appropriate for the support group setting. At any given time, one or more members will need to transition out of the group. It will become apparent to you that self-examination, awareness of the needs of others, and articulation and comprehension skills have begun to recede. (See Section 8.1 for information on handling transitions.)

8.3.3 The Need for Continuing Early Stage Programming

A typical Graduation Club has 10 to 16 early stage members, and care partners, in each group on a given day. There are definite benefits to keeping admission criteria at early stage level. However, given the resources of your agency, the demand in your community, the constraints, and the presence or absence of other support programs, you may choose to have less exclusive criteria. We are confident that you will find a continuation model appropriate to your group's needs.

We feel fortunate to have excellent mid-to-moderate activity and enrichment programs in our community to which we can refer our graduates. Invariably, however, we found that many of our new graduating members were still in need of a place to:
• talk about their feelings
• address their issues and face concerns head-on
• work on solutions to problems as they arise
• spend quality time with a peer group

It is not difficult to identify which Memory Club® graduates are still able to participate in a support group – particularly one that is structured enough to provide them with many of the same benefits they derived from the Memory Club. For some graduates, the Memory Club® series just whetted their appetites for more peer support, education, and continuing opportunities to examine their changing roles. Most of our Graduation Club members are not attending an activity program, feeling it is not yet right for them. On the other hand, a few of our Graduation Club members do take advantage of both types of programs. As you can see, countless scenarios are possible.

8.4 How the Graduation Club Works

The Graduation Club is designed to be a peer support group—time-limited, with quarterly breaks. How long a dyad continues to return after each break is up to facilitators, and, of course, the family. Attendance is encouraged but not critical in this group or phase of their lives. We do use the same Memory Club membership criteria. Also, we ask ourselves the following questions:

• What are they getting from the Graduation Club?
• What are they contributing to the Graduation Club?
• Are they identifying things they want to work on in the group?
• How do they utilize group time?
• How well are they expressing themselves?
• How well are they relating to others in the program?
• Can they identify what they gain from the experience?
• Are they here for themselves, or are they attending only because of their care partner?
• Would this person/dyad be better served in another program?

8.4.1 Graduation Club Program Structure and Mission

The Graduation Club is not as structured and theme-organized as the Memory Club®. We prefer to let our Graduation members direct the choice of topics. They are also free to decide, as a group, if and when they would like a guest speaker for a particular topic. As facilitators we bring suggestions, ideas, materials, and resource information. We also provide guidance and support based on their questions, concerns, and challenges. The Graduation Club is not meant to be as intensive as the Memory Club®. Rather, it serves as an intermediate transition step for persons with ADRD who were diagnosed early in the course of the disease and remain in the early stages.

Throughout the Graduation Club experience, we encourage members to identify other supportive services, and we assist them in transitioning to other groups and services. At some point, all members will be leaving the group. The Graduation Club meets for about three months with two-week breaks, so we can introduce new members and graduate others. We hope our members can commit to and remain appropriate for Club membership during a three-month period. However, things do change, and you should be prepared for premature exits, initiated by members or by facilitators.

8.4.2 Does the Graduation Club Require Dyad Participation?
In almost all cases, we have required that both members of the dyad attend the Graduation Club. There are always exceptions, depending on the ancillary services available in your community. For example, we enrolled a care partner (adult child, female) in the Graduation Club without her mother for the following reasons:

- The mother, person with ADRD, was still in early stage, but did not want to be in a support group.
- No group was available to the care partner that would discuss early stage issues.
- The daughter wanted to continue, even though the majority of care partners were spouses.

Making decisions about Graduation transitions is a challenging task. Since every dyad is different, we encourage you to be flexible in your attempts to meet the needs of both the person with ADRD and the care partner.

**8.4.3 Transitioning from Grad Club**

Throughout the Graduation Club experience it is important that facilitators continue to assess the ability of ADRD members to function in group. It is important to determine if the person with ADRD can still express emotions regarding the diagnosis, is contributing appropriately, relates to the other group members, can identify what they are gaining from the group experience and finally, is free of behavioral symptoms that disrupt or negatively impact group process.

Some examples of reasons that would prompt a transition out of Graduation Club:
- Increased confusion in regards to cognitive stimulation activities
- Inappropriate outbursts such as interrupting, singing, swearing
- Increased difficulty organizing thoughts
- Difficulty remaining interested in group discussion for the duration of meetings (falling asleep or restlessness)
- Repetitive statements or movements that are distracting to other group members
- Unwillingness/inability to acknowledge symptoms, or a belief that symptoms are part of normal aging.
- Frequent absences from scheduled group meetings
- Combativeness
- Severe agitation
- Wandering
- Incontinence
- Major difficulty understanding and/or contributing to group discussion.
  - The individual has declined in communication skills, such as the inability to sustain conversation, inability to express themselves (word finding) and difficulty comprehending others.
  - The individual is unable to discuss feelings and experiences related to the illness.
  - The individual discusses topics not appropriate for group discussion or off topic creating a non-therapeutic environment.

Assessing the care partner is also important to determine if they are discussing mid or late stage issues as the Graduation Club is an early stage support group. The Graduation Club is an early, not mid stage or late stage group. Someone with disruptive behaviors/symptoms compromises the dynamic, process flow
and integrity of the early stage group. Additionally, the facilitator cannot be responsible for supervision and safety of members in the middle stages.

We have found that early stage ADRD persons prefer to be in groups with people that are presenting at the same or similar level. When a fellow ADRD member progresses, although the members tend to be supportive of each other, it is not conducive for the group dynamic and process. The job of a group facilitator is to protect the group dynamic. Additionally, when new members transition into Graduation Club from Memory Club® they may not feel comfortable with persons who are mid stage since new members are told they are being transitioned into an early stage support group.

Someone in the mid stages starts to require more care and supervision. Additionally, someone in the mid stages might respond better to more stimulating activities than a twice a month support group. Usually, you will find that a person in the mid stage is no longer contributing to the group, which is a critical part of being a group member.

It is important to continually discuss and reiterate transition policies in Graduation Group. A good time to do this is as you prepare Graduation Group for new members that you will be transitioning from Memory Club®. During this time you can remind Graduation Club that this group is a time limited and everyone will eventually transition out of this group.

### 8.5 Alumni Club

Alumni Club was developed as a response to care partners voicing a need for continued support once Graduation Club was no longer a good fit. Most care partners that participate in Graduation Club form very strong, solid bonds.
When it is time to transition out of Graduation Club, it can be very difficult for care partners to find a group that they feel comfortable and safe in. Alumni Club was developed to offer continued support, sharing and education for care partners that are no longer eligible for Graduation Club.

Group facilitators should work with care partners to find appropriate programing for the person with ADRD. There might be community options that offer activities programs that would be a better fit. Alzheimer’s Los Angeles offers some programs which might be appropriate options, including Memories in the Making and Memory Mornings.

### 8.5.1 Alumni Club Structure

Alumni Club is a group only for care partners, it is not themed or structured. Alumni Club welcomes appropriate members from Graduation Club who are in need of continued support. Group can meet twice a month but attendance is not mandatory. As facilitators we provide guidance and support as well as connection to community partners based on their questions, concerns and challenges.

Alumni Club members will discuss mid to end stage themes, questions and challenges. Many of the conversations might be related to placement concerns, hiring care in the home, the progression of the disease as well as grief and loss. For the most part, group members transition out of Alumni Club once they decide to place the person with ADRD or when the person with ADRD has died.
Conclusion

We trust you have gained the knowledge and understanding you have been seeking regarding the Alzheimer’s Los Angeles Memory Club®. Hopefully, you now have a stronger background about ADRD and its impact on recently diagnosed individuals, their care partners, the entire family system, and their network of support. As stated previously, our goal for writing this manual has been to prepare our readers for the important task of making early stage and young onset programming readily available to all who need it. We pass the torch to you and hope you will go on to create meaningful early stage programs that educate and encourage others to do the same. If you have not already discovered our secret, it is this: we guarantee you will find this work to be life changing, life affording, and deeply fulfilling for yourself, and for all those whose lives you touch.
Glossary
Definitions & Acronyms

Activities of Daily Living (ADL) - The things we normally do in daily living including any daily activity we perform for self-care, (i.e., feeding ourselves, bathing, dressing, grooming, etc.) work, homemaking, and leisure. The ability or inability to perform ADLs can be used as a very practical measure of ability or disability in many disorders.

Alzheimer's Disease (AD) and Related Disorders (ADRD) - A degenerative disease process, Alzheimer's produces a protein that begins gradually to attack brain cells, progressing at a variable rate. AD results in impaired memory, thought processing, and behavior. It can last from three to twenty years, dating from the earliest observable onset of symptoms.

Care Partner - DASNI, Dementia Advocacy and Support Network International, a dynamic non-profit organization founded by individuals with early stage ADRD, coined the term “care partner.” The term care partner describes any individual who is the primary support agent for someone with ADRD. In most cases, this is an immediate family member. However, to be inclusive of all others providing support and care, “care partner” will be used throughout our manual. Furthermore, many care partners and individuals with ADRD do not feel comfortable using the term caregiver; they are not comfortable with the relationship implied by the term. Rather, partnering and collaborating in their own care defines the desired relationship during the early stages. In many ways, all people playing a supportive role in the life of a person with ADRD are care partners including health professionals.
**Dyad** - The couple/pair participating in the Memory Club. Throughout the manual, we refer to the dyad, which consists of two people: the care partner and the PWCI.

**Early Stage (ES) Alzheimer’s Disease (ESAD)** - Anyone, regardless of age, experiencing the early symptoms of ADRD. Individuals with ESAD and related disorders experience impairment in recent memory, and may experience difficulty with reasoning, language, orientation, judgment, concentration, and spatial relations. Some individuals in the early stages may also experience behavioral changes such as changes in personality or sexuality.

**Person with Cognitive Impairment (PWCI)** - PWCI is another term used by DASNI. The individuals with whom we work seem to prefer it as well.

**Young On-Set Alzheimer’s Disease** - Anyone under the age of 65 with Alzheimer’s disease or a related dementia – at any stage of the illness.

**Mild Cognitive Impairment (MCI)** - National Institute on Aging defines MCI as a stage of marked symptoms of memory and/or thinking problems that are greater than normal for a person’s age and education, but that do not interfere with his or her independence. People with MCI may or may not progress to Alzheimer’s dementia. To determine MCI is not due to Alzheimer’s disease, a doctor must rule out other brain diseases or causes, such as medications, depression, or major life changes that could account for cognitive decline.
MEMORY CLUB®
Facilitator’s Notes
8 Week Series

SESSION 1  Welcome to the Club!

10:00 – 10:20 • Introduction to Memory Club®
   • Facilitator Introductions
   • Logistics & Announcements
      1. Resource Table
      2. Bathrooms
      3. Snack Sign-Up
      4. Participant Binders/Folders – Do not need to bring every week, materials in binders/folders are not always reviewed, but solidify and add to each session
      5. Guest Speakers
      6. Review, Aloud ‘Group Agreement and Appreciation’
      7. Limits of Confidentiality
      8. Create group rules/agreements

10:20 – 10:55 – Member Introductions
   • Name
   • Type of dementia/When diagnosed
   • Something you would like the group to know about you – hobby, special talent, career
   • What do you hope to get out of the group experience? Expectations?

10:55 – 11:05 • Create list of questions for physician, week 2 speaker
11:05 – 11:15 • Break

11:15 – 12:00 • Small Groups

**Discussion Ideas - Small Groups**

- What does the word dementia mean to you?
- What dementia diseases are you familiar with?
- Key story about when you or your care partner (CP) first noticed changes? What initial symptoms were experienced?
- How did you know that something else was going on beyond normal aging?
- How did you react/feel when you received the diagnosis?
- What symptoms are you experiencing now?
- How has the diagnosis affected your life? Hardest aspects? Limitations?
- Concerns relating to dementia and your future?
- Topics you would like addressed?

**Conclusion**

- Our next session, features a speaker, Dr. _____, who will discuss the medical aspects of dementia, hopefully dispelling a few myths and some degree of confusion. Again, there will be a 15-20 min. Q&A.
- What do you want the doctor to address? Questions?

**Materials**

- Participant Binders/Folders
- Pens
- Blank informed consent forms
- Snack sign up list
- Name tags for everyone
SESSION 2  What You Need to Know about Alzheimer's Disease & Related Disorders in the Early Stage, Medical Information

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

- Welcome: “We want to welcome everyone back to our second Memory Club® session as well as our guests. We would also like to take a moment to acknowledge that it isn’t easy to come to a series like this, but we think you will find that it is a safe place, where you can say exactly what you are thinking or feeling. We also think you will find that in time you will look forward to our times together. But again, we wanted to acknowledge everyone’s willingness and openness in participating in this process, even though it might be a tad scary/hard at first.”

- Announcements
  1. Information Table – Always invited to bring materials to share with group, I will make copies
  2. Materials in Binder – Will not review each item, literature included can compliment the section by going into further depth of what was discussed
  3. Upcoming events – Walk4ALZ, Early Memory Loss Conference, etc.
  4. Review group rules

10:10 – 11:15 • Guest Speaker, Physician with 15-20 min. Q&A

11:15 – 11:25 • Break

11:25 – 12:00 • Small Group discussion

Discussion Ideas - Small or large group

- Did the presentation by the doctor increase your understanding of dementia? Do you have additional questions? Concerns? Reactions?
- Are you clear on the difference between dementia and Alzheimer’s?
What challenges, if any, did you and your family face when getting a diagnosis?
Were you happy with the way the doctor told you and your family the news of the diagnosis? What was good? Bad?
What could health care professionals do/change to improve the way they deliver care?
Who are the people in your life you want to include in your healthcare?
What are the qualities you look for in a doctor?

Partnering With Your Doctor
- Developing a working relationship with your doctor is a very important part of managing your illness. It can take some time. However, it is very important that your doctor gets to know you. You can help by being open and honest with your doctor.
- What do you find helps you get the medical care you need?
- How can you prepare for your visit with your doctor?
  - Make a list of questions
  - Take a family member or friend (It helps to have someone there to ask questions and remember what the doctor states.)
  - Write down all the changes experienced
  - Bring a list of all medications

Sometimes being in a support group can illicit a range of reactions. The disease, for example, may impact people in different ways and you may be observing varying impairments. With that said, would some of you be willing to share your feelings about being in this early stage support group?

Last week some of you shared that after receiving a diagnosis there was a period of denial, depression, anxiety, etc. How do you cope with these feelings?

Conclusion

- Our next session, is designed to encourage the on-going expression and exploration of feelings related to coping with dementia.

Materials
Computer/LCD/Projector

**Facilitators Questions for Doctor**

- What is the research showing on new treatments?
- Can you discuss the pros and cons of vitamins and supplements? (E, C, Folic Acid, B, Curcumin)
- What is the research showing us about lifestyle choices? (Exercise, Diet, Stress, Education, etc.)
- Can you discuss genetics/heredity issues in more detail?
- Should family with an Alzheimer's disease history be given the blood test to decipher if they have the Alzheimer's disease gene?
- Difference between early stage and early on-set?
- What about the term mild cognitive impairment (MCI)? What does this mean?
SESSION 3  Do I have to talk about my feelings?

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

- Announcements
  1. Group Roster – Discuss staying connected by sharing emails if desired
  2. Upcoming events – Walk4Alz, Early Memory Loss Conference, etc.

10:10 – 11:00 • Feeling words discussion

Discussion Ideas – Large group

“Learning that you or a loved one has a diagnosis of dementia can bring about many feelings…feelings that may be unfamiliar to you…may be overwhelming. These feelings are a natural response to the disease. Feeling is the topic for today session.”

1st – Review Bill of Rights

- Identify the range of feelings experienced as CP or persons with a dementia diagnosis (PWD)
  1. Denial – coping mechanism for painful issues and/or lack of awareness or insight
  2. Shock
  3. Alienation/Loneliness – no one knows or understands what we are going through, others treat us differently
  4. Sadness, Depression, Grief or Anxiety
  5. Worry/Fear – what will become of me/my loved one
  6. Positive Emotions – more compassionate, appreciative, deepened appreciation for life’s simple pleasures
  7. Shame/Embarrassment

- Has this diagnosis contributed anything positive to your relationship? Can you identify it?
11:00 – 11:10 • Break

11:10 – 12:00 • Small Groups

**Discussion Ideas - Small Groups (PWD)**

- From the large group session do you feel you have a deeper understanding of the feelings of your care partners?
- Were any of the feelings expressed surprising?
- Have you shared with friends that you or loved one has diagnosis?
- Is there something scary about telling others?
- When you think about telling others about your diagnosis, how do you feel?
- How do you know when it’s time to tell people you have a diagnosis?
- How have friends reacted?
- How are you dealing with other’s reactions to the diagnosis?
- Have you had to adapt to changing relationships with friends? In what ways?
- What do you want people to know about your diagnosis?
- Does this illness still carry a stigma?
- Impact diagnosis has played on self, family, friendships. What changes have occurred in your lives or relationships as a result of the diagnosis? Can you identify these changes?
  1. Impact on parent-child relationship – balance of power has shifted/too involved
  2. Impact on social or job interactions – friends more/less supportive
  3. Loss of autonomy – increased reliance on others
  4. Increased stress on family system
  5. Doing less vs. doing more/taking over
  6. Left out, ignored, dismissed, discredited, devalued
  7. Role transformations - taking over finances, housework, scheduling, driving vs. letting go of finances, housework, scheduling, driving, medication management
- Is an activity or task more frustrating and less enjoyable then before the diagnosis?
- Have you stopped doing something you enjoy because you can no longer do all the steps?
• How are you handling changes in abilities?
• If you needed assistance with an activity (finances), how could your CP be of assistance?
• Have you spoken to your CP about your changes in abilities?
• Everyone has limitations. Because of your diagnosis, limitations might be more prevalent. What everyday activities at this point would be acceptable for you to get help with?
• How, if at all, does requiring or giving more assistance affect your relationships with CP, Children, Friends, etc.? Feelings experienced?

**Conclusion**

• Has this session illustrated that you are not alone in how this disease has impacted your life or on the range feelings experienced?
• I want to acknowledge that this has been a very serious session in which we have been discussing some heavy issues. I want to acknowledge that I see a lot of strength in each of you.
  o Can each person, acknowledge a strength in their character?
• For our next session an attorney will discuss the importance of planning for the future. In our small groups we will discuss and explore concerns and feelings related to anticipating the future. Bring questions for the attorney regarding health care, legal and financial planning, Medicare, Medi-Cal.
• Remind CP in small group that attorney can follow you into smaller CP group for more sensitive questions if needed.

**Materials**

• White board/markers
SESSION 4 Getting the Facts Straight – Legal & Financial Issues

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

- Announcements
  1. Group Roster – Review, changes required, re-circulate following week
  2. Upcoming events – Walk4Alz, Early Memory Loss Conference, etc.

10:10 – 11:10 • Guest Speaker, Attorney

11:10 – 11:25 • Break

11:25 – 12:00 • Small Groups

Discussion Ideas - Small Group (PWD)

- Reaction to Speaker/Topic?
- How does making legal, financial, healthcare decisions about your future make you feel?
- What are your feelings about allowing others to make decisions for you? Guilty/Relief/Angry
- Have you and your family discussed your wishes for daily care-support options?
  - Type of caregiver, adult day care, long-term care, and end-of-life care?
- What would be important to you in future care?
- Have you and your loved one spoken openly about what symptoms would require long-term care placement?
- What are your wishes?
- Have these been easy or hard conversations?
- Who initiates them?
- For those that have broached these topics, how have you started the conversation? What has worked?
- If there comes a time when you are unable to make decisions for yourself about daily/personal care, healthcare, finances, social activities, living arrangements etc., who would you want to make decisions for you? Does this person know this?
- Has anyone here delegated decision making to someone else?
- How many group members take care/took care of (household finances) before diagnosis? How would you feel if you couldn’t do this role any longer?
- Review Five Wishes – document helps broach the conversation
  - Review page #9/Discuss
- For those who have not engaged in future planning discussions, do you think you might after today’s topic?

**Discussion Ideas - Small Group (CP)**

- Lawyer may remain to speak to the CPs if available.
- Reaction to Speaker/Topic?
- Have you and your family discussed your loved one’s wishes for daily care, long-term care, and end-of-life care?
- Have you spoken about what types of symptoms (wandering, incontinence, etc.) would prompt long-term care placement?
- How has this topic been brought up?
- Have these been easy or hard conversations? Who initiates them?
- How well do you feel you know your loved one’s long term care wishes?
  - Review Five Wishes document...help broach the conversation
  - What if something happens to you?

**Conclusion**

- Our next session we will discuss how every person has the capacity to draw from within themselves or the world around them to help cultivate strength and cope with the many challenges life throws our way. We will focus on how we maintain emotional, spiritual, mental and physical wellness.
SESSION 5 I Get By With A Little Help From My Friends....

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

  • Announcements
    1. Upcoming Events – Walk4Alz, Early Memory Loss Conference, etc.
    2. Schedule Exit Interviews to discuss group experience, pros & cons, support group continuation – Graduation Group. Circulate sign-up sheet

10:10 – 11:10 • Guest Speaker (Suggestions for guest speakers: Community partner that offers Early Stage programs, DMV Ombudsman, Nutritionist, meditation session, review Alzheimer’s Los Angeles programs and services)

11:10 – 11:25 • Break

11:25 – 12:00 • Small Group

Discussion Ideas - Small Group (PWD)

  • Were you aware that these types of support options are available?
  • Do you think you would be open to utilizing any types of support options available? If no, why?
  • What steps are you taking to stay involved and engaged in life?
  • What types of activities do you currently do?
  • What types of activities or opportunities would you like to see in the community?
  • How do you feel when you accept help from others?
  • How would you like family and friends to support you?
  • Communication – Alzheimer’s disease affects many parts of your brain. Because of this, you may need to explore new ways to communicate with people.
    o Have you experienced communication changes? What type of changes?
      ▪ Problems finding the correct words
      ▪ Repeating words, stories, questions
• Getting words confused or out of order
• Problems understanding what someone is saying to you
  o When do you find talking/communicating most frustrating?
  o When is the best time for you to have an important discussion?
  o When it is difficult to communicate, what helps you?
  o How would you like people to help or respond when you are having communication difficulties?
• The last few weeks we have discussed areas that you may need some extra assistance, such as driving/transportation, housekeeping, finances, making meals, taking meds. How does accepting assistance from others make you feel?
• In which areas are you willing to accept help?

Conclusion

• Review next week’s agenda and topic. Our next session we will discuss how you take care of yourself and nurture relationships with family and friends.
SESSION 6 Taking Care of Yourself & Each Other

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

• Announcements
  1. Upcoming events – Walk4Alz, Early Memory Loss Conference, etc
  2. Discuss Graduation Group. Circulate sign-up sheet for exit interviews

10:10 – 11:10

Discussion Ideas - Large group

• How do you take care of/nurture yourself?
• How do you nurture your relationship?
• How do you honor independence while not taking over?
• Intimacy
  1. How do you keep intimacy alive in your relationships?
  2. What is your favorite part of the day with your significant other?
  3. Changes in motional intimacy
  4. Changes in physical intimacy
• How do you keep your relationships strong?
• Do you affirm each other? How?
• What do you appreciate most about your CP/loved one?

11:10 – 11:25 • Break

11:25 – 12:00 • Small groups

Discussion Ideas - Small Group (PWD)

• Health Body/Healthy Brain Review
• End with Meditation Exercise
Conclusion

- Review next week’s agenda and topic. Our next session we will have a guest speaker, researcher, discussing clinical trials.
SESSION 7  What are Clinical Trials? Current Clinical Trials?

10:00 – 10:10  •  Brief Check-In/Welcome, Announcements, Review Agenda

•  Announcements
  1. Grad Group Schedule
  2. Offer 1:1 consultation interviews to discuss group
  3. Upcoming events – Walk4Alz, Early Memory Loss Conference, etc.
  4. Next week – Last group, graduation Party

10:10 – 11:10  •  Guest Speaker, Research/Clinical Trials

11:10 – 11:20  •  Break, if needed

11:20 – 12:00  •  Guest Speaker, Research/Clinical Trials

Conclusion

•  Session 8 is meant to be a recap and a celebration of the work accomplished in the last 7-weeks. Additionally, we will discuss the pros and cons of group; how to make it better and what you personally gained from this series.
SESSION 8  New Outlooks, Graduation!

10:00 – 10:10 • Brief Check-In/Welcome, Announcements, Review Agenda

- Announcements
  1. Upcoming events – Memory Walk, Advocacy Day, Early Memory Loss Conference
  2. Safe Return Applications
  3. Exit Interview Reminders
  4. Post Surveys/Evaluations & Geriatric Depression Scale

10:20 – 11:00 • Large group

Recognition of the group’s completion. Each person has grown, faced personal challenges and embraced this opportunity to openly share. We came in here strangers, but we are leaving with many new friends.

- Special acknowledgement of group involvement - seed packets
- Memory Club Experience
- Pro’s and con’s of group
- What’s missing
- How to make it better for the future
- What did you like best?
- What did you personally gain from this series? Impact on self? Places of growth?
- Feelings around group ending
- Q&A Opportunities

11:00 – 11:15 • Break

11:15 – 12:00

Discussion Ideas - Small Groups

- Reactions from last week topic and speaker
- Has anyone ever been involved in a trial? Share personal experiences with trial...positive/negative?
I would be willing to participate in a research study if…?

Safety
- Do you feel safe?
- Things that make me concerned about my safety or loved one’s safety are…?
- Things that are important for my loved one’s safety are…?
- Who are people who can help you stay safe?
- Making safety plans for the future makes me feel…?

Driving
- Identify what you like most about driving?
- What you like least about driving?
- Making the decision to stop driving makes you feel…?
- Identify why driving is such a big deal. What does it signify/represent to you?
- How does a person know when it is no longer safe to drive?
- I knew it was time or I will know it is time to stop driving when…?
- Did the doctor tell you, you were no longer able to drive? Did this challenge your relationship?
- If your family began to become worried about your driving, what would you want them to do? Have you discussed your wishes with your CP?
- Have you ever considered creating a Safety Agreement?
- Review of community transportation resources available
- Identify which resources you use?
- Identify family and friends you can request assistance from

Wandering
- Safe Return
- Living alone/being without support when alone – preparing meals, taking medications, driving, etc.

Disaster Planning
- Have you made disaster plans? What are they?
  - Life Alert, Refrigerator Emergency List
- If your CP sees things that are unsafe (driving, cooking, finances, wandering, driving), how would you want him/her to address this with you? Have you made a plan regarding some of these issues? What are the plans?
• Are there items we have not addressed that we need to cover in our last session together before Grad Group?

• Do you have concerns about the future? If so, what are they?
• Coping with the changing nature of the disease and the need for ongoing or intermittent guidance/support such as needing to accept a paid caregiver or other supportive services.
Memory & Graduation Clubs
Agreement/Guidelines/Informed Consent

The Wilshire Office of Alzheimer’s Los Angeles agrees to provide the Memory Club® support and information program. The Memory Club® will meet once a week for eight (8) weeks beginning ____________ and ending ______________.

The Memory and Graduation Club sessions will be held at Alzheimer’s Los Angeles at 4221 Wilshire Blvd., Suite 400, Los Angeles, CA  90010. Club members will be supplied with a calendar and notified of any changes in time or location.

Participation in the Memory or Graduation Clubs are voluntary and free of charge, however, to support the Club’s activities, a participation donation, per session is suggested.

Please review the following agreement, guidelines and informed consent:

1. We understand that an in-person interview is required prior to joining the Memory Club®. Interviews do not guarantee membership; the Club facilitator/Program Manager will make the final decision regarding Club participation based on program eligibility² criteria.

2. We understand the Memory Club® is a time-limited group. (8 sessions)

3. We understand the Graduation Club is offered to persons with dementia and their care partners whom have completed the Memory Club® series and who continue to meet criteria for early stage group participation. (Due to the nature and progression of the diagnosis, the Grad Club, at some point, will no longer be appropriate for these individuals. The group facilitators will discuss with them the need to transition and create a transition timeframe. The Club facilitator/Program Manager makes the final decision regarding program eligibility and appropriateness.)

4. We understand we may be asked to participate in voluntary and confidential evaluations of the programs.

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² Group participation criteria includes being able to express emotions regarding the diagnosis, contributing appropriately, relating to other group members, identifying what they are gaining from the group experience and finally, being free of behavioral symptoms that disrupt or negatively impact the group process.
5. We understand that the Club facilitators will store written and verbal records involving Club members in a confidential and secured location.

6. We understand that the Club facilitators, contractual professionals and Alzheimer’s Los Angeles Development staff, who sign confidentiality agreements upon hire, may share your basic demographic information. This will be done in a confidential and secure manner. Communication with any other professional (physician, social worker, etc.) will require your permission and additional ‘Consent to Release’ document.

7. We understand that information exchanged between Club facilitators and the early stage Club members are strictly confidential except in the following situations, which are required by law to report to the appropriate authorities:
   - The group facilitators are ordered by a court to release information.
   - I/we present a serious physical danger to self or others (including threats related to terrorist activities.)
   - The group facilitators have reasonable suspicion of elder, dependent, adult or child abuse, or has observed or been told of physical/psychological/financial abuse to an elder, dependent adult or child.

8. We understand that all Alzheimer’s Los Angeles’ support groups are provided at no cost to the participant. However, the organization relies on the generosity of donors to support the programs provided. We welcome donations that exceed the suggested amount; however, we have provided suggested donations amounts below. If you choose to make a gift, please make your check payable to the Alzheimer’s Los Angeles. To restrict the gift to the early stage program, in the memo of the check write, ‘Memory Club® – LA’. Credit cards are accepted.
   - Memory Club® – A participation donation of $50 per session, per couple is suggested.
   - Graduation Club – A participation donation of $40 per session, per couple is suggested.

9. We understand that once a donation is made, the name of the donor will go into Alzheimer’s Los Angeles donor database. The development department periodically reviews the donor database and follows-up with individuals to determine interest in becoming more involved or extending and expanding their gifts.
10. We will not hold Alzheimer’s Los Angeles, its staff, Club facilitators, or any of the Foundations that partially support our programs liable for any injury, harm, or other damages related to participation in the Clubs or other services provided.

11. In case we cannot attend a Memory or Graduation Club session, we will notify the Project Manager/Club facilitators by calling 323.930.6289.

We have read, understood and accept the Clubs Agreement, Guidelines and Informed Consent.

___________________________________    ___________
Signature of Early Stage Participant    Date

___________________________________    ___________
Signature of Early Stage Care Partner    Date

Alicia Villegas, Director Early Stage Services    Date
MEMORY CLUB®
Group Agreement & Appreciation

TRUST ♡ SAFETY ♡ FRIENDSHIP ♡ SUPPORT ♡ LAUGHTER ♡ HOPE ♡ JOY ♡ RESPECT

• Everyone in the group has some kind of memory loss and we need to acknowledge that our symptoms may be different, that we come from diverse backgrounds and our relationships with family and friends will vary. We’re all doing the best we can in our own style.

• Our time together will fluctuate depending on the session. Given our limited time together we must take extra strides to ensure that everyone has a chance to share their thoughts, feelings and concerns.

• There will be times when we will disagree and feel differently about a certain topic. We aim to honor these differences and avoid criticizing or dismissing another member’s ideas or thoughts.

• It is okay and even encouraged to share what happened in group with family and friends, however we must agree not to mention the names of other group members or the personal details about what they shared.
MEMORY CLUB®
Participant’s Bill of Rights*

As a person with dementia, I have the right to:

- Take care of myself
- Be supportive of my care partner and help where I can
- Seek assistance from others
- Actively try to deal with the changes in life that occur with Early Stage Alzheimer’s
- Take steps to plan for the future
- Grieve and acknowledge losses while nurturing happiness
- Focus on my strengths
- Try to avoid the guilt and resentment cycle
- Give and receive consideration, affection, forgiveness, and acceptance
- Be proud of and continue to seek out meaningful activities
- Make new friends and remain connected to my community
- Educate others about Alzheimer’s so they can better know how to respond
- Receive a thorough diagnostic work-up and the latest medical, medication, and support treatments for individuals with Alzheimer’s disease and related disorders.
MEMORY CLUB®
Care Partner’s Bill of Rights*

As a Care Partner, I have the right to:

• Take care of myself
• Take care of my family
• Seek assistance from others
• Actively try to deal with the changes in life that occur with Early Alzheimer’s
• Take steps to plan for the future
• Grieve and acknowledge losses while nurturing happiness
• Try to avoid the guilt and resentment cycle
• Give and receive consideration, affection, forgiveness, and acceptance
• Be proud of and continue to achieve accomplishments in life
• Preserve our sense of autonomy and pursue a life that will sustain us
• Educate others about Alzheimer’s so they can better know how to respond
• Receive a thorough diagnostic work-up and the latest medical, medication, and support treatments for Alzheimer’s disease care partners

Created by Jennifer Watson, Ph.D., Laura Rice-Oeschger, LCSW, and Bernadette Kakos for the Early Stage Alzheimer’s Project, a collaborative project between the Center for Aging, Research, and Evaluation (CARE) at Granada Hills Community Hospital (818-366-1967) and Alzheimer’s Los Angeles, San Fernando Valley office.

*Adapted from Caregiving: Helping an Aging Loved One by Jo Home.
Alzheimer's Caregiving Tips

WHAT ARE THE FIRST SIGNS OF ALZHEIMER'S?

Mild forgetfulness can be a normal part of the aging process. But when memory problems begin to seriously affect daily life, they could be early signs of Alzheimer’s disease or another dementia. Here are some of the early warning signs:

**MEMORY LOSS THAT DISRUPTS DAILY LIFE**

Asking the same question or repeating the same story over and over again. Forgetting information just learned or losing track of important dates, names and places. Relying heavily on memory aids like Post-it notes or reminders on your smartphone.

**DIFFICULTY PLANNING OR SOLVING PROBLEMS**

Difficulty concentrating on detailed tasks, especially involving numbers; for example, keeping track of bills and balancing a checkbook.

**FORGETTING HOW TO DO FAMILIAR TASKS**

Forgetting how to do activities that were previously routine, such as cooking, making repairs, or playing cards.

**CONFUSION WITH DATES, TIME OR PLACE**

Distorted perception of dates, time or place. Becoming disoriented or feeling lost in familiar places.

**TROUBLE WITH SPATIAL RELATIONSHIPS**

Difficulty reading words on a page, judging distances, telling colors apart.

**NEW PROBLEMS WITH WORDS IN SPEAKING OR WRITING**

Trouble finding the right word or calling things by the wrong name. Conversations can be a struggle and difficult to follow.

**MISPLACING OBJECTS AND THE INABILITY TO RETRACE STEPS**

Finding objects in unusual places, like a watch in the refrigerator. Misplacing things and inability to retrace steps; accusing people of taking things.

**ALTERED DECISION MAKING: POOR JUDGEMENT OR RELYING ON SOMEONE ELSE, SUCH AS A SPOUSE TO MAKE DECISIONS OR ANSWER QUESTIONS**

Making poor decisions, such as giving away money inappropriately.

**WITHDRAWL FROM WORK OR SOCIAL SITUATIONS; DIFFICULTY INITIATING ACTIVITIES PARTICIPATING IN SOCIAL INTERACTIONS**

Watching television or sleeping more; lacking motivation. Scaling back on work projects or becoming less involved in favorite hobbies.
MOOD SWINGS AND CHANGES IN PERSONALITY

Getting upset more easily, feeling depressed, scared or anxious. Being suspicious of people.

IF YOU HAVE QUESTIONS OR CONCERNS, CONTACT ALZHEIMER'S LOS ANGELES AT:

844.HELP.ALZ (844.435.7259) | AlzheimersLA.org
Dementia is the loss of cognitive functioning, which means the loss of the ability to think, remember, reason, as well as behavioral abilities, to such extent that it interferes with a person’s daily life and activities. Dementia is a general term that refers to a group of symptoms, and there are several different types of dementia. Alzheimer’s disease is the most common type of dementia, which is why we hear this term most often.

Alzheimer’s disease is an irreversible brain disorder that gets worse over time. It slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks. Alzheimer’s affects people’s ability to communicate, think, problem-solve, behave, and function physically. In addition, some people with dementia cannot control their emotions, their personalities may change, they can have delusions (strong beliefs without proof, such as the idea that someone is stealing from them) and may also have hallucinations (seeing or hearing things that are not really there).

**SIGNS & SYMPTOMS**

Memory problems are usually one of the first signs of cognitive impairment related to Alzheimer’s disease. Symptoms can vary from person to person and will change throughout the progression of the disease.

**MILD ALZHEIMER’S**
As Alzheimer’s disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes.

**MODERATE ALZHEIMER’S**
As Alzheimer’s disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes.

**SEVERE ALZHEIMER’S**
People with severe Alzheimer’s cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

**VASCULAR DEMENTIA**

Vascular dementia is caused by injuries to the vessels supplying blood to the brain. These...
disorders can be caused by brain damage from multiple strokes or any injury to the vessels carrying blood to the brain. Dementia risk can be significant even when individuals have suffered only small strokes. Vascular dementia arises as a result of risk factors that similarly increase the risk for stroke, including atrial fibrillation, hypertension, diabetes, and high cholesterol. Symptoms of vascular dementia and VCI can begin suddenly and progress or subside during one’s lifetime.

**LEWY BODY DEMENTIA (DBL)**

DBL is one of the more common forms of dementia. Symptoms such as difficulty sleeping, loss of smell, and visual hallucinations often come before movement and other problems by as long as 10 years, which consequently results in DBL going unrecognized or misdiagnosed as a psychiatric disorder until its later stages.

Later in the course of DBL, some signs and symptoms are similar to Alzheimer’s disease and may include memory loss, poor judgment, and confusion. Other signs and symptoms of DBL are similar to those of Parkinson’s disease, including difficulty with movement and posture, a shuffling walk, and changes in alertness and attention. Given these similarities, DBL can be very difficult to diagnose. There is no cure for DBL, but there are drugs that control some symptoms. The medications used to control DBL symptoms can make motor function worse or exacerbate hallucinations.

**FRONTOTEMPORAL DEMENTIA (FTD)**

In FTD, changes to nerve cells in the brain’s frontal lobes affect the ability to reason and make decisions, prioritize and multitask, act appropriately, and control movement. Some people decline rapidly over 2 to 3 years, while others show only minimal changes for many years. People can live with frontotemporal disorders for 2 to 10 years, sometimes longer, but it is difficult to predict the time course for an affected individual.

In some cases, FTD is associated with progressive neuromuscular weakness otherwise known as amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease). The signs and symptoms may vary greatly among individuals as different parts of the brain are affected. No treatment that can cure or reverse FTD is currently available.

**PARKINSON’S DISEASE DEMENTIA (PDD)**

Parkinson’s disease dementia is a clinical diagnosis related to DBL that can occur in people with Parkinson’s disease. PDD may affect memory, social judgment, language, or reasoning. Autopsy studies show that people with PDD often have amyloid plaques and tau tangles similar to those found in people with AD, though it is not understood what these similarities mean. A majority of people with Parkinson’s disease develop dementia, but the time from the onset of movement symptoms to the onset of dementia symptoms varies greatly from person to person. Risk factors for developing PDD include the onset of Parkinson’s-related movement symptoms followed by mild cognitive
impairment and REM sleep behavior disorder, which involves having frequent vivid nightmares and visual hallucinations.

**MIXED DEMENTIA**

Autopsy studies looking at the brains of people who had dementia suggest that a majority of those age 80 and older probably had “mixed dementia,” caused by both AD-related neurodegenerative processes and vascular disease-related processes. In fact, some studies indicate that mixed vascular-degenerative dementia is the most common cause of dementia in the elderly. In a person with mixed dementia, it may not be clear exactly how many of a person’s symptoms are due to AD or another type of dementia. In one study, approximately 40 percent of people who were thought to have AD were found after autopsy to also have some form of cerebrovascular disease. Several studies have found that many of the major risk factors for vascular disease also may be risk factors for AD.

**HUNTINGTON’S DISEASE**

This hereditary disorder is caused by a faulty gene for a protein called huntingtin. Symptoms begin around age 30 or 40 years and include abnormal and uncontrollable movements called chorea, as well as gait changes and lack of coordination. Huntington’s disease may affect a person’s judgment, memory, and other cognitive functions. As the disease progresses, these cognitive problems worsen, and motor difficulties lead to complete loss of ability for self-care. Children of people with Huntington’s disease have a 50 percent chance of having the disorder.

**FOR MORE INFORMATION ABOUT ALZHEIMER’S:**

Contact Alzheimer’s Los Angeles to find more disease education, support, & guidance. 844.HELP.ALZ (844.435.7259) | AlzheimersLA.org

Information adapted from the National Institute on Aging, part of the National Institutes of Health. www.nia.nih.gov

Reviewed by Alzheimer’s Los Angeles, January 2016 | NIH, July 2012
Alzheimer’s Caregiving Tips

ALZHEIMER’S DISEASE MEDICATIONS

Several prescription drugs are currently approved by the US Food and Drug Administration (FDA) to treat people who have been diagnosed with Alzheimer’s disease. Treating the symptoms of Alzheimer’s can provide patients with comfort, dignity, and independence for a longer period of time and can encourage and assist their caregivers as well.

It is important to understand that none of these medications stops the disease itself.

TREATMENT FOR MILD TO MODERATE ALZHEIMER’S

Medications called cholinesterase inhibitors are prescribed for mild to moderate Alzheimer’s. These drugs may help delay or prevent symptoms from becoming worse for a limited time and may help control some behavioral symptoms. The medications include Razadyne® (galantamine), Exelon® (rivastigmine), and Aricept® (donepezil).

Scientists do not yet fully understand how cholinesterase inhibitors work to treat Alzheimer’s disease, but research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and thinking. As Alzheimer’s progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect. No published study directly compares these drugs. Because they work in a similar way, switching from one of these drugs to another probably will not produce significantly different results. However, an Alzheimer’s patient may respond better to one drug than another.

TREATMENT FOR MODERATE TO SEVERE ALZHEIMER’S

A medication known as Namenda® (memantine), an N-methyl D-aspartate (NMDA) antagonist, is prescribed to treat moderate to severe Alzheimer’s disease. This drug’s main effect is to delay progression of some of the symptoms of moderate to severe Alzheimer’s. It may allow patients to maintain certain daily functions a little longer than they would without the medication. For example, Namenda® may help a patient in the later stages of the disease maintain his or her ability to use the bathroom independently for several more months, a benefit for both patients and caregivers.

The FDA has also approved Aricept® and Namzaric®, a combination of Namenda® and donepezil, for the treatment of moderate to severe Alzheimer’s disease.

Namenda® is believed to work by regulating glutamate, an important brain chemical. When produced in excessive amounts, glutamate may lead to brain cell death.
Because NMDA antagonists work very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination. Patients should be monitored when a drug is started. Report any unusual symptoms to the prescribing doctor right away. It is important to follow the doctor’s instructions when taking any medication, including vitamins and herbal supplements. Also, let the doctor know before adding or changing any medications.

**DOSAGE & SIDE EFFECTS**

Doctors usually start patients at low drug doses and gradually increase the dosage based on how well a patient tolerates the drug. There is some evidence that certain patients may benefit from higher doses of the cholinesterase inhibitors. However, the higher the dose, the more likely are side effects. The recommended effective dosages of drugs prescribed to treat the symptoms of Alzheimer’s and the drugs' possible side effects are summarized in the table (see inside).

**TESTING NEW ALZHEIMER’S DRUGS:**

Clinical trials are the best way to find out if promising new treatments are safe and effective in humans. Volunteers are needed for many Alzheimer’s trials conducted around the United States. To learn more, talk with your doctor or visit the ADEAR Center’s listing of clinical trials at [nia.nih.gov/alzheimers/clinical-trials](http://nia.nih.gov/alzheimers/clinical-trials). More information is available at [nia.nih.gov/alzheimers/volunteer](http://nia.nih.gov/alzheimers/volunteer).
Alzheimer’s Caregiving Tips

EARLY STAGE OF DEMENTIA

Jan Phillips, an individual with early-onset dementia, compiled the following article. It is intended as a guide and source of help and hope to those who have been newly diagnosed with Alzheimer’s disease or a related memory disorder.

You may have been wondering and anxious for some time now about changes that have been occurring that others perhaps have not noticed.

Certainly being diagnosed with dementia is upsetting. However, for some who have been worrying about themselves, the diagnosis can come as a relief. They know that something is not right, and having a diagnosis can be helpful. It often helps the person cope with the present and plan for the future.

IT’S IMPORTANT TO KNOW THAT:

- You are still the same person.
- The changes that you are experiencing are because of a disease of the brain - dementia.
- Each person is affected differently and symptoms will vary.
- This is an illness that was not acquired by any action or inaction on your part.
- You will have good and bad days.
- You are not alone. There are people who understand what you are going through and can help.
- Accept help when it is offered. Ask for help when you need it.
- There are ways to help yourself – call Alzheimer’s Los Angeles, join an Early Stage support group, connect with peers through the internet. Don’t be afraid to continue to learn – challenge yourself. Many resources are available to you for the positive support you need.

YOUR FEELINGS

You may feel angry, frustrated or upset about the changes in your life, and even guilty at the thought of becoming a burden. Talking about these feelings and concerns with trusted family members or friends may help. The Alzheimer’s Los Angeles also has counselors and services tailored specifically to your needs. They can be reached at: 844.HELP.ALZ

SEEKING SUPPORT
Many people are not ready to seek support. Sometimes they feel overwhelmed by the diagnosis, or not well enough to socialize or talk to other people. Apathy and social withdrawal are common and may be experienced early on in the disease. Understanding this may assist you to embrace help and reach out to others.

Sometimes in sharing with others you may find that you are put on the defensive, or in a position of having your diagnosis challenged and discounted by well-intentioned people. You may encounter comments such as, “You don’t look like you have Alzheimer’s (dementia).” Or, when asked, “What makes you think you have dementia?” and you reply by anecdotal experience, their reply will be, “Oh, that always happens to me.” You must not take it as a personal affront or discounting of your diagnosis; Most are simply trying to support you as best they know how. Unfortunately, most of society is uneducated about early dementia and have a stereotypical image of someone with dementia as being very old and fragile in appearance and severely cognitively impaired.

You may find that a support group with others recently diagnosed with dementia may help you to not feel so isolated in these feelings. They may be experiencing many of the same insensitivities.

**FOCUS ON YOUR ABILITIES**

There is a lot that you can do to make your life easier. Here are some ideas shared by other people with dementia:

**FIND OUT ABOUT DEMENTIA**

You have a right to know about and understand your illness. Empower yourself with knowledge so that you can be an integral part of your own care.

**SEEK SPECIALIZED HELP**

Not every doctor is familiar with the unique challenges facing the dementia patient. Find someone who specializes in dementia care to help you deal with your diagnosis, emotions, changing family dynamics, and develop coping strategies.

**GET SUPPORT**

We all need extra help at some point in our lives – don’t be afraid of asking for support. Think about joining a group with other people with dementia, either in your community or on the Internet. “In an environment of our peers, we can be completely honest in our sharing without the need to try and hide the fact that we have dementia.”

**PRIORITIZE**

Don’t try to resolve all your problems or make all your decisions at once.

**BECOME ATTUNED TO YOURSELF**

Try and make your life as stress free as possible. Be aware of noisy malls and restaurants; they may cause extra agitation, decisions may be harder to make, and you may be easily sidetracked.
**SIMPLIFY**

Try to eliminate the unnecessary clutter in your life, be it material things or thoughts and worry over things that are not in your control.

**REGULAR ROUTINE**

Try and keep a routine in your life. Doing things in the same order, and putting things away in the same place each time can help.

**INFORM OTHERS**

Explain what you know about dementia. It will help other people to understand what you are going through.

**TALKING HELPS**

If you can, talk to your friends and family about your concerns and worries. Keep in touch with people who are supportive and helpful. Don’t bottle things up. “If you keep it in too long, at some point you implode!”

**EVERYDAY SUGGESTIONS THAT MAY HELP**

- Take a break if something is too difficult. Allow yourself a lot of time and don’t let others hurry you.
- Carry a notepad of paper with you. Write down important things that you want to remember. This might include appointments, people’s names, a list of things to do and any thoughts or ideas you may want to remember.
- Keep a calendar or weekly listing with the things that you want to and are scheduled to do – mark each day off at its conclusion. Or try keeping a large desk type calendar where all predicted events of the day are written. Make a habit of checking it each morning.
- Have a daily newspaper delivered; the day and date are always on the front page. Also you may want to look into purchasing a clock with the day and date displayed along with the time.
- Prominently display helpful numbers by the phone. Also include your own address and phone number, and major cross streets to your home. Should an emergency arise, it will be there for your easy access.
- Buy a large weekly pill holder for your medications – it will allow you to easily see if you’ve missed a dose.

**COMMUNICATION**

You may find that it is difficult to express yourself the way you used to. Not being able to find the right word to express your thoughts is not uncommon. Also, you may find that at times it is more difficult to understand what others are saying.

Try these hints:
• Take your time.
• Explain that you need a little time and patience.
• Ask a person to repeat a statement or question if you did not understand what they said.
• Often times you may lose your train of thought because of outside disturbances (traffic, phone, loud noises, other conversations, etc). Don’t be afraid to ask your conversation partner to help you get back on track.
• If you forget a thought, it’s okay, continue on and it may come back. Try not to get frustrated when this happens. Relax; slow down a little and it may get easier.
• Oftentimes, too much stimuli - both physical and audible input to your senses - can become overwhelming. Try to reduce distractions by finding a quiet place to converse away from TV’s, radios, and loud talk.

YOUR SAFETY

The gradual loss of memory and the difficulties with decision-making and communication often raise concerns about your safety. Here are a few suggestions.

• Make a card that you carry with you at all times. It should include:
  o Your name
  o Your complete address
  o Your home phone number
  o An emergency contact: name/phone number/address
  o Medications you are taking and the dosage
  o Your Physician, and any other doctors whose care you are under: name/phone number/address
• Write reminders to yourself to lock the door at night or put the trash out on a certain day for example. Put a note on the front door to remind you to take your keys with you.
• Install devices such as gas detectors and smoke alarms.
• Carry a small timer with you. Set it when you turn the stove on or turn the water on. Even if you walk away from your task and get sidetracked, carrying the timer in your pocket will help to remind you.
• Wear a “fanny pack” instead of using a purse or wallet.
• Join MedicAlert, a bracelet identification program that identifies and assists in the safe return of persons with dementia who have become lost in the community.
• Arrange for direct deposit of your checks, such as retirement or Social Security benefits.
• Leave a set of extra house keys with a trusted neighbor.

DRIVING

In the State of California, it is the law that your doctor must report your diagnosis to the Department of Health who, in turn, must report it to the DMV. You may not be able to
continue driving. At some point your ability to make decisions and react quickly may be impaired by the disease affecting your brain. For your safety, and for the safety and well being of others, it may be wise to discontinue driving. This is not always easy, as you may feel that you are losing your independence – this need not be the case. There are alternate forms of transportation that you may want to consider. Perhaps you can have a friend or family member take over the job of driving, or use public transportation such as buses, taxis, or the Metrolink. Some cities have transportation services that are no cost or for a nominal fee. You can check with your local city hall for information.

GETTING LOST

Should you find yourself out alone and you become confused and feeling lost, the first thing you should do is try and remain calm and not panic. You should be carrying with you a card with important phone numbers on it. Find the nearest restaurant or store, tell them you are confused as to your location, and ask them to help you call someone who can assist you. People, in general, are willing to help when you explain your dilemma.

It might be helpful for future reference when out shopping to remember when you get out of your car, before you move away from it, to find a point of reference – a landmark, to help you remember where you are parked. Before you enter the store, look back and locate your car visually – this will give you a clue as to what you will see when you leave. Also, always try to exit from the same door in which you entered.

WORKING

We all tend to comment how we look forward to not working anymore and enjoy retirement. That is certainly true for most of us. However, we all want it to be on our own terms and schedule. But Alzheimer’s changes the equation somewhat. By the time of the diagnosis, you may have already experienced problems with how you function at work. It can run the whole spectrum from forgetting schedules, or not understanding directions or routine tasks that you previously had no problem with performing.

Therefore, sound decisions have to be made about your ability to continue working. There are issues of liability for yourself and your employer that must be considered, such as your ability to function in your current position and the safety of yourself and your co-workers. Seek out advice from your physician, your family, your employer and others who can help you to make the right decision.
Alzheimer’s Caregiving Tips

LEGAL & FINANCIAL PLANNING

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer’s disease. Legal and medical experts encourage people recently diagnosed with a serious illness—particularly one that is expected to cause declining mental and physical health—to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial instruments, such as a will, a living trust, and advance directives, are available to ensure that the person’s late-stage or end-of-life health care and financial decisions are carried out.

A complication of diseases such as Alzheimer’s is that the person may lack or gradually lose the ability to think clearly. This change affects his or her ability to participate meaningfully in decision making and makes early legal and financial planning even more important. Although difficult questions often arise, advance planning can help people with Alzheimer’s and their families clarify their wishes and make well-informed decisions about health care and financial arrangements.

When possible, advance planning should take place soon after a diagnosis of early-stage Alzheimer’s while the person can participate in discussions. People with early-stage disease are often capable of understanding many aspects and consequences of legal decision making. However, legal and medical experts say that many forms of planning can help the person and his or her family even if the person is diagnosed with later-stage Alzheimer’s.

There are good reasons to retain the services of a lawyer when preparing advance planning documents. For example, a lawyer can help interpret different State laws and suggest ways to ensure that the person’s and family’s wishes are carried out. It’s important to understand that laws vary by state, and changes in situation—for instance, a divorce, relocation, or death in the family—can influence how documents are prepared and maintained.

LEGAL, FINANCIAL, & HEALTH CARE PLANNING DOCUMENTS

When families begin the legal planning process, there are a number of strategies and legal documents they need to discuss. Depending on the family situation and the applicable State laws, some or all of the following terms and documents may be introduced by the lawyer hired to assist in this process. Broadly speaking, these documents can be divided into two groups:

- documents that communicate the health care wishes of someone who may no longer be able to make health care decisions
- documents that communicate the financial management and estate plan wishes of someone who may no longer be able to make financial decisions
ADVANCE DIRECTIVES FOR HEALTH CARE

Advance directives for health care are documents that communicate the health care wishes of a person with Alzheimer’s disease. These decisions are then carried out after the person no longer can make decisions. In most cases, these documents must be prepared while the person is legally able to execute them.

A **LIVING WILL** records a person’s wishes for medical treatment near the end of life. It may do the following:

- specify the extent of life-sustaining treatment and major health care the person wants
- help a terminal patient die with dignity
- protect the physician or hospital from liability for carrying out the patient’s instructions
- specify how much discretion the person gives to his or her proxy (discussed below) about end-of-life decisions

A **Durable Power of Attorney for Health Care** designates a person, sometimes called an agent or proxy, to make health care decisions when the person with Alzheimer’s disease no longer can do so. Depending on State laws and the person’s preferences, the proxy might be authorized to:

- refuse or agree to treatments
- change health care providers
- remove the person from an institution
- decide about making organ donations
- decide about starting or continuing life support (if not specified in a living will)
- decide whether the person with Alzheimer’s will end life at home or in a facility
- have access to medical records

A **Do Not Resuscitate (DNR) Order** instructs health care professionals not to perform cardiopulmonary resuscitation if a person’s heart stops or if he or she stops breathing. A DNR order is signed by a doctor and put in a person’s medical chart.

Access to private medical information is closely regulated. The person with Alzheimer’s disease must state in writing who can see or use personal medical records.

ADVANCE DIRECTIVES FOR FINANCIAL & ESTATE MANAGEMENT

Advance directives for financial and estate management must be created while the person with Alzheimer’s still can make these decisions (sometimes referred to as “having legal capacity” to make decisions).

These directives may include some or all of the following:
A **Will** indicates how a person’s assets and estate will be distributed upon death. It also can specify:

- arrangements for care of minors
- gifts
- trusts to manage the estate
- funeral and/or burial arrangements

Medical and legal experts say that the newly diagnosed person with Alzheimer’s and his or her family should move quickly to make or update a will and secure the estate.

A **Durable Power of Attorney for Finances** names someone to make financial decisions when the person with Alzheimer’s disease can no longer do so. It can help people with the disease and their families avoid court actions that may take away control of financial affairs.

A **Living Trust** provides instructions about the person’s estate and appoints someone, called the trustee, to hold title to property and funds for the beneficiaries. The trustee follows these instructions after the person no longer can manage his or her affairs.

The person with Alzheimer’s disease also can name the trustee as the health care proxy through the durable power of attorney for health care.

A living trust can:

- include a wide range of property
- provide a detailed plan for property disposition
- avoid the expense and delay of probate (in which the courts establish the validity of a will)
- state how property should be distributed when the last beneficiary dies and whether the trust should continue to benefit others

**WHO CAN HELP?**

**HEALTH CARE PROVIDERS**

Health care providers cannot act as legal or financial advisors, but they can encourage planning discussions between patients and their families. Qualified clinicians can also guide patients, families, the care team, attorneys, and judges regarding the patient’s ability to make decisions.

**ELDER LAW ATTORNEYS (ELAs)**

An ELA helps older people and families:

- interpret state laws
- plan how their wishes will be carried out
- understand their financial options
- learn how to preserve financial assets while caring for a loved one

The National Academy of Elder Law Attorneys and the American Bar Association can help families find qualified ELAs. See the list of resources at the end of this fact sheet for...
more information.

**GERIATRIC CARE MANAGERS (GCMs)**

GCMs are trained social workers or nurses who can help people with Alzheimer’s and their families:

- discuss difficult topics and complex issues
- address emotional concerns
- make short and long-term plans
- evaluate in-home care needs
- select care personnel
- coordinate medical services
- evaluate other living arrangements
- provide caregiver stress relief

**OTHER ADVANCE PLANNING ADVICE**

**START DISCUSSIONS EARLY.**

The rate of decline differs for each person with Alzheimer’s, and his or her ability to be involved in planning will decline over time. People in the early stages of the disease may be able to understand the issues, but they may also be defensive or emotionally unable to deal with difficult questions.

**STEPS FOR GETTING YOUR AFFAIRS IN ORDER**

- Gather everything you can about your income, property, investments, insurance, and savings
- Put copies of legal documents and other important papers in one place. You could set up a file, put everything in a desk or dresser drawer, or just list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check regularly to see if there’s anything new to add.
- Tell a trusted family member or friend where you put your important papers. You don’t need to tell this friend or family member your personal business, but someone should know where you keep your papers in case of emergency. If you don’t have someone you trust, ask a lawyer to help.

**REVIEW PLANS OVER TIME.**

Changes in personal situations—such as a divorce, relocation, or death in the family—and in state laws can affect how legal documents are prepared and maintained. Review plans regularly, and update documents as needed.

Alzheimer’s LOS ANGELES

844.HELP.ALZ
AlzheimersLA.org
REDUCE ANXIETY ABOUT FUNERAL AND BURIAL ARRANGEMENTS.

Advance planning for the funeral and burial can provide a sense of peace and reduce anxiety for both the person with Alzheimer’s and the family.

RESOURCES FOR LOW-INCOME FAMILIES

Families who cannot afford a lawyer still can do advance planning. Samples of basic health planning documents can be downloaded from state government websites. Area Agency on Aging officials may provide legal advice or help. Other possible sources of legal assistance and referral include state legal aid offices, the state bar association, local non-profit agencies, foundations, and social service agencies.

SUMMARY

Facing Alzheimer’s disease can be emotionally wrenching for all concerned. A legal expert and members of the health care team can help the person and family address end-of-life issues. Advance health care and financial planning can help people diagnosed with Alzheimer’s and their families confront tough questions about future treatment, caregiving, and legal arrangements.

### Overview of Medical, Legal, and Financial Planning Documents

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<thead>
<tr>
<th>Medical Document</th>
<th>How It Is Used</th>
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<tbody>
<tr>
<td>Living Will</td>
<td>Describes and instructs how the person wants end-of-life health care managed</td>
</tr>
<tr>
<td>Durable Power of Attorney for Health Care</td>
<td>Gives a designated person the authority to make health care decisions on behalf of the person with Alzheimer’s</td>
</tr>
<tr>
<td>Do Not Resuscitate Form</td>
<td>Instructs health care professionals not to perform CPR in case of stopped heart or stopped breathing</td>
</tr>
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<tr>
<td>Will</td>
<td>Indicates how a person’s assets and estate will be distributed among beneficiaries after his/her death</td>
</tr>
<tr>
<td>Durable Power of Attorney for Finances</td>
<td>Gives a designated person the authority to make legal/financial decisions on behalf of the person with Alzheimer’s</td>
</tr>
<tr>
<td>Living Trust</td>
<td>Gives a designated person (trustee) the authority to hold and distribute property and funds for the person with Alzheimer’s</td>
</tr>
</tbody>
</table>

FOR MORE INFORMATION

Alzheimer’s Disease Education & Referral (ADEAR) Center
PO Box 8250, Silver Spring, MD 20907-8250
1.800.438.4380 (toll-free) | nia.nih.gov.alzheimers

The National Institute on Aging’s ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer’s.
disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer’s and other dementias, find clinical trials, and sign up for email updates.

**Eldercare Locator**  
1.800.677.1116 (toll-free) | eldercare.gov

Families often need information about community resources, such as home care, adult day care, and nursing homes. Contact the Eldercare Locator to find these resources in your area. The Eldercare Locator is a service of the Administration on Aging.

**National Institute on Aging Information Center**  
PO Box 8057, Gaithersburg, MD 20898-8057  
1.800.222.2225 (toll-free) | 1.800.222.4225 (TTY/toll-free)  
nia.nih.gov/health | nia.nih.gov/espanol

This service of the NIA offers many helpful publications, including:

- AgePage: Getting Your Affairs in Order
- Advance Care Planning: Tips from the National Institute on Aging
- End of Life: Helping with Comfort and Care
- So Far Away: Twenty Questions and Answers About Long-Distance Caregiving

**National Library of Medicine MedlinePlus**  
medlineplus.gov

Search for: “Advance Directives” or “End-of-Life Issues”

**NIHSeniorHealth**  
nihseniorhealth.gov

This senior-friendly website from the National Institute on Aging and the National Library of Medicine has health and wellness information for older adults. Special features make it simple to use. For example, you can click on a button to make the type larger.

**OTHER ORGANIZATIONS**

**AARP**  
601 E St, NW Washington, DC 20049  
1.888.OUR.AARP (1.888.687.2277; toll-free) | aarp.org

**Aging with Dignity**  
PO Box 1661, Tallahassee, FL 32302-1661  
1.888.5WISHES (1.888.594.7437; toll-free) | aarp.org

**American Bar Association**  
Commission on Law and Aging  
1050 Connecticut Ave, NW Suite 400, Washington, DC 20036  
1.202.662.8690 | americanbar.org/aging
MEETING WITH AN ELDER LAW ATTORNEY

It is important to prepare in advance for your meeting with an Elder Law Attorney. Many times, an attorney will try to speed the information-gathering process by sending you a questionnaire to fill out in advance. Even if an attorney doesn’t ask for documentation beforehand, it is still a good idea to bring a copy of all documents relevant to your situation to the meeting. Spend some time thinking about what you may have on hand and try to organize the documents in a logical manner.

MEETING CHECKLIST

The following is a checklist that will assist you in preparing for your meeting:

- Personal information
- Itemized list of the property (assets), including current value and the names listed as owners or account holders
- A list of your professional advisors
- A detailed list of assets and liabilities
- Banking and financial account information
- Copies of all estate planning documents, including wills, trusts and powers of attorney
- Copies of all deeds to real estate
- Copies of recent income tax returns
- Life insurance policies and cash values of policies
- Health insurance policies or benefit booklet
- Choice of executors, trustees and other personal representatives
- Admission agreements to any health care facilities
- List of names, addresses and telephone numbers of involved family members and caregivers, as well as financial planners and/or accountants
- Contact information for beneficiaries, and a list of specific requests

WHAT TO DISCUSS WITH YOUR ATTORNEY

Be sure to talk to your attorney about these three key issues:
1) Options for health care decision-making for the person with dementia
2) Options for managing the person’s property
3) Possible coverage of long-term care services, including what is provided by Medicare, Medi-Cal and other health insurance policies

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov
Reviewed by Alzheimer’s Los Angeles, January 2016 | NIH, July 2012
Scientist across the globe are researching medications that have the potential to prevent, slow or stop the progression of Alzheimer’s. There is an urgent need for more people to enroll in clinical studies and trials. This includes individuals 65 and older who don’t have any outward signs of Alzheimer’s but may be at risk for the disease.

For a complete list of clinical trials in your community, visit clinicaltrials.gov

Mary S. Easton Center for Alzheimer’s Disease Research at UCLA
710 Westwood Plaza 1-123
Los Angeles, CA 90065
310.794.6191
adc.ucla.edu

Rancho/UCS California Alzheimer’s Disease Center
7601 East Imperial Highway
800 West Annex
Downey, CA 90242
562.401.8130
adrc.usc.edu

Brain, Behavior, and Aging Research Center
VA Greater Los Angeles Healthcare System
1121 Wilshire Blvd.
116AE, Bldg. 401, A2111
Los Angeles CA 90073
310.478.3711 x42386
semel.ucla.edu/alzheimers

University of Southern California
1510 San Pablo Street, HCC 643
Los Angeles, CA 90033
323.442.7686
adrc.usc.edu

CNS
2600 Redondo Avenue, 5th floor
Long Beach, CA 90806
855.425.1515
cnstrial.com

Schuster Medical Research Institute
5000 Van Nuys Blvd. Ste. 216
Sherman Oaks, CA 91403
818.788.0747
smrionline.com

Cedar-Sinai Medical Center
Department of Neurology
217 S. San Vicente Blvd. A6600
Los Angeles CA 90048
310.423.5357

Parexel International Memory Clinic
1560 E. Chevy Chase Drive, Ste 140
Glendale, CA 91206
818.254.1970
parexel.com/losangeles

Huntington Medical Research Institutes
686 South Fair Oaks Avenue
Pasadena CA 91105
626.795.4343
hmri.org/aging-brain-study/