

Early Memory Loss Programs: A Best Practice Guide

April 2012

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THE VISION

Early Memory Loss (EML) Programs and Clubs are slowly emerging across the country at grass-root levels as the spotlight on preserving memory and independence takes center stage. Growing research indicates there are steps we can take to promote brain health and sustain cognitive abilities (Fratiglioni et al., 2004; La Rue et al., 2010) and to enhance well-being in persons with dementia (Olazarán et al., 2010). Although there is no magic ingredient to ensure protection of the mind, a combination of physical activity and mental exercise in a social group setting is now being emphasized. These interventions can foster a pathway to active aging, improving quality of life, and helping to maintain independent living.

New technology and improvements in diagnostic criteria have enabled dementia and other memory disorders to be detected and diagnosed with a high degree of accuracy (McKhann et al., 2011). Advances are also being made in identifying milder forms of cognitive loss that often precede dementia by several years (Albert et al., 2011). Many individuals with early memory loss are faced with fear of the future, loss of jobs and income, and the addition of new expensive medicine to an already costly medical regime. They are seeking ways to be more proactive regarding their brain health and seeking interventions that offer hope and a sense of control of their lives. The message from these advancements is to expand opportunities for early detection, and utilize treatment and intervention recommendations.

The present guide is the product of an informal collaboration between community-based care providers and researchers who share an interest in helping people with early memory loss. Project partners have included staff members from the Wisconsin Alzheimer's Institute (WAI) in the School of Medicine and Public Health at the University of Wisconsin-Madison; the Helen Bader and Brookdale Foundations; the Alzheimer's Association of Southeastern Wisconsin; the Alzheimer's and Dementia Alliance of Wisconsin; and professionals in the area of dementia care from WI: Curative Care Network (Milwaukee/Waukesha), The Lutheran Home (Wauwatosa), Luther Manor (Wauwatosa), MemoryMatters (Sheboygan Falls) and MemoryMindors (Ozaukee County) and Brain Boosters, (Fairfield, CA).

Wisconsin has a unique asset in its network of more than 40 Wisconsin Alzheimer's Institute affiliated diagnostic clinics located throughout the state. These clinics are playing a key role in identifying dementia in early stages, when available interventions may have their greatest benefit. In response, our goal has been to facilitate the development of EML programs in every Wisconsin community having a memory diagnostic clinic. By providing practical guidelines and research based best practices, our hope is that throughout the United States, other quality early memory loss programs will emerge. These programs are critically needed in every community to help support and offer hope to those living with memory loss.

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DEFINITIONS

What is Early Memory Loss?

A broad descriptive term – **Early Memory Loss (EML)** – is used to refer to the set of cognitive conditions that may affect people who could benefit from EML programs. Two of the most common conditions that produce early memory loss are Mild Cognitive Impairment and early-stage dementia.

Individuals with **Mild Cognitive Impairments (MCI)** have cognitive problems that exceed what is expected for their age and background but are not severe enough to warrant a dementia diagnosis. Most persons with MCI function well in familiar everyday activities and are usually aware of, and often worried about, their cognitive changes. MCI is a risk factor for developing AD or other dementias. Some experts think of it as a preclinical stage of dementia, but not everyone with MCI goes on to develop dementia.

Dementia is a clinical syndrome characterized by decline in cognitive function severe enough to interfere with everyday social and occupational function. Deficits in learning and memory are prominent in the most common forms of dementia, and there may also be changes in judgment, reasoning, language, attention, and visual-spatial skills, as well as mood and personality problems. **Alzheimer's disease (AD)** is the most common cause of dementia among older adults. AD is a progressive neurological disorder, but the rate of decline varies. In early stages, persons with AD retain many important skills.

At a very early (borderline) stage of clinical dementia, individuals can still perform all basic activities of daily living satisfactorily. If they withdraw from demanding jobs or hobbies, they may function well (in less demanding circumstances) for years. At a mild dementia stage, individuals can still function well in the community with some assistance (mainly oversight and planning help for more complex tasks). They can dress, bathe, choose their own clothing, and travel to familiar locations with few or no problems.

There are many other neurological conditions that can cause a dementia syndrome, including cerebrovascular changes and head injury. Each type of dementia has its own typical clinical course, and in some cases, dementia is not progressive. All share the common feature, however, of decline from a previous higher level of cognitive ability. Most importantly, persons with any of these disorders may be candidates for EML programs.

It is important to distinguish between EML, which can affect individuals of any age, and **younger-onset dementia**, which refers to dementia that starts prior to age 65. EML programs may be appropriate for adults of any age, but most participants are likely to be over age 65.

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What is an Early Memory Loss Program?

Early Memory Loss Programs focus on enhancing cognition and well-being for those with mild memory loss or early stage dementia with the intent to promote and prolong independence. These programs are specifically designed to preserve and challenge cognitive abilities, teach memory strategies and encourage active lifestyles.

THE PERSON SERVED

Who is a good candidate for EML programs?

People attending EML programs have early stage memory loss. They may still be driving, working, or recently retired due to memory issues. Problems with memory and other cognitive changes may be displayed in several ways (e.g., missing appointments, difficulties managing personal finances, forgetting to take medications, not eating as well, etc.), and the earliest changes may be subtle and evident only to those who know them well. Participants in EML programs may recognize their cognitive changes, but if not, they do accept that others recognize their memory loss symptoms. They could be showing personality changes such as increased anxiety, decreased self-confidence, depression and/or withdrawal from familiar activities. Persons attending these programs should be able to manage their personal hygiene and medication needs independently during the program hours. It is common for an individual to be curious about the program but unsure of how they will “fit in”.

People who receive the greatest benefit from an EML program typically have a Mini-Mental State Score between 21 and 30 and score in the range of 1-4 on the Reisberg Global Deterioration Scale, with a majority at stage 2 or 3, taking into consideration education level, literacy and situational factors. (See assessment tools- Appendix A) They are generally able to express ideas in a small group setting either verbally and/or in writing and engage in mental fitness with minimal frustration. They are able to transition from one activity to another throughout the days’ programming. Even though they may choose not to, they are able to engage in social activities and conversation and feel comfortable with topics related to memory loss.

Another key aspect to consider when evaluating prospective participants for an EML program is to assess the potential they have to utilize the memory techniques/strategies and mental fitness exercises recommended throughout the program. These individuals will have the potential to learn new strategies to live with memory loss and apply them in their daily lives. With encouragement, they could be motivated to further engage in community life and to proactively address their health and cognitive concerns.

It is important to remember that there is not a universal template to use when considering someone for an EML program. During the assessment process, it is

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essential to look at each person's individual strengths and how their experience with memory loss can be addressed by the program.

Current EML providers are identifying different support needs for persons diagnosed with younger onset dementia. Concerns commonly expressed by these individuals include potential loss of job/income, changing family roles, desires for community engagement and opportunities to connect with peers.

THE FRAMEWORK

EML programs are unique in that the framework is designed to specifically address memory loss concerns at the earliest stage. Individualized EML interventions have been developed and implemented (e.g., Arkin, 2007; Clare et al., 2002; La Rue, 2011); however, this guide focuses on social EML programs that give persons living with memory loss the opportunity to meet with peers in a small, confidential group setting. Research on the efficacy of cognitive enhancement programs for persons with MCI and mild dementia is in early stages, but some promising outcomes have been observed for small-group programs (e.g., Bellevue et al., 2006; Fritsch et al., 2011; Olazarán et al., 2004). Existing EML programs are predicated on the assumption that, by working on preservation of abilities, individuals will have a better sense of their own health and well-being and will be empowered to implement strategies and lifestyle modifications to live with memory loss. This goal is addressed with support from peers as well as trained professionals.

A successful EML program incorporates the following pillars as core components in the overall program:

- Cognitive and mental fitness exercises
- Education related to memory and brain function
- Social interaction with peers that encourages participant input
- Incorporates physical activity and/or education on the benefits of physical activity and nutrition
- Opportunities to learn memory enhancement techniques and strategies to live with memory loss
- Access to information about local resources and support services for individuals living with memory loss and their families
- Emphasis on laughter and humor
- Camaraderie and support from peers living with memory loss
- Opportunities for creativity
- Encouragement to participate in civic engagement and community life

Individuals are encouraged to attend the program on a regular basis to reach the following program goals:

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- Build self confidence
- Provide personal support
- Foster independence
- Encourage mental and physical fitness outside of class
- Promote physician evaluation and/or memory clinic assessment and follow up

THE LOGISTICS

Types of Programs

EML programs are able to be formatted in a variety of ways to meet the needs of consumers in the community. Models currently operating use terms such as “class”, “club” or “program” to describe offerings available. Programs can be time limited such as 4, 8 or 12 weeks in duration, and these often have a strong educational component. Participants in these programs have the option of utilizing the program once or registering for additional series. Other programs are ongoing and meet on a regular, weekly basis. These programs focus more on the ongoing integration of physical, mental, creative and social activities.

Many groups meet two days weekly; however, in some communities one day a week meets the demand. In other communities, the demand for services requires programs to be offered up to five days weekly. The length of a program session varies from two to four hours. The groups that offer four hour programming also provide a meal which is included in the daily fee. Community outings may be offered but are not a key component in these types of groups. Some groups offer a structured component for caregivers while other groups provide one-on-one support to families as needs arise. All programs should, however, refer caregivers to resources in a timely manner. Even though the groups offer diverse programming options, they all utilize the core components mentioned in the framework section of this guide.

Leadership

Program Director: Oversight of EML programs needs to be provided by a degreed professional who has thorough knowledge of dementia with a specific focus on early symptoms. This individual needs to be comfortable communicating with persons served and their families on topics related to memory loss. They will be able to effectively assess individuals for the program, communicate participant changes/progress, and implement transition plans when the program no longer meets the needs of the person served.

Program Facilitator: This person does not need to be a degreed professional; however, he/she needs thorough knowledge of dementia with a specific focus on early symptoms. The facilitator must have the appropriate skills to work with a group, usually older adults, in a way that promotes positive engagement and peer support. The facilitator needs to

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have good communication skills, be flexible with the daily agenda, and be knowledgeable of each participant's strengths and deficits.

The program director and facilitator can be one and the same; however, this person must have the qualifications of the program director as defined above. It is important to remember that memory loss affects each person and his/her care partners differently. To accommodate these differences, both the program director and facilitator need to possess skills to empathetically work with participants who have early memory loss in a way that values their personhood. It is strongly recommended that programs have a ratio of one qualified staff to no more than 6 participants (1:6). This ratio can be met with paid staff and/or reliable trained volunteers.

Assessment Process

Initial Evaluation: There are two processes to consider when conducting assessments for potential new participants entering an EML program. These are both informal and formal in nature. The informal evaluation is conducted in a variety of ways. This could be an interview process in which specific questions are asked such as "What brings you here today?" and "Why are you interested in this program?" The intent is to be able to assess the individuals' awareness of their memory loss concerns and what their interests are in attending the program. Another informal assessment method is to welcome them to participate in a day of programming. This allows program facilitators to assess each individual's personality, cognitive abilities, social skills and level of comfort with mental fitness work.

Various formal assessment tools such as the Mini-Mental State Exam (MMSE), the Global Deterioration Scale, the Saint Louis University Mental Status (SLUMS), the Mini-Cog, the Animal Naming Test and the Clock Draw may also be used in the enrollment process as well as the ongoing assessment of the individual. (See Assessment Tools - Appendix A) It is important to understand that each person is unique and that test scores should not sit in isolation when assessing an individual's ability to successfully participate in the program. If formal tools are used as part of the assessment process, it is important to understand that the tools alone will not fully gauge the person's ability to benefit from the program. A balanced use of formal and informal processes will provide a comprehensive assessment of an individual's full potential.

Ongoing Assessment: A good benchmark for program participation is to look at abilities in key areas such as attention, concentration, language, calculation, reasoning, following of directions and memory. If an individual's mood, frustration level and/or affect is changing and posing challenges in multiple areas of abilities, it may be time to consider a transition plan. Ongoing assessments can be useful if conducted on a six to twelve month basis.

Transition Plan/Referrals for other or additional services: Ongoing communication with participants and their care partners is essential for smooth transition planning. For programs that are ongoing, it is recommended that transition planning begin at

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enrollment. Program leaders should clearly communicate that the person may need to transition out of the program at some point due to the fact that memory loss may be progressive. As a person's needs change, additional resources may be necessary to support the individual. When assessments are conducted on a regular basis (either formal or informal), this provides the opportunity to connect people to the appropriate professionals and supportive resources. Repeat assessments also engage the program leadership, the participants with memory loss and their care partners in the transition process.

Formalized Enrollment

The following items are recommended as necessary to have available on site for all EML programs:

- Assessment tool addressing activities of daily living skills, social skills and physical abilities
- Brief Medical History
- Consent for Photo Release
- Emergency Contact Information
- Enrollment Agreement
- Fees for Service
- Permission for Medical Emergency Care
- Self-Assessment of Memory Loss Concerns

Environment

The program needs to meet in a physically dedicated space. This can be a stand-alone building or a room within a building that offers other programs. However, the space needs to be utilized exclusively for EML participants during the program's hours so as not to compete with activities/distractions from other programs. The layout of the space should be conducive to group interaction and safe mobility.

Small groups are essential for the success of these programs. Group sizes are recommended to be between four to twelve participants per session. This allows program facilitators time to meet the individual needs of each participant when completing mental fitness work. Participants also have the opportunity to build trusting relationships with one another thus gaining the benefits of peer support. The value of small group programming for persons living with early memory loss cannot go understated. The goals of EML programs will not be attainable in a large group structure thus defeating the original intent of these programs.

Program Quality Assessment

Program assessment needs to be done on an annual basis to evaluate quality and effectiveness for the individuals and their care partners. Areas to address may include, but are not limited to: person served goal achievement, cost, accessibility, and overall satisfaction to the participants, their care partners and referral sources. These

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assessments will guide the program leadership to maintain a therapeutic, sustainable and viable service for those with early memory loss.

Participants' Perspectives

Early memory loss programs are critically needed in every community to help support and offer hope to those living with memory loss. This guide identifies specific goals for individuals attending early memory loss programs. People who have attended programs that implement these guidelines have expressed their personal success in achieving these goals. Here are their words:

Build self confidence

"I started to close myself in and stay in my apartment because I didn't trust my ability to converse with others. I've found I need to do just the opposite and be around people. The class has given me a lot of confidence in myself." Rita, program participant

"The program helps me evaluate my present condition. The assignments are the tools that help my cognitive thinking abilities. I like the presentations. Also, the informal discussions help to or force you to stay active in current events; and, the exercises do help physically. They help reduce my problems with brain fog. I like the test at the end of the presentations". Trent, program participant

"I love being in this group of people. I have learned a lot about myself. It makes my mind work harder. And it actually makes you look at yourself." Colette, program participant

Provide personal support

"The program has been a very positive experience for both my husband and me because of the socialization, education and recreation that he receives. The smallness of the group makes the experience more comfortable- for instance he feels less inhibited when sharing his story about his journey through this disease. Most of all, I believe that his self-esteem has been enriched by attending." Pat, wife & care partner of participant

"We meet new people who are in the "same place" you are – knowing you're not alone. You become friends and enjoy each other. My mind is clearer since I started coming here". Bev -volunteer at program

"It's the highlight of my week!" Bee, program participant

Foster independence

"I'm using all the memory tips and they are helping!" Betty, program participant

"I believe over the many sessions of which my husband has been a part, he has gained a sturdier sense of managing on his own in a social situation. Because he remembers so little, I have no way of knowing how much he has interacted, but I know he has made

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all his own phone arrangements to be picked up, has paid the bus driver, and has completed all the paper work that is part of each week's session.

His density of memory loss increases, but his relationships with his family and with our closest friends has actually been enhanced as he has seemed to grow in that area of his brain." Winn, wife of program participant

Encourage mental and physical fitness outside of class

"It has been life-changing for me. I have made friends, broadened my horizons and tremendously enjoyed the mental challenges. I like learning from others and exploring new topics our discussions raise. I have learned new skills and helpful ways to retain information. It has given me a focus and a purpose which has greatly enriched my life."

June, program participant

Promote physician evaluation and/or memory clinic assessment and follow up

"The brain needs stimulation as the body needs food. Memory clubs provide a stimulating and social environment for the ongoing benefit of participants." Piero Antuano MD

"My neurologist says that this (EML program) has been the best thing that has happened to my memory!" Jim, program participant

Concluding Comments

People living with memory loss are being uniquely impacted by early memory loss programs. Intervention at the earliest stages and attendance at these programs provide hope, new opportunities and the ability to maintain independent living for as long as possible.

Early memory loss programs will continue to evolve as additional research surfaces and individuals affected voice their needs. This guide integrates evidence based research and consumer input to provide a firm foundation to build future programming.

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THE APPENDICES

Appendix A

Assessment Tools

This section describes and references a few of the standardized assessment tools that may be useful in evaluating candidates for EML programs and tracking their cognitive changes over time. As noted in the Guide, both informal and formal approaches to assessment are invaluable in deciding about individuals' prospects of benefitting from a particular program. Standardized tools are especially valuable for documenting benefits of EML programs for health care administrators, granting agencies, and the community at large.

This brief survey of assessment tools is not intended to be exhaustive, but rather, the aim is to highlight a few simple instruments appropriate for community-based programs.

Global Deterioration Scale (GDS):

The Global Deterioration Scale rates the severity of an individual's dementia on a scale from 1 (no cognitive decline) to 7 (very severe cognitive decline). Information for ratings is obtained through interview of a caregiver or other person knowledgeable of the everyday living skills of the person with dementia. Staff members at the Wisconsin Alzheimer's Institute have found the GDS to be useful in staging dementias of all types, with the possible exception of frontotemporal dementia.

The original reference for the GDS is: Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry* 1982;139:1136-1139.

The Alzheimer's Association website provides a good description of the seven stages on the dementia as defined by the GDS: see http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

A user-friendly form of the GDS can be obtained at: <http://web.missouri.edu/~proste/tool/cog/Global-Deterioration-Scale.pdf>

Mini-Mental State (MMSE):

The MMSE, developed in 1975, has been the most widely used cognitive mental status exam in the United States. It takes about 10 minutes to administer to older adults and taps several important cognitive abilities. Because the MMSE has been available for many years and extensively studied, it remains a useful tool. However, users should be aware that it is relatively insensitive to Mild Cognitive Impairment and early-stage dementia, at least as commonly used.

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The MMSE is a copyrighted test. Since the developers transferred intellectual property rights to Psychological Assessment Resources (PAR), Inc., the copyright is being enforced, and users must purchase the test manual and forms from PAR. Purchase information can be obtained at: <http://www4.parinc.com/ProductSearch.aspx?q=MMSE>. PAR is also marketing an updated version, the MMSE-II.

The original reference to the MMSE is: Folstein MF, Folstein SE, McHugh PR (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician". *Journal of Psychiatric Research*, 12 (3): 189–198.

The Mini-Cog:

The Mini-Cog is a very brief cognitive screening tool comprised of learning and recall of 3 words and an easy-to-score clock draw task. It takes only about 3 minutes to administer and has demonstrated utility for cognitive screening in diverse populations of older adults, including persons with limited education.

A useful early reference for the Mini-Cog is: Borson, S., Scanlan, J.M., Chen, P., & Ganguli, M. (2003). The Mini-Cog as a screen for dementia: Validation in a population-based sample. *Journal of the American Geriatrics Society*, 51(10),1451-1454.

A helpful guide to the use of the Mini-Cog has been prepared by the Hartford Institute of Geriatric Nursing. It can be accessed at:

<http://www.wai.wisc.edu/pdf/phystoolkit/screeningtools/mini-cog.pdf>

The Mini-Cog is a copyrighted test. The test developer, Dr. Soo Borson, has been generous in approving various uses of this test at no cost. New users of this test should contact Dr. Borson directly (soob@u.washington.edu) to describe their plans for the Mini-Cog and request permission.

The Saint Louis University Mental Status (SLUMS) Examination:

The SLUMS is another relatively brief cognitive mental status exam that has shown promise for detecting milder stages of dementia.

The SLUMS test form is available at:

<http://aging.slu.edu/index.php?page=saint-louis-university-mental-status-slums-exam>

The original reference for the SLUMS is: Tariq, S.H., Tumosa, N., Chibnall, J.T., Perry, H.M. III, & JE Morley, J.E. (2006). The Saint Louis University Mental Status (SLUMS) Examination for detecting mild cognitive impairment and dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. *American Journal of Geriatric Psychiatry*, 14, 900-910.

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Animal Naming:

Naming of items from a specified category has long been used as a test of verbal fluency and ability to access semantic memory. Because word-finding problems are an early and often bothersome sign of dementia, tasks such as animal naming have proved useful as cognitive screening tools.

Animal naming is included in the Boston Diagnostic Aphasia Examination and has been used in many clinical research studies. Administration instructions vary. Researchers at the Wisconsin Alzheimer's Institute have documented the utility of a simple 60-second version in screening for Alzheimer's disease and several other types of dementia.

Instructions and findings for this version of Animal Naming can be found in: Sager, M.A., Hermann, BP, La Rue, A., & Woodard, JL. (2006). Screening for dementia in community-based memory clinics. *Wisconsin Medical Journal*, 105, 25-29.

Clock Draw:

Drawing of a clock and setting the hands to a specified time has also been used for many years as a cognitive screening task. As with Animal Naming, administration instructions and scoring vary across sites and applications.

The version of Clock Draw included as part of the Mini-Cog is among the easiest to administer and score, and use of that form is recommended for screening in community settings.

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Appendix B

Deciding whether to participate in Clinical Trials and Studies

Adapted from “Participating in Alzheimer’s Disease Clinical Trials and Studies Fact Sheet” (NIH Publication No. 09-7484 September 2009) with permission by the Alzheimer’s Disease Education & Referral (ADEAR) Center, a Service of the National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services.

Our understanding of Alzheimer’s disease and how to treat the illness is dependent on the contribution of research volunteers. Study investigators recognize the important role of research volunteers, and want potential participants to have all the facts. Having a conversation with study personnel and asking some key questions will help you make an informed decision.

What type of research is being conducted? Could I receive a placebo?

Clinical research is medical research involving people. It includes *clinical studies*, which use long-term observation and analysis in large groups to determine how a disease or condition may occur and progress, and *clinical trials*, which test possible interventions to diagnose, prevent, treat, and someday cure a disease.

Clinical studies observe people by asking questions, collecting samples or performing tests. Clinical studies do not involve treatment or interventions. Researchers gather baseline information, group volunteers according to broad characteristics, and compare changes over time. Clinical studies of Alzheimer’s disease may help identify new possibilities for early detection of the illness or new methods to slow the progression of memory loss.

Clinical Trials involve interventions. Scientists conducting Alzheimer’s disease research test a theory by using the classic scientific method. They first identify a valid question related to Alzheimer’s. The question is posed as a hypothesis that is either proven or disproven by the clinical trial.

The “gold standard” for testing interventions in people is the randomized, placebo-controlled clinical trial, because it is designed to reduce error or bias. Volunteers are *randomly assigned*—that is, selected by chance—to either a test group receiving the experimental intervention or a control group receiving a *placebo*, an inactive substance resembling the drug tested, or a behavioral intervention thought to have little or no effect on the outcomes. By comparing results between the treated and placebo-groups, the investigators learn whether changes in the test group result from the treatment.

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What Happens When a Person Joins a Clinical Research study? What tests and treatments will be given? How long will it last? How much time will it take?

It is important to learn as much as you can about the trial. Staff members at the research center are trained to explain the research in detail and describe possible risks and benefits. Ask questions if you do not understand. Staff will also clarify your rights as a research participant. Participants and their families can have this information repeated until they are sure they understand it.

What are the risks of participating in the research study?

There are risks involved in clinical research, just as in everything we do throughout our day. However, you take the risks in research for the benefit of science and society. You will not benefit directly in a clinical study and may or may not benefit from an intervention in a clinical trial.

What are the Benefits of Volunteering?

Most people to participate in clinical research do so because it will help others, including future family generations, who may be at risk for Alzheimer's disease. Even if we find out that a treatment does not work, it helps. For example, we will know to invest time and resources in other treatment options. Still, there are some indirect benefits to being in research. Participants in clinical research receive regular monitoring by Alzheimer's professionals, and learn more about the disease from experts. Knowledge is power. Additionally, participants can get information about support groups and other community resources.

What is the purpose? Who is funding the research?

Ask why the research is being done, and who is funding the research. The federal government funds research through National Institutes of Health, the Department of Veterans Affairs, and numerous other agencies. Pharmaceutical companies also fund clinical trials. Finally, much research is supported by a partnership of federal, state and pharmaceutical entities.

Why do I sign a consent form?

After questions are answered, participants sign an *informed consent form*, which contains key facts about the trial. The form does not obligate you in any way. You sign it in order to document that you and the research staff had a discussion about the research, and that you are a willing and informed volunteer. Clinical research volunteers have a right to receive clear, complete information and to withdraw from a project anytime.

Clinical Trials and Studies Need All Kinds of People

Clinical trials and studies are a partnership between researchers and volunteer participants, who work together to answer questions about humans. We cannot answer these questions in any other way. Ensuring that those answers are correct requires that projects include volunteers of all kinds: men and women, African

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Americans, Latinos, Native Americans, Asian Americans, whites, people with Alzheimer's or a family history of the disease, people with conditions that may lead to Alzheimer's, and those without the disease (controls).

An intervention may work differently in one group than in another. Without adequate representation of a particular group, questions about safety and effectiveness of a treatment in that group may remain unanswered. In addition to diversity, the number of people included in research can affect results. Changes or effects seen in smaller groups may or may not show up significantly in larger groups.

List of Questions you might ask about Clinical Trials and Studies

What is the purpose?

What tests and treatments will be given?

What are the risks?

What side effects might occur?

What may happen with/without this research?

Can I continue with treatments for Alzheimer's and other conditions as prescribed by my regular doctor?

How will you keep my doctor informed about my participation in the trial?

Does the study compare standard and experimental treatments?

How long will it last? How much time will it take?

Where and when will the testing occur?

How much flexibility will I have?

How will it affect my activities?

If I withdraw, will this affect my normal care?

Will I learn the results?

Could I receive a placebo?

What steps ensure my confidentiality?

Are expenses reimbursed?

Will I be paid?

For More Information

Wisconsin Alzheimer's Disease Research Center

UW Hospital

600 Highland Avenue, J5/1 Mezzanine

Mail code: 2420

Madison, WI 53792

Phone: (608)263-2582

Fax: (608)265-3091

E-mail: wcmp@medicine.wisc.edu

Wisconsin Alzheimer's institute

University of Wisconsin School of Medicine and Public Health

7818 big Sky Drive, Suite 215

Madison, Wisconsin, 53719

Phone: (608-829-3300)

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Fax: (608) 829-3315

www.wai.wisc.edu

Alzheimer's Association

www.alz.org

24/7 Helpline 800-272-3900

Contact the 24-hour, toll-free telephone line to link with local chapters, community resources, care/support resources, and TrialMatch. TrialMatch is a free service that makes it easy for people with Alzheimer's, caregivers, families and physicians to locate clinical trials based on personal criteria (diagnosis, stage of disease) and location. TrialMatch can be accessed through our 24/7 Helpline, 800-272-3900, 7:00 am – 7:00 pm CT, Monday-Friday or by visiting www.alz.org/trialmatch.

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250

Silver Spring, MD 20907-8250

1-800-438-4380 (toll-free)

www.nia.nih.gov/alzheimers/topics/research.

U.S. Food and Drug Administration (FDA)

www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ParticipatinginClinicalTrials/

The FDA regulates all U.S. clinical trials of drugs and devices and offers information and resources for clinical trials participants and professionals.

Center for Information and Study on Clinical Research Participation (CISCRP)

www.ciscrp.org

www.smartparticipant.org

CISCRP is an independent, national nonprofit organization working to promote greater understanding and awareness of clinical research participation and the role it plays in public health.

Project IMPACT (Increase Minority Participation and Awareness of Clinical Trials)

www.impact.nmanet.org

Project IMPACT, an initiative of the National Medical Association, seeks to increase awareness and participation of African Americans and other minorities in clinical trials and research.

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Appendix C

Mental Fitness Resources

Card Packs/Games

Logic Links © 2006 Mindware
Mental Fitness Cards Attainment Company
Qbitz © 2009 Mindware
Sharpen Your Senses Cards... Attainment Company
Thinking Cards Attainment Company
Triplica © 2009 fund Q Games, Inc.
Tri-Spy © 2008 IQ-Spiele © HUCH! & Friends (distributed by Fat Brain Toy Co.)
Twenty Question Cards™ University Games

Books:

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Websites:

<http://www.alz.org>

<http://www.eyecanlearn.com>

<http://www.factacular.com>

<http://www.happy-neuron.com/>

<http://www.kenken.com>

<http://www.mathfactcafe.com>

<http://www.peoplequiz.com>

<http://www.printactivities.com>

<http://www.sciencedaily.com>

<http://www.sharpbrains.com/>

<http://www.timeslips.org>

<http://www.tribond.com>