



Living Well: Replication Manual

*A description of a pilot program for people with early dementia/
mild cognitive impairment and their care partners*

J U N E 2 0 1 5

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Contents

Introduction.....	2
Background information.....	4
Pilot program partners.....	4
Program replication.....	6
Major program goals and components.....	6
Programming for persons with early dementia.....	7
Programming for care partners.....	8
Schedule.....	9
Program basics.....	11
Marketing and recruitment.....	11
Intake.....	11
Staffing considerations.....	13
Physical space and equipment.....	13
Privacy issues and safety.....	14
Communication.....	14
Miscellaneous program considerations.....	14
Evaluation.....	17
Appendix.....	20
Appendix A: Definitions.....	20
Appendix B: Marketing materials.....	21
Appendix C: Screening and intake forms.....	24
Appendix D: Registration materials and program forms.....	32
Appendix E: Waivers and safety information.....	41
Appendix F: Sample email communications.....	44
Appendix G: Sample poetry.....	45
Appendix H: Physical assessment protocols and scoring.....	47
Appendix I: Participant and care partner information.....	52

Introduction

Living Well offers person-centered services to enrich and enhance the lives of people with early dementia, and their care partners. The program fills a critical service gap by providing structure, meaningful activities, and opportunities for social connections through participation in health, fitness, education, creative arts, and community outings. Living Well supports people with early dementia to actively engage in the community and feel confident about their participation. The program also provides care partners with an opportunity to receive support early in the process of caring for someone with early dementia, through participation in educational activities with peers and access to other community resources.

The following program components make Living Well unique:

- It fills a gap in services for people with early stage dementia
- Education, exercise, and the creative arts encourage full participation and engage people with early dementia in a holistic and meaningful way
- Professional artists provide enhanced programming with purpose, meaning, and creativity.
- It provides simultaneous and separate support for care partners, and connections to other community resources
- Program participants are engaged and integrated in the community
- Program participants build connections with each other in a group setting
- Access to the dedicated transportation services has improved the capacity and flexibility of the program to provide activities according to a schedule that meets participants' needs
- The curriculum is flexible and adaptable, and customized for the participants

Living Well is offered in 12-week sessions, meeting once a week for four hours. Program participants and care partners meet at the Jewish Community Center. The schedule of activities remains consistent, while the activities and topics themselves vary each week.

Living Well is a collaborative program of the Jewish Community Center of the Greater St. Paul Area, the Alzheimer's Association of Minnesota-North Dakota, and Amherst H.

Wilder Community Services for Aging. It was funded by a three-year Community Service/ Services Development (CS/SD) grant from the Minnesota Department of Human Services.

To satisfy grant requirements, Wilder Research was hired to create a replication manual for the Living Well program.

A reference guide of definitions for terms used in this document is located in Appendix A.

Background information

According to the 2015 Alzheimer's Disease Facts and Figures report¹, published by the Alzheimer's Association, there are now more than 5 million Americans with Alzheimer's disease. As the population of older people increases, the incidence of Alzheimer's disease is also increasing. In fact, the number of people with Alzheimer's disease in Minnesota is expected to increase by nearly 35 percent from 2015 to 2025.

A number of initiatives recently implemented by the Alzheimer's Association promote early identification and diagnosis of Alzheimer's disease and related dementias (ARD), with the hope of empowering people and families to make informed plans for their futures. The goals of these initiatives included improving the number of and access to early-stage services, working to reduce the stigma of Alzheimer's disease, and collaborating with a variety of organizations and services to achieve these goals.²

In spite of the push for earlier diagnosis, it is also generally accepted that there are few community-based programs available to people diagnosed with early stage dementia, with the majority of services provided for people with mid- to late-stage dementia. Many of the available programs are offered to the participant/care partner dyad. Through CS/SD funding received in 2009, the Wilder Foundation and Alzheimer's Association implemented the Memory Club and Graduate Club in response to the unique needs of people with early-stage dementia and their care partners.

Numerous studies have identified the importance of social connections and physical activity in improving general well-being, including overall cardiovascular health, for people with dementia.

Pilot program partners

This program was funded by a Community Services/Service Development grant. Three partners collaborated to develop, market, provide in-kind contributions, and deliver the Living Well Program: Jewish Community Center of the Greater St. Paul Area, the Alzheimer's Association Minnesota-North Dakota, and the Wilder Foundation.

The Jewish Community Center of the Greater St. Paul Area (JCC) is a social service agency that offers programs and services for individuals and families from birth to the most senior members of the community. Currently serving over 6,000 individuals living

¹ Retrieved from: http://www.alz.org/downloads/Facts_Figures_2015.pdf

² History of the Alzheimer's Association Early-Stage Initiative.
Retrieved from: <https://www.alz.org/documents/national/EDInitiative.pdf>

in the east metro area, the JCC provides nurturing childcare for the children of working families; a highly-rated, state-of-the-art fitness facility for active adults; cultural and educational programs for all ages; a wide range of services for older adults striving to live independently; and a comprehensive program of inclusion and accessibility for individuals with disabilities. The JCC provided the physical facility for programming and fitness, transportation, and materials for activities. The director of adult services was also the on-site liaison for Living Well.

The Alzheimer's Association Minnesota-North Dakota (AAMND) has been providing services, information, and advocacy for over 30 years to people with dementia, their families, and health care providers. The AAMND agreed to provide support staff (the Early Stage Services Manager) to assist in the development and implementation of the program, as well as provide copies of the Living Well Workbook, an evidence-based educational tool used in Living Well³. THE AAMND also developed and distributed marketing materials, and helped recruit participants by making information about the program available through referrals.

The Amherst H. Wilder Foundation, founded in 1906, has a long history of providing community-based services for older adults in the east metro area. Wilder provided two staff people from its Aging Services division to design, coordinate, and deliver program activities through the Occupational Therapy program, and one social worker from the Caregiver Services program to deliver care partner education and support services. A number of occupational therapy and master's degree-level social work interns also provided assistance. Wilder also helped recruit participants, recruited and trained volunteers, and managed the program delivery.

³ Living Well: A Guide for Persons with Mild Cognitive Impairment & Early Dementia was produced in 2011 by the Alzheimer's Association of Minnesota-North Dakota, in partnership with HealthPartners Center for Memory & Aging, and the University of Minnesota Center for Spirituality & Healing. The workbook includes information about wellness strategies and practical suggestions for building a personal plan for living with dementia. It is available for download at http://www.alz.org/mnnd/documents/Alz_LIVING_WELL_Workbook_2011_web.pdf

Program replication

This replication manual documents the components of the program, as well as key lessons and best advice gained during the implementation of this pilot program.

One of the key features of the Living Well program is its ability to respond to the changing needs of program participants and care partners in each session. As such, this manual should be viewed as a description of the Living Well program as it functioned during the pilot phase, rather than a prescriptive outline for replication. The information contained in this manual can be used to create a program, based on a framework, which will be responsive to the needs of the participants and care partners being served in the new iteration.

Major program goals and components

Living Well uses a multi-disciplinary approach that combines social work and occupational therapy principles. The result is a unique and comprehensive framework that promotes every day applications to support health and wellness in community settings.

Living Well has two main goals:

- Improve the system of support for persons with early stage dementia and their care partners
- Improve the quality of life of persons with early stage dementia and their care partners through consistent high-quality programming designed to address their physical, emotional and social needs.

Living Well has four main components for persons with early stage dementia:

- Education
- Exercise
- Creative arts
- Community engagement

Living Well has four main components for care partners:

- Education

- Support
- Community network building
- Personal respite

Programming for persons with early dementia

Programming is intentionally fluid and flexible in order to meet the needs of the particular group of participants. As a result, each session is different, although the key components of creative arts, exercise, education, and community outings are similar throughout. Each program day is also a unique combination of physical activity, creative arts, community outings, education, and time for socializing. A general schedule is developed for each session, including formal contracts with the professional artists for specific dates, and formalizing group accommodations when necessary for community outings. Memory Care specialists are also engaged for presentations on topics related to cognitive impairment.

Participants are also asked to complete the Life Balance Inventory⁴ prior to the first class of the session (also in Appendix D). The Living Well workbook (see footnote on page 5) is used as a guide for goal-setting, and is referenced throughout each session.

The program partners built on prior relationships in the community with a number of creative arts specialists, including:

- Ageless Grace™: A fitness and wellness program that promotes a mind-body connection to improve health and well-being⁵
- Alzheimer’s Poetry Project™: A program designed to facilitate the creativity of people living with Alzheimer’s disease and other dementias, by engaging them in the performance and creation of poetry⁶ (A sample of this poetry is located in Appendix G.)
- Kairos Alive™ An interactive dance and storytelling program that promotes movement and creativity⁷
- Northern Clay Center: A national ceramic arts organization that provides workshops for adults at all skill levels⁸
- A variety of media arts specialists

⁴ Retrieved from: <http://minerva.stkate.edu/LBI.nsf>

⁵ <http://agelessgrace.com/about/>

⁶ <http://www.alzpoetry.com/>

⁷ <http://kairosalive.org/pages/about-kairos-dance/>

⁸ <http://www.northernclaycenter.org/about>

Community outings included:

- Nature locations (e.g., nature walks, parks)
- Historical locations (e.g., museums)
- Cultural events and locations
- Creative arts activities
- Community locations
- Service activities (e.g., Little Free Library)

Outings include lunch on site or at a location nearby.

Guest speakers included:

- Dr. Terry Barclay, Ph.D., Director of Neuropsychology, Health Partners Center for Memory and Aging
- Sara Tucker, M.A., Alzheimer's Association Minnesota-North Dakota
- Dr. Michael Rosenbloom, M.D., Clinical Director, Health Partners Center for Memory and Aging
- Community presenters on a variety of topics

Participants and care partners are provided with a membership to the JCC for the duration of the session, which allows unlimited access to the community center, fitness equipment, and fitness programs such as Silver Sneakers yoga.

Programming for care partners

Programming for care partners balances education and support with free time for respite through the Caregiver Café model. Caregiver Café is a caregiver support model created by the Wilder Foundation that is less formal than normal support groups and is led by two facilitators. The cafés provide informal family care partners an opportunity to discuss their unique caregiving situations through guided table talk in a relaxed café-like setting with coffee, water, and tea. The facilitator proposes questions and encourages personal reflection surrounding important issues experienced by care partners. The participants then converse with a partner before bringing highlights of their discussions back to the larger group. Through this method, caregivers are hearing and learning from others in

similar situations, as well as studying themselves in their roles as caregivers and gaining useful community resources.

Sessions cover a wide range of topics including:

- Travel accommodations
- Retirement
- Intimacy
- Self-care
- Future housing options
- When to encourage the person with the diagnosis to give up driving
- Communication with the person with early dementia
- Understanding behaviors of the person with early dementia
- Future planning

A social worker specializing in caregiving and dementia is also available for a one-on-one session with each care partner.

Schedule

The Living Well program is offered as a 12-week session, meeting for 4 hours once a week.

Care partners meet from 9:30 to 11:30 am for Caregiver Café for six of the twelve sessions. They are required to attend the first and last day of each session. In addition, care partners are invited to attend the Caregiver Cafés, which meet approximately every other week, to gain support from each other, participate in educational programming, and learn about other resources they may find helpful. The “off” weeks for the care partners allow them time for respite or to do tasks they have not been able to complete due to their caregiving responsibilities.

The following are examples of daily schedules designed for Living Well participants with early dementia, organized according to location (whether activities take place at the JCC or at another location). The first and last meetings of a 12-week session follow a different format.

The following are examples of the schedules.

First class for a new session schedule (example)

Time	Activity
9:30-10 am	Welcome/introductions of staff, participants, and care partners
10-11:30 am	Assessments: blood pressure, fitness, orientation to the JCC and tour of the fitness center*
10:30-noon	Caregiver Café (care partners)
11:30-noon	Lunch/social time (participants)
Noon-1:45 pm	Education—Living Well workbook
1:45 pm	Depart

Typical schedule 1—Stay at JCC

Time	Activity
9:30-10 am	Arrival, coffee, review schedule; Living Well workbook
10-noon	Arts Component
12:15-12:45 pm	Lunch/social time
12:45-1:45 pm	Fitness OR Education component
1:45	Depart

Note: No Caregiver Café this week

Typical schedule 2—Community Outing

Time	Activity
9:30 am	Bus departs for outing
9:30 am – 12 pm	Caregiver Café (care partners)
10-noon	Community activity
12:15-12:45 pm	Lunch/social time
1:00 pm	Bus returns to JCC
1:15-1:45 pm	Fitness OR Discussion
1:45 pm	Depart

Final class for a session schedule (example)

Time	Activity
9:30-10 am	Welcome/review daily schedule
10-11:30 am	Assessments: blood pressure, fitness, goals, post-session evaluation (participants)
10-11:30 am	Caregiver Café, post-session evaluation (care partners)
11:30 am-12:45 pm	Lunch/social time for all (participants, care partners, artists)
12:45-1:45 pm	Celebration, arts, and accomplishments for participants, care partners, and staff
1:45 pm	Depart

Program basics

Marketing and recruitment

Marketing and recruitment efforts were designed for broad outreach with a range of approaches, including:

- Agency partner referrals, including websites
- Agency helpline or case consultation
- Agency e-newsletters or e-blasts
- Agency outreach efforts
- Word-of-mouth
- Connections with individual communities
- Print materials (postcard, flyer)
- Media

Examples of marketing materials are located in Appendix B.

Intake

The intake process was modeled after the process used by Memory Club⁹, which has proved successful. Staff also determined that scheduling intake in one place (one agency), with one person was most efficient.

Interested people call for a phone screening, and if identified as potentially appropriate for Living Well programming, they are provided with written or electronic information about the program and are added to a queue for the next formal screening and interview series. Phone screenings include discussion of diagnosis, including stage of memory loss. A specific set of questions guide the phone screening with the care partner.

At the same time, staff share information about Living Well and participation in the program, including:

1. Education, exercise, arts or music, community outings and volunteering

⁹ Memory Club information retrieved from: <http://www.alz.org/mnnd/>

2. Group participation and dynamics
3. Transportation
4. Fees

Formal in-person screenings are completed with the people with early dementia to assess cognitive level and program fit. The screenings include interviews and implementation of the SLUMS¹⁰. At the same time, care partners are interviewed regarding their needs, and learn more about how they and their care recipients might benefit from participation. A specific set of questions guide the in-person screening. Information about the program is also provided to participants and care partners. Examples of the screening forms are located in Appendix C.

In order to be considered eligible for participation in Living Well, the following qualifications must be met:

1. Participants must have an awareness of their illness
2. Participants must have sufficient cognitive functioning to allow for active participation in the program
3. Participants must have sufficient social skills to allow for positive group interactions, as well as a willingness to try new things.
4. Baseline scores on standardized tests, and/or a score of 18 or higher on the SLUMS.
5. Participants must be in stable physical health, and independent in ambulation and personal care.

Following formal screening appointments, staff meet to discuss placement. The staff use their professional judgments and results from the screening to make a decision about inclusion in the program.

People with more advanced memory loss are referred to other programs, including the Alzheimer's Association, Wilder Adult Day Health, and Wilder Caregiver Services Program.

¹⁰ The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is a screening test that uses 11 questions to score cognitive impairment on a scale of 0-30. With consideration of educational level, scores indicate normal, minor neurocognitive disorder or dementia. The tool has been found to be particularly useful in detecting early symptoms of cognitive impairment.

Care partners are sent electronic copies of intake forms and asked to complete and return them prior to the first class session. Examples of registration forms are located in Appendix D.

Staffing considerations

Living Well staff have determined that Caregiver Café for care partners is most effective when two people facilitate the group. Staff have also determined that the program portion for participants is most effective when there are four to five staff people, and especially when the program is at capacity (12 participants), and for community outings. In both components of Living Well, student interns¹¹ and trained volunteers have proved to be an excellent resource for additional staffing.

Physical space and equipment

Space must be handicapped accessible and ADA approved. It is also important for participants to have a consistent space that will feel familiar to them, which they will be able to locate independently. Care partners need a designated room that will allow privacy and confidentiality.

Equipment was used to support and enhance multiple program activities and includes:

- Computer (and software) and an internet connection
- Music
- iPod and speaker
- Screen for computer hook up
- Paper flip chart, markers, and tape
- White board

Program staff also suggest developing a connection with an adult day center program (or similar) in order to access and borrow supplies such as cognitive games, art supplies, educational materials, and an emergency backpack for outings that may not be affordable individually. Wilder Adult Day Health program provided these materials for the use by the Living Well program.

¹¹ Student interns have been drawn from the following programs: St. Catherine's University and University of Minnesota (Occupational Therapy and Master's of Social Work), Augsburg University (Master's of Social Work)

Privacy issues and safety

Clear guidelines and an understanding between all program partners regarding HIPAA Privacy Rules is important in order to protect health information about program participants. Confidentiality is also important in conversations between staff members, and for data entry.

It is also important for staff to have emergency plans in place, including emergency phone numbers, for program participants. Samples of the emergency form and back of the name tag are located in Appendix E.

All participants must sign waivers. Samples of the Living Well Liability Waiver and Media Release Waiver are located in Appendix E.

Communication

Consistent communication between program partners, as well as participants and care partners, allows everyone to be prepared. Communication with participants and care partners occurs via email and telephone (for those without access to the internet or a computer). Two days before each meeting, program staff send out emails to remind participants and care partners about the upcoming schedule of activities, and to communicate any new information. Information may include new details about weather conditions that may influence the scheduled activity, or reminders about items to bring to the meeting. Samples are located in Appendix F.

Miscellaneous program considerations

Program staff and partners offered the following observations and advice for organizations considering replicating Living Well.

For program partners:

- Clearly defined program partner roles, including a clear division of labor, help to sustain strong communication on an on-going basis. The program is only as strong as its partners.
- Planning meetings need to include Caregiver Café and program participant staff, in order to represent the needs and schedule requirements of both partners in the dyads.
- Have dedicated computer equipment, time, and staff for data entry.

- Have dedicated time and staff for marketing, both initially and prior to each new session series.

For care partners:

- Be flexible, creative and responsive in order to keep topics fresh for repeat attendees.
- Adjust the frequency of sessions to offer an appropriate balance of support and respite.
- A key to the success of Caregiver Café is to establish a welcoming environment. This is achieved by providing a stable and permanent location to facilitate set-up, and a private space to protect confidentiality.

For arts component partners:

- Make sure that the artists have experience with or understand how to work/interact with people with early dementia.
- Provide education trainings to professional artists through ArtSage.¹²
- Provide information and instructions in advance.

For planning:

- Have a formal process for brainstorming and creating program activities.
- Designate a staff person outside of program participant staff to organize meeting dates and minutes, and perform administrative roles as needed.
- Allow 12 to 18 months for comprehensive planning and capacity building to launch the program.
- Planning for the initial program session requires 8 to 12 hours. Planning for subsequent sessions requires 3 to 4 hours.
- Allow 2 weeks for intake interviews and acceptance into program.
- Allow 1 hour for each intake interview.
- Allow 4 hours/week for record keeping.
- Always look ahead for ideas for the next sessions.

¹² ArtSage provides training and resources to facilitate connections between the creative arts and older adults.
<http://www.artsagemn.org/resources/>

- Do not underestimate the importance of planning and program time to support care partners, in addition to the program participants.

For marketing:

- Add a marketing person dedicated to outreach. Meet with doctors and clinics to inform them, and develop referrals.
- Find connections and programs where people are being diagnosed early and where professionals are interested in referring to programs. (This may help alleviate any challenges due to the stigma associated with early dementia, and reluctance to self-identify.)
- Create a letter that can be directed to professionals.
- When talking to potential participants, get their contact information and have the facilitator call them to enhance personal contact with program staff and expedite the process.

For budgeting:

- Make sure the costs of the care partner component (Caregiver Café) are included.
- Sustainability is a big issue. The program is very staff time intensive, including for planning. It is difficult to sustain Living Well on participant fees alone. Having no scholarships will exclude low income participants.
- Consider using a budgeting worksheet, in order to capture overhead with items such as stipends for presenters, equipment rental, office supplies, postage, and refreshments.

Evaluation

Thirty-seven people with early dementia and 32 care partners participated in the seven pilot sessions of Living Well. Eleven participants attended two or more sessions. Participants and care partners completed brief evaluation forms at the completion of each session to provide feedback on their experiences.

Perceptions of care partners. Thirty care partners in sessions one through four of Living Well completed the post-session evaluation form. Care partners appreciate the support they receive as caregivers and from each other, having a place in which their partners feel comfortable, and activities that broaden their partners' interests and skills.

- 80 percent of care partners rated the program as “excellent,” and 20 percent rated it as “good.”
- Examples of their comments about the program include the following:

The best part is the respect and dignity, smiles and warmth expressed by staff.

This is the only time I truly feel my love is in a safe place and I do not have to worry. He loves the activities, the community...and the staff's inclusivity.

I like the balance of educational activities and physical activities.

This program is extremely helpful to both me and my husband. We both feel we are doing much better because of the things we are doing and learning in the program.

We are thriving since starting [Living Well].

Care partners also provided specific feedback about their experiences with Caregiver Café.

- All care partners reported that the Caregiver Café was very helpful overall.
- All care partners said that it was very important that they have the chance to talk with others.
- All care partners said that participation in Caregiver Café will make it easier to ask for help with caregiving in the future.
- Care partners heard things that were consistent with their own experiences as caregivers, and learned new information.

Perceptions of program participants. Thirty program participants in sessions one through four completed the post-session evaluation forms.

- Overall, 70 percent rated the program as “excellent” and 30 percent rated it as “good.”

Other responses include the following:

	More than I expected	As I expected	Less than I expected
I did something new or unfamiliar every class. (N=29)	59%	38%	3%
I discovered something interesting about another group member.	60%	37%	3%
I socialized with my peers.	37%	60%	3%
I kept physically/mentally active. (N=29)	28%	69%	3%
I improved my mood. (N=29)	55%	41%	3%
I expressed myself in a creative way.	57%	40%	3%
I connected to the community through outings and volunteerism.	53%	47%	0

Examples of their comments include the following:

Living Well has been like a launching pad for helpful activities.

I liked the art (painting and poetry) best...They convinced me that I could do something artistic.

I was surprised that there was more art that I thought there was going to be, which I was happy about. I was impressed by the professionalism of the artists.

I enjoyed the outings with the group.

[Staff] were great! I really enjoyed writing my own poetry. They opened a new door for me!

Outcomes. Dr. Joe Gaugler, University of Minnesota School of Nursing, completed the outcome evaluation for Living Well. Overall, Dr. Gaugler states that “Broadening early-stage dementia support to include not only psychosocial support, but also a vibrant set of physical activity programs such as in Living Well, is a potentially promising approach.”¹³

Pre and post-session assessments were completed with people with early dementia on the following activities:

- Chair Stand¹⁴
- Arm Curl¹⁵
- Eight-foot Up-and-Go¹⁶

¹³ J. Gaugler (email communication to program partners, June 30, 2013)

¹⁴ Robert E. Rikli and C. Jessie Jones, *Senior Fitness Test Manual*. (Champaign, IL: Human Kinetics.

¹⁵ Ibid.

¹⁶ Ibid.

- Life Balance Inventory
- Perceived Stress
- Pleasant Events Schedule
- Living Well at Home Goals

Dr. Gaugler's key observations include the following:

- Living Well has the most positive influence on the physical measures, and the person-centered achievement of goals.
- Most participants believe that participating in the program helped them exceed the individual goals they set out at the beginning of the project.
- Participants' ability to pick and choose activities in which to engage may have been a key factor in the achievement of goals and improved physical measures.

His recommendations include the following:

- Consider the best ways to incorporate care partners in program delivery and practice.
- Increase the number of matched pairs of participants and care partners in order to allow for empirical analysis of outcomes.

Guidelines for physical testing and scoring are located in Appendix H. Further information about the demographic characteristics of participants and care partners, and assessment results is located in Appendix I.

Appendix

Appendix A: Definitions

The following is a reference guide of definitions for terms used in this document.

Care Partner

Care partners are the family and friends who are providing unpaid care for an older adult or someone with early dementia. As the journey of caregiving continues, the support person moves from partnering with the older adult in making decisions and future plans to taking over responsibility and acting on that person's behalf. At this point the care partner has moved from being a partner to being the giver and thus is renamed "caregiver."

Mild Alzheimer's Disease

With mild Alzheimer's disease the following may be true: symptoms interfere with everyday functioning; MMSE/SLUMS score of 19-26; noticeable forgetfulness; trouble with numbers, managing finances/money; more mental energy needed to process; trouble multi-tasking; writes reminders, but may lose them; personality/mood changes; misses appointments; preferences for familiar things.

Mild Cognitive Impairment (MCI)

Mild cognitive impairment is a general term most commonly defined as a subtle but measurable memory disorder. A person with MCI experiences memory problems greater than normally expected with aging, but does not show other symptoms of dementia, such as impaired judgment or reasoning.¹⁷

Participant

The participant is a person with early dementia or MCI who is enrolled in the program.

¹⁷ Retrieved from www.alz.org. Mild Cognitive Impairment.pdf

Appendix B: Marketing materials

Referral letter

Dear Health Professional,

Thank you so much for your interest in **Living Well** early memory loss program. We rely on your referrals to help make the program a success and are providing this letter at the request of professionals to help guide you in the referral process.

PROGRAM DESCRIPTION

Living Well offers **person-centered services** to enrich and enhance the lives of **people with early stage memory loss** through participation in *health, fitness, education, creative arts, and community outings*. The program fills a critical service gap by providing structure, meaningful activities, and opportunities for social connections. Living Well supports people with memory loss to actively engage in the community and adopt healthy living habits. The program also provides **care partners with an opportunity to receive education and support** early in the process of caring for someone with memory loss, through Caregiver Café.

We are requesting your assistance with appropriate referrals. The recruitment process is ongoing, and following a telephone screening, interviews are conducted prior to each 8 week series. At that time, care needs are reviewed and community resources offered to those who do not qualify. A flyer about the program is attached.

Candidates who are most likely to benefit from *Living Well* fit these guidelines:

1. A diagnosis of MCI, early Alzheimer's disease or related dementia: SLUMS of 18 or MOCA of 20 and above is the qualifying score.
2. Awareness that memory loss is impacting their lives
3. Willingness to participate in all of the programs activities
4. Ability to be part of a conversation for up to 45 minutes at a time
5. Absence of significant psychiatric symptoms
6. The ability to hear sufficiently to understand group discussion
7. Willingness to accept the assistance of others (i.e. companions in unfamiliar places)

We are counting on you to help us with referrals to support and empower individuals and families as they deal with early Alzheimer's disease or related dementia. Thank you for your interest and support.

The number to call for referrals is 651-280-2290. Please contact Susan Ryan with any questions or concerns at susan.ryan@wilder.org



Living Well: A Holistic Program for People with Early Memory Loss

What: Living Well is an exciting program for those who have early dementia, mild cognitive impairment (MCI), and their caregivers. If this is you, join us for an engaging program that will provide comprehensive health, fitness, education, creative arts, and community outings. Participants will have the opportunity to set individual goals and choose from a variety of activities.

Why: Research and experts agree that it is important to be socially, physically, and cognitively active to reduce the impact of symptoms and improve daily life. This program combines each of these elements in a fun program led by experts in the field.

When: 8-week sessions, Thursdays, 9:30 a.m. – 1:45 p.m.
Next series: June 11, 2015 – July 30, 2015

Where: St. Paul Jewish Community Center,
1375 St. Paul Avenue, St. Paul, MN 55116

*Free transportation is available for those living in the Highland Park/West 7th neighborhoods.



Who: Offered by the Alzheimer's Association of Minnesota-North Dakota, the St. Paul JCC, and the Wilder Foundation. Living Well is for individuals with early dementia, MCI, and their caregivers. For Caregivers: Caregiver services include an opportunity to meet with peers, share the rewards and challenges of care giving, participate in an education based curriculum, and consult with a social worker for community resources.

Cost: \$50 per week / Fee adjustment available based on income level. 3 month membership to the JCC for participant and their caregiver is included.

For more information and to register, call Susan Ryan 651-280-2290 or susan.ryan@wilder.org

alzheimer's  association®

Minnesota-North Dakota Chapter



This activity is made possible in part by a grant provided by the Minnesota State Arts Board through an appropriation by the Minnesota State Legislature from the State's arts and cultural heritage fund with money from the vote of the people of Minnesota on November 4, 2008.

This program is supported, in part, by a CS/SD grant from Department of Human Services (DHS). Points of view or opinions do not necessarily represent official DHS policy.

Marketing Testimonial

To Whom It May Concern:

We are [name], 60, and [spouse], 57. [Name] was given the diagnosis of Mild Cognitive Impairment; Early Onset Alzheimer's at the Mayo Clinic in April 2012. We immediately sought out any program or intervention that could help with the expected changes that this disease brings. We heard about the Living Well program and signed up for the first session in the fall of 2012. We participated in the second session and currently are part of the 3rd session. Needless to say, it has been a wonderful program for both of us.

A few thoughts from [spouse]: The Living Well program offers the care partners the chance to meet together under the guidance of a Social Worker in the "Caregiver Café." We meet to talk about our challenges, laugh (lots of laughing which has been wonderful), listen to each other, offer support and have some of our questions answered. The greatest gift these meetings have give to me is HOPE. Yes [name] and my life will be different from what I expected but I have come to the realization that we can still enjoy life. Our life together isn't just about the illness and we are not alone or isolated in the midst of this disease. There are many others who are learning to cope and adjust to a changed life with Alzheimer's. So as [name] is trying new experiences to challenge his brain, I too am developing new insights and friendships in my life and seeing that our life will be ok.

A few thoughts from [name]: Whe I was diagnosed with MCI at Mayo in the spring of 2012, it was devastating. I lost my job (and work friends). I felt that I was useless. I felt that I had failed my family and others. I suppose anyone with a serious illness feels this way, but Alzheimer's is different because it's the brain that is failing. There is no cure and it carries a nasty stigma. Yes, we went to the Habit program at Mayo, which was a good program but it's 80 miles south of the Twin Cities and there may a span of months between meetings. It's was not a family friendly program for us. In comparison, Living Well is a weekly program that I can drive to. The program provides a wide variety of activities such as poetry, humor, a range of arts, which I struggled through at first, but now enjoy. Living Well also provides bus services to special activities, such as the Como Zoo, the Walker Art Center, and the Minnesota History Museum. But because the Living Well program runs weekly for several weeks, the participants grow to know each other, and the air of comradary helps us with the diagnosis. We are not alone.

Appendix C: Screening and intake forms

Telephone Screening Form

Living Well Telephone Screening Form

Date of call: _____

Name of individual with memory loss: _____

Date of birth: _____ Gender: _____

Address: _____

Phone: _____ Email: _____

Name of primary family member or friend contact: _____

Address: _____

Phone: _____ Email: _____

Questions for the Person with the Diagnosis (may be reused at interview meeting)

1. **What have you heard about this group? How did you hear about it?** (Correct any misperceptions.)
2. **Have you noticed any changes lately in your memory or daily life/functioning (give examples if needed)? What do you think is causing those changes?**
3. **Have you seen a doctor about the changes? What is your diagnosis? What do you know about that diagnosis?**
4. **Would you feel comfortable talking about these changes with other people facing similar issues? If so, what would you like to talk about with those people?**
5. **Our Living Well group includes 4 main activities: education, exercise, arts or music, community outings and volunteering. What do you think might be helpful about an activity group for someone in the early stages of memory loss?**
6. **Have you ever attended any other early stage programs? If so, what was that experience like for you?**
7. **Do you think a group like this might be helpful to you? In what ways?**

Questions for the Primary Family/Friend Contact:

1. What is the diagnosis of the person with the disease? When and how was the diagnosis made?
When _____ (month/year) By whom _____
If no diagnosis: Are you currently seeking an evaluation diagnosis? Do you need resources/contacts? (use Alz Assoc list)

2. How has the person reacted to the diagnosis and what it means?

3. What are some of the symptoms you have been noticing recently? More specifically, has the individual experienced changes in mood or behavior such as agitation; problems following a conversation; problems with speech or comprehension; lack of interest in social situations; inability to sit, stay focused and interested in a group for 90 minutes?

4. Does the person talk about the diagnosis of his/her symptoms or changes often? If so, what is the nature of those discussions? How does the person respond when you talk about the diagnosis directly?

5. How will the person get to and from the group meeting? Does the person face any problems with mobility or other health issues that could affect his/her attendance? (Explain bus transportation/metro mobility)
_____ Metro Mobility (# _____)
_____ Family/Friend
_____ Self
_____ JCC transportation _____ Register front desk

Medical or emergency needs: _____

Take medication mid-day? _____ Must be independent _____

Results:

- _____ Schedule for in-person interview
- _____ Not appropriate for Living Well/Early Stage group
- _____ Referred to:
- _____ Email or mailed:

In-person Screening Form

Living Well In-Person Screening Form

Date of INTERVIEW: _____

Name of individual with diagnosis: _____

Date of birth: _____ Gender: _____

Address: _____

Phone: _____ Email: _____

Name of primary family member or friend contact: _____

Address: _____

Phone: _____ Email: _____

Name of emergency contact: _____

Address: _____

Phone: _____ Email: _____

Questions for the Individual with the Diagnosis (With CP present assisting if needed)

1. What have you been told about your memory problems? Who told you?
2. What was your reaction?
3. How do you feel your mood has been over the past couple of months? Some common feelings are happy, angry, sad, and irritable.
4. How do you spend your time these days (work, hobbies, and activities)?
5. What are some of the struggles you are having now?
6. Our Living Well group includes 4 main activities: education, exercise, arts or music, community outings and volunteering. Do any of those activities sound interesting to you? Which ones?
7. As part of the program we will be asking you to set some health and wellness goals. Is that something you are willing to do?

Cognitive Testing: Date _____

SLUMS score _____ 20 and better

Sliding Fee/cost agreement discussed/provided Yes _____ No _____

Questions for the Primary Family/Friend Contact (CP only):

1. Since our phone call how have you and (name of the person with the diagnosis) been doing in general? Have you noticed any changes in his/her overall mood this past month?

2. How does your partner do when the two of you are apart for periods of time?

3. Can you give examples of your partner's cognitive difficulties (word finding, comprehension, repeating questions, misplacing items, getting lost, etc)?

4. How does (partner's name) interact when in a social situation?

5. What behavior or emotional changes have you observed (agitation, frustration, sadness)?

6. Will you be able to support your partner's participation and attendance for twelve weeks?

7. What would you like to see your partner gain from participation in the program?

8. What are your personal goals for this time as well?

9. Would you like to be in a group with other care partners and/or have one-on-one time with a social worker?
Yes _____ No _____

Questions to assist with final determination:

1. Is the PWD aware of their memory loss?

Yes _____ No _____

2. Are PWD and CP willing to participate as required for full 12 weeks?

Yes _____ No _____

3. Is PWD emotionally stable and able to participate in the group sessions?

Yes _____ No _____

4. Is the PWD able to participate for four hours without restlessness or without needing to rest?

Yes _____ No _____

5. Does PWD have sufficient language and social skills to participate?

Yes _____ No _____

6. Is PWD willing to learn how to identify and set goals to improve health and wellness?

Yes _____ No _____

_____ Recommend to program _____ Do not recommend to program

_____ Provide with resources for services

Comments:

VAMC SLUMS Examination

Questions about this assessment tool? E-mail aging@slu.edu.

Name _____ Age _____

Is patient alert? _____ Level of education _____

____/1
____/1
____/1

____/3
____/3
____/5

____/2

____/4
____/2

____/8

1. What day of the week is it?

2. What is the year?

3. What state are we in?

4. Please remember these five objects. I will ask you what they are later.

Apple Pen Tie House Car

5. You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20.

1 How much did you spend?

2 How much do you have left?

6. Please name as many animals as you can in one minute.

1 0-4 animals 2 5-9 animals 3 10-14 animals 4 15+ animals

7. What were the five objects I asked you to remember? 1 point for each one correct.

8. I am going to give you a series of numbers and I would like you to give them to me backwards.

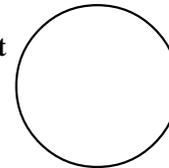
For example, if I say 42, you would say 24.

1 87 2 649 3 8537

9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.

2 Hour markers okay

2 Time correct



1 10. Please place an X in the triangle.



1 Which of the above figures is largest?

11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.

Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.

2 What was the female's name?

2 When did she go back to work?

2 What work did she do?

2 What state did she live in?

TOTAL SCORE



SAINT LOUIS
UNIVERSITY



SCORING

HIGH SCHOOL EDUCATION

27-30

21-26

1-20

Normal

MNCD*

Dementia

LESS THAN HIGH SCHOOL EDUCATION

25-30

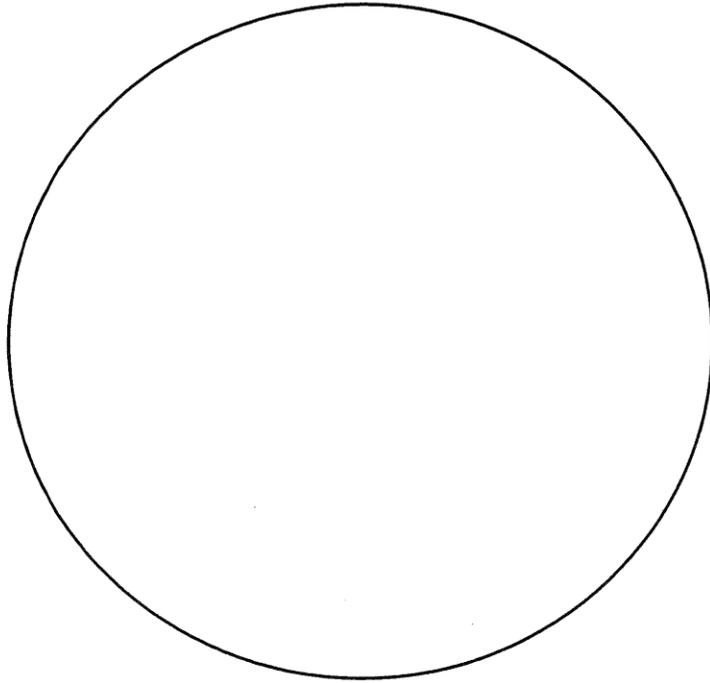
20-24

1-19

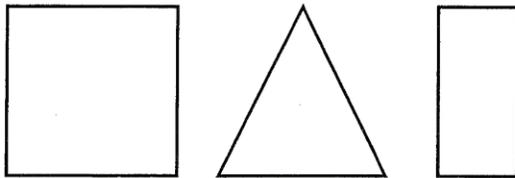
* Mild Neurocognitive Disorder

SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. 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. J Am Geriatr Psych (in press).

9. This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.



10. Please place an X in the triangle.



Which of the figures above is largest? _____

Letter of admission

Dear Participant and Care Partner,

Thank you for agreeing to participate in **LIVING WELL: A HOLISTIC PROGRAM FOR PEOPLE WITH EARLY MEMORY LOSS** program offered by the Alzheimer's Association of Minnesota-North Dakota, the St. Paul JCC and the Wilder Foundation.

DATES: April 24 – July 24, 2014

NO CLASS June 5 & JULY 3

TIME: Thursdays, 9:30am – 1:45pm

PLACE: St. Paul JCC, 1375 St. Paul Avenue, St. Paul MN 55116

Please dress in **casual, comfortable, and washable active wear**. Active footwear such as tennis shoes is recommended. There may be some distance walking so safety and comfort will be important. Water, coffee, and a light snack will be provided in the morning. **Bring your own bag lunch and beverage for lunch.**

A picture ID is needed for entry to the St. Paul JCC – no exceptions can be made.

Need to cancel a class? Please call Sue Ryan at 651-280-2290 by Wednesday (the day before class). If you are ill on the day of class, please call **Barbie Levine at 651-255-4734** as soon as you can to let us know. Classes will begin at **9:30am** so plan to arrive in plenty of time for personal needs. Class is over at **1:45pm**.

We look forward to experiencing the Living Well program with you!

Please call or contact with any questions or concerns: 651-280-2290
susan.ryan@wilder.org.

Warm regards,

Susan Ryan, Carol McWalters & Barbie Levine

Appendix D: Registration materials and program forms

Checklist

Living Well Checklist

Screening:

- Telephone Screening Form
- In-Person Interview Form
- SLUMS Examination

Require Signatures:

- JCC Membership & Release Form (both)
- Liability Waiver (both)

- Consent for Research Form (PWD)
- Photo Release (PWD) (Annual)
- Photo Release (CP) (Annual)
- Quality Improvement Tools (CP)
- Assent for Research Form (CP)
- Cost Sharing Agreement (CP)

Welcome Packet:

- Welcome Letter
- LBI handout & link (hard copy if requested)
- Referral (Wilder CG Brochure)

Returnees**First Class:**

- Fitness & BP Assessments (PWD)
- Arts Pre-evaluation (PWD)
- LBI Scores (PWD)
- BP (CP)
- Pleasant Events Schedule (CP)
- LBI Scores (CP)
- Emergency contact (CP)
- Goal Setting 2nd class (PWD)

Last Class:

- Fitness & BP Assessments (PWD)
- Post Assess & Evaluation (PWD)
- LBI Scores (PWD)
- Arts Post-evaluation (PWD)
- BP (CP)
- Pleasant Events Schedule (CP)
- LBI Scores (CP)
- Program Evaluation (CP)

Cost Sharing Agreement

Living Well 2012 Cost Sharing Agreement

Dear Participant:

Living Well: A Holistic Program for People with Early Memory Loss, is brought to you and your community by the Alzheimer’s Association of Minnesota-North Dakota, the St. Paul JCC, and the Wilder Foundation. The fee for this program is \$50 per day, or \$600 per 12-week series, and we are asking participants to partner with us in a cost-sharing opportunity. The fee of the course will depend upon your income and is calculated using a sliding fee scale.

Fees are per 12-week course. Fee covers assessment, 4-hour weekly program, and transportation for those in the Highland Park/West 7th neighborhoods and transportation for all to outings. Fees do not include lunch or additional costs associated with outings.

Check Your Annual Income	Single Person Annual Income Range	Two Person Household Annual Income Range	% of Fee	Fee Per 12-Week Series
	Below 200% of poverty or \$20,664	Below 200% of poverty or \$27,990	0	\$0**
	\$20,665 to \$22,339	\$27,991 to \$30,259	25%	\$150
	\$22,340 to \$25,132	\$30,260 to \$34,042	35%	\$210
	\$25,133 to \$27,924	\$34,043 to \$37,824	45%	\$270
	\$27,925 to \$33,509	\$37,825 to \$45,389	55%	\$330
	\$33,510 to \$44,679	\$45,390 to \$60,519	70%	\$420
	\$44,680 to \$49,999	\$60,520 to \$99,999	85%	\$510
	\$50,000 and Over	\$100,000 and Over	100%	\$600

**You are also welcome to make a voluntary contribution to help off-set the cost of supplies. \$60 is the suggested donation.

Please make your payment and/or voluntary contribution to: The St. Paul JCC

Participant Name _____

Date _____

Participant Signature _____

This program is supported, in part, by a CS/SD grant from the Department of Human Services (DHS). Points of view or opinions do not necessarily represent official DHS policy.

For Office Use Only: Amount Paid: _____ Payment form: ___ Check ___ Cash Class Location: _____ Class Dates: _____

Life Balance Inventory

Life balance is a satisfying pattern of daily activities that is healthful, meaningful, and sustainable to an individual within the context of his or her current life circumstances. (Matuska & Christiansen, 2008, p. 11)

The Life Balance Inventory (LBI) was developed by Dr. Kathleen Matuska to measure your life balance based on the following principles,

Your everyday activity patterns must enable you to meet the following important needs:

1. Have basic health and safety
2. Have rewarding and satisfying relationships
3. Have regular activities that are interesting and challenging
4. Have a satisfactory personal identity

In order to meet these needs through your activities, you also need to be able to

5. Organize your time to meet your personal goals

This is a tool that will help you determine areas in your life where you are balanced or imbalanced. After completing the inventory you will learn:

- Your overall life balance score
- Subcategory scores for each of the four needs (health, relationships, challenge, and identity).
- Your level of stress using the Perceived Stress Scale, short version (Cohen, Kamark, & Mermlestein, 1983)

References:

- Matuska, K., & Christiansen, C. (2008). A proposed model of lifestyle balance. *Journal of Occupational Science*, 15, 1, 9-19.
- Cohen, S., Kamark, T. & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385-396.
- Matuska, K. (2012). Validity evidence for a model and measure of life balance. *Occupational Therapy Journal of Research*, 32, 1, 229-237.
- Matuska, K. (2012). Development of the Life Balance Inventory. *Occupational Therapy Journal of Research*, 32, 1, 220-228.

About You

Please indicate the option that best describes you by putting an X in the box next to the answer or fill in the blank.

What is your age? _____ (fill in)

What is your sex?

- Male
 Female

What is your race?

- American Indian or Alaskan native
 Asian
 Black
 Hispanic or Latino
 Native Hawaiian or Pacific Islander
 White

What is your marital status?

- Single
 Married/partnered
 Divorced
 Separated
 Widowed

Number of children _____ (fill in)

If you have children, how many are living with you?
_____ (fill in)

What is your employment status? (check all that apply)

- Full time
 Part time
 Temporary leave from job
 Unemployed and looking for work
 Retired
 In school
 Not employed outside the home

What is the highest level of education you completed?

- Less than high school
 High school diploma or GED
 Associate degree
 Bachelor's degree
 Master's or professional degree
 Doctoral degree

What is your yearly household income?

- Less than \$10,000
 \$10,000- \$22,999
 \$21,000-\$39,999
 \$40,000-\$52,999
 \$53,000-\$72,999
 \$73,000- \$110,000
 \$110,000 or more

Perceived Stress

The questions below ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

1. In the past month, how often have you felt that you were unable to control the important things in your life?

- Never Almost Never Sometimes Fairly Often Very Often

2. In the past month, how often have you felt confident about your ability to handle your personal problems?

- Never Almost Never Sometimes Fairly Often Very Often

3. In the last month, how often have you felt things were going your way?

- Never Almost Never Sometimes Fairly Often Very Often

4. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

- Never Almost Never Sometimes Fairly Often Very Often

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Life Balance Inventory

To rate the following items, **STEP 1** indicate if you **do** the activity or **want** to do the activity by circling YES or NO. Then, **STEP 2**, for the activities you circled YES, think about yourself doing each activity in the past month, and rate how much time you **actually** spend in each activity compared to the amount of time you **want** to spend in each activity.

STEP 2: For the activities you circled YES, The amount of time I spend doing this activity is:

STEP 1:			ALWAYS LESS	SOMETIMES LESS	ABOUT RIGHT	SOMETIMES MORE	ALWAYS MORE
I DO this activity			than I want	than I want	for me	than I want	than I want
Or WANT to do this activity							
Yes	No	Taking care of personal hygiene and bathing	1	2	3	2	1
Yes	No	Taking care of your appearance	1	2	3	2	1
Yes	No	Getting adequate sleep	1	2	3	2	1
Yes	No	Relaxing	1	2	3	2	1
Yes	No	Getting regular exercise	1	2	3	2	1
Yes	No	Eating nutritiously	1	2	3	2	1
Yes	No	Managing your health needs	1	2	3	2	1
Yes	No	Managing money (bills/budget/investments)	1	2	3	2	1
Yes	No	Driving	1	2	3	2	1
Yes	No	Taking the bus	1	2	3	2	1
Yes	No	Doing things with family members	1	2	3	2	1
Yes	No	Doing things with spouse/significant other	1	2	3	2	1
Yes	No	Doing things with friends	1	2	3	2	1
Yes	No	Taking care of children or family members	1	2	3	2	1
Yes	No	Having an intimate sexual relationship	1	2	3	2	1
Yes	No	Participating in groups (clubs, classes, etc.)	1	2	3	2	1
Yes	No	Meeting new people	1	2	3	2	1
Yes	No	Working for pay	1	2	3	2	1
Yes	No	Gaining competence in your job	1	2	3	2	1
Yes	No	Socializing at work	1	2	3	2	1
Yes	No	Participating in formal religious activities	1	2	3	2	1
Yes	No	Participating in traditional rituals, holidays	1	2	3	2	1
Yes	No	Participating in educational opportunities	1	2	3	2	1
Yes	No	Participating in professional organizations	1	2	3	2	1
Yes	No	Volunteering in the community	1	2	3	2	1
Yes	No	Participating in organized sports	1	2	3	2	1
Yes	No	Doing outdoor activities (hunting, fishing)	1	2	3	2	1

©Kathleen Matuska

STEP 2: For the activities you circled **YES**, The amount of time I spend doing this activity is:

STEP 1:			ALWAYS	SOMETIMES	ABOUT	SOMETIMES	ALWAYS
I DO this activity			LESS	LESS	RIGHT	MORE	MORE
Or WANT to do this activity			than I want	than I want	for me	than I want	than I want
Yes	No						
		Gardening	1	2	3	2	1
Yes	No	Communing with nature	1	2	3	2	1
Yes	No	Planning and coordinating events	1	2	3	2	1
Yes	No	Decorating or organizing spaces	1	2	3	2	1
Yes	No	Cooking	1	2	3	2	1
Yes	No	Doing housework	1	2	3	2	1
Yes	No	Shopping	1	2	3	2	1
Yes	No	Taking care of pets	1	2	3	2	1
Yes	No	Going to restaurants/bars	1	2	3	2	1
Yes	No	Going to plays, movies, sporting events	1	2	3	2	1
Yes	No	Doing crafts, hobbies	1	2	3	2	1
Yes	No	Making music	1	2	3	2	1
Yes	No	Making Art	1	2	3	2	1
Yes	No	Maintaining or repairing equipment	1	2	3	2	1
Yes	No	Sewing/needlework	1	2	3	2	1
Yes	No	Reading	1	2	3	2	1
Yes	No	Using computers (text, internet, blogs)	1	2	3	2	1
Yes	No	Reflecting or meditating	1	2	3	2	1
Yes	No	Journaling	1	2	3	2	1
Yes	No	Composing, writing, (music, poetry etc)	1	2	3	2	1
Yes	No	Dancing, yoga, etc.	1	2	3	2	1
Yes	No	Playing games of skill (cards, electronic, etc)	1	2	3	2	1
Yes	No	Watching TV	1	2	3	2	1
Yes	No	Mentoring (teaching) others	1	2	3	2	1
Yes	No	Traveling (any means, locally, globally)	1	2	3	2	1
Yes	No	Storytelling	1	2	3	2	1

©Kathleen Matuska

Pleasant Events Schedule

Instructions: This schedule contains a list of events or activities that people sometimes enjoy. It is designed to find out about things your relative has enjoyed during the past month. Please rate each item twice. The first time, rate each item on how many times it happened in the past month, (frequency); the second time, rate each event on how much your relative enjoys the activity.

Activity	Frequency			Enjoy		
	Not at all	1 to 6 Times	7 or more Times	Not At All	Some what	A Great Deal
1. Being outside						
2. Shopping, buying things						
3. Reading or listening to stories, magazines, newspapers						
4. Listening to music						
5. Watching T.V.						
6. Laughing						
7. Having meals with friends or family						
8. Making or eating snacks						
9. Helping around the house						
10. Being with family						
11. Wearing favorite clothes						
12. Listening to the sounds of nature (birdsong, wind, surf)						
13. Getting/sending letters, cards						
14. Going on outings (to the park, a picnic, etc)						
15. Having coffee, tea, etc. with friends						
16. Being complimented						
17. Exercising (walking, dancing, etc.)						
18. Going for a ride in the car						
19. Grooming (wearing make up, shaving, having hair cut)						
20. Recalling and discussing past events						

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Pre-program Goals Form

Name:

Date:

What do you hope to gain from this program? (Check all that apply.)

- To do something new or unfamiliar in class.
- To discover something interesting about another group member.
- To socialize with my peers.
- To keep physically/mentally active.
- To improve my mood.
- To express myself in a creative way.
- To keep connected to the community through outings and volunteerism.

Post Assessment

Living Well

Post Assessment & Evaluation (Participant)

Name: _____ Date: _____

Thank you for your participation in *Living Well*. Please take a moment to complete the survey below. Circle your answer.

1. I did something new or unfamiliar in every class.

More than I expected As I expected Less than I expected

2. I discovered something interesting about another group member.

More than I expected As I expected Less than I expected

3. I socialized with my peers.

More than I expected As I expected Less than I expected

4. I kept physically/mentally active.

More than I expected As I expected Less than I expected

5. I improved my mood.

More than I expected As I expected Less than I expected

6. I expressed myself in a creative way.

More than I expected As I expected Less than I expected

7. I connected to the community through outings and volunteerism.

More than I expected As I expected Less than I expected

8. Please rate the overall program.

Excellent Good Fair Poor

9. What did you like best about the program?

10. What would you like to see included in future programs?

11. Other comments?

Appendix E: Waivers and safety information

Emergency contact form

Participant Name: _____

1. Emergency Contact (Name): _____

Phone Number(s): _____

Phone Number(s): _____

2. Emergency Contact (Name): _____

Phone Number(s): _____

*****Emergency Contact must be someone who is in town and available during program hours**

For the back of the nametag

MISSING PERSON – WHAT TO DO:

If a family member tells you they cannot find their family member with dementia

- Calmly reassure the family that we will work with them
- Ask where they last saw the person
- Stay in the general area and contact

Barbie Levine: 651-255-4734 or Sue Ryan: 651-262-9793

If a person with dementia tells you he or she cannot find their family member

- Calmly reassure the family that we will work with them
- Ask if they can tell you where they last saw their family
- Stay in the general area and contact

Barbie Levine: 651-255-4734 or Sue Ryan: 651-262-9793

Liability Waiver

Living Well Liability Waiver

Living Well is offered by the **St. Paul Jewish Community Center**, the **Wilder Foundation**, and the **Alzheimer's Association of Minnesota-North Dakota**, and is an engagement program for people with the early stages of memory loss and their caregivers. In collaboration with **Sandra Menefee-Taylor, Kairos Alive**; Living Well will offer participants opportunities to improve brain health while strengthening their knowledge, skills, and appreciation of the arts. Participation in comprehensive health, fitness, education, creative arts and community outing programs can improve quality of life and health for older adults. Potential benefits associated with the Living Well program include:

- enhanced life engagement and interaction
- improved mood and flexibility
- transformational community experiences
- greater self-expression
- appreciation of the present
- heightened self-esteem and confidence

Potential risks associated with Living Well Program:

The majority of Living Well participants have accessibility needs based on the diagnosis of early stage memory loss, as well as other accessibility needs. Sandra Menefee-Taylor, and Kairos Alive are experienced in adapting their programs to fit a wide range of abilities. However, these activities may involve physical movement and perhaps a health risk.

Living Well includes a series of events that may include physical or other risks including, but not limited to, injuries, falls, interactions with other participants, effects of weather, traffic and other event conditions.

By signing this form, I am indicating that:

- I have read and understand this form and have had the opportunity to ask questions about it. My questions have been answered to my satisfaction.
- I represent that I do not have a medical and/or physical condition that would preclude them from participating in the Living Well program.
- I assume all risks, including bodily or personal injury, death, property loss or other damages of any kind arising in any way out of my participation in or attendance at the events and related activities.
- I release the St. Paul Jewish Community Center, the Wilder Foundation, and the Alzheimer's Association of Minnesota-North Dakota, Sandra Menefee-Taylor, Kairos Alive and their officers, agents, employees and volunteers from all liability for any accident, injury, lawsuit, and damages of any kind to persons or property that might occur while participating in Living Well: A Holistic Program for People with Early Memory Loss.

Signature

Date

Signature

Date



This activity is made possible in part by a grant provided by the Minnesota State Arts Board through an appropriation by the Minnesota State Legislature from the State's arts and cultural heritage fund with money from the vote of the people of Minnesota on November 4, 2008.

Media Release Waiver



This activity is made possible in part by a grant provided by the Minnesota State Arts Board through an appropriation by the Minnesota State Legislature from the State's arts and cultural heritage fund with money from the vote of the people of Minnesota on November 4, 2008.

Amherst H. Wilder Foundation Consent to Use/Disclose Video, Photograph and/or Interview

Client #: _____

This program is supported, in part, by a CS/SD grant from Department of Human Services (DHS).

Client Information: (Care Partner)	Client Name: _____ Address: _____ City, State, Zip: _____ Phone: _____ Date of Birth: ____/____/____	
Agency or Person who maintains information:	The following Wilder program: Program Name: <u>Living Well</u> Program Address: <u>650 Marshall Avenue</u> City, State, Zip: <u>St. Paul, MN 55104</u> Phone: <u>651-280-2500</u>	Is authorized to: <input type="radio"/> Disclose to <input type="radio"/> Obtain from <input type="radio"/> Exchange with (Fill in below)
	The following person OR organization: Person/Organization Name: <u>Alzheimer's Association, St. Paul Jewish Community Center</u> Address: _____ City, State, Zip: _____ Phone: _____ FAX: _____	
Information to be Released:	<input type="radio"/> Photographs <input type="radio"/> Audiotape <input type="radio"/> Interview <input type="radio"/> Other: _____ <input type="radio"/> Videotape	
Reason for Release:	<input type="radio"/> At your request to a third party by you <input type="radio"/> As part of Wilder Foundation reports, articles, or publications <input type="radio"/> Marketing and fundraising materials and presentations <input type="radio"/> Other (provide description): <u>By signing this form you are authorizing all of the organizations that participate in Living Well to use your photo, interview, videotape for promotional purposes.</u>	
Expiration:	If not previously revoked, this consent will expire one year from the date the form is signed unless an earlier date or event is indicated here: Date _____ or Specific Event: _____	
Signature of Consent to Release Information:	I understand that: <ul style="list-style-type: none"> • I may refuse to sign or revoke this consent by notifying in writing the organization/person who maintains the information to be released, except to the extent that action has already been taken in reliance on this consent. • When the information specified above is sent to a third party, the information could be re-disclosed by the third party that receives it and may no longer be protected by state or federal privacy laws. • I understand ownership rights will be retained by the Agency/Person. • The Wilder Foundation may not condition my treatment/service or payment of my bills on my decision to sign this consent form. • A photocopy of this form is as valid as the original. • I will receive a copy of this signed form upon request. 	

Representative: _____ Date: _____

Relationship to Client: _____

Appendix F: Sample email communications

Dear participants & care partners,
Class on Thursday will begin with exercise – LifeMoves and Ageless Grace. Care partners will participate in the Caregiver Café (9:30-11:30). We will be using our Living Well workbooks to discuss Healthy Eating and Exercise. We will wind up the afternoon with options for Yoga or another fitness offering. Please dress casual, bring athletic shoes, Living Well bag and a cold bag lunch with beverage.

I look forward to seeing everyone on Thursday!

Dear Participants & Care Partners,
Let's start the day out with Ageless Grace and get our joints juicy! Care Giver Café follows with participants working in paint with Sandra. Bring your lunch and a beverage. Following lunch we will learn all about The Little Free Library and introduce you to our newest service project. We will end up the day with Yoga or fitness.
See you on Thursday!

Dear Participants and Care Partners;
This week we are traveling to Ft. Snelling for a tour. We will be outside so dress accordingly. I am bringing bug spray so never fear! Bring your regular lunch & beverage to eat on site. At 12:30 we have a guest speaker Terry Barclay to talk about Healthy Relationships & Communication. Remember to bring your bag and Living Well workbook for the afternoon session.
See you on Thursday!

Dear Participants and Care Partners:
The morning will include exercise and discussion. We will be travelling to Silverwood Park at 11:00 for our poetry session. Zoe & Rachel suggest we all wear a funny hat in honor of Halloween. Lunch will be on site and you will need to bring \$20 or a credit card to purchase your lunch and beverage. Please dress comfortably for exercise and the bus trip. We will return at our regular ending time of 1:45pm.
See you on Thursday!

Dear Participants and Care Partners,
Our schedule for this week includes am & pm exercise – please wear comfortable clothes you can move in and tennis shoes. We have a guest speaker, Dr. Terry Barclay, neuropsychologist from Health Partners. He welcomes questions on many topics related to memory loss and healthy living. Please bring your bag lunch and beverage. After lunch we will explore poetry with our resident poets, and attend the yoga class.
See you on Thursday!

Appendix G: Sample poetry

This poem was created on November 21, 2013 by participants in Living Well. The poetry session was facilitated by teaching artists from the Alzheimer's Poetry Project Minnesota, whose mission is to enhance the creativity of older adults with memory loss and help their myriad voices be heard. Each stanza is from a different person and the artists use a call and response technique for presentation.

In My Mind's Eye

Fishing with my dad on Leech Lake
with the sounds of geese,
sinking lines.
You can hear the loons
way over across the lake
in the Northwoods.

Peaceful water:
I see the clouds and sun,
a nice Northern jumping out of the lake.

My dad and I weren't very close,
but he loved jazz.
The two of us went to see Buddy Rich—
it was the best jazz
I'd ever seen or heard.
He soloed for about ten minutes on the drums.
It was in a dark nightclub,
what used to be the Riverview.

The sun setting
on the mirrored lake
with the ripple of the current
running through it—
I've seen it.

Black flies and deerflies so thick
they cover your jeans.
I was exploring for archaeological sites,
hundreds of miles in a canoe.
Good thing we wore head nets,
like beekeepers.

Mayflies in the spring:
suddenly they come up off the lake
and cover the whole house.
You have to sweep them away.

I like it here.
It doesn't have to be in front of my eyes—
I can just think about it.

I remember hoeing the vegetable garden
with my grandmother,
one of the Victory Gardens
during the Second World War.
I'd get on the bus with my hoe
and ride to her house.

I thought back thirty years,
to visiting my friends at their winery
in Northern Washington
where hummingbirds
would sit in your hands.
You hear about the beating of their hearts—
and you could feel that vibration,
right in your hands.
There was no door on the outhouse,
but once you settled down
you had quite a view of the Cascades.

I'm thinking about the beautiful sunsets
over the ocean in Hawaii.
We don't see sunsets
the way they happen there—
the sun shimmers
over the ocean.

Living Well Poets, November 21, 2013

Appendix H: Physical assessment protocols and scoring

Chair Stand Test (Scoring follows)

Purpose: To measure lower-body strength

Equipment: Straight-back chair (17 in or 43.18 seat height); stopwatch

Procedure:

- Have the participant sit in the middle of the chair, feet flat on the floor, arms across the chest.
- On signal “go” have the participant rise to a full stand, then return to a fully seated position.
- After a warm-up trial to check for correct form, administer one test trial.
- The score is the number of stands completed in 30 seconds.

Arm Curl Test (Scoring follows)

Purpose: To measure upper-body strength

Equipment: Straight-back or folding chair without arms, stopwatch, 5-lb and 8-lb dumbbells

Procedure:

- Have the participant sit in the chair, with feet flat on the floor.
- The participant should hold the weight down at the side, perpendicular to the floor, with a handshake grip.
- On the signal “go” have the participant curl the weight through a full range of motion as many times as possible in 30 seconds. The palm should rotate up during the curl-up phase, then should return to a handshake position at extension. The upper arm must remain still throughout the test.

8-Foot Up-and-Go Test (Scoring follows)

Purpose: To assess agility and dynamic balance

Equipment: Folding chair with 17-in (43.18 cm) seat height, stopwatch, tape measure, and cone (or similar marker)

Procedure:

- Have the participant sit in the middle of the chair, hands on thighs, one foot slightly ahead of the other, body leaning slightly forward.
- On the signal “go” have the participant get up from the chair, walk as quickly as possible around a cone placed 8 feet away, and return to the chair.
The timer must start the stopwatch exactly on the “go” signal and stop it at the exact time the participant sits in the chair.
- After one practice trial, administer two test trials. The score is the best of two trials, recorded to the nearest tenth of a second.

Chair Stand Test Scoring (Women)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	21	19	19	19	18	17	16
90	20	18	18	17	17	15	15
85	19	17	17	16	16	14	13
80	18	16	16	16	15	14	12
75	17	16	15	15	14	13	11
70	17	15	15	14	13	12	11
65	16	15	14	14	13	12	10
60	16	14	14	13	12	11	9
55	15	14	13	13	12	11	9
50	15	14	13	12	11	10	8
45	14	13	12	12	11	10	7
40	14	13	12	12	10	9	7
35	13	12	11	11	10	9	6
30	12	12	11	11	9	8	5
25	12	11	10	10	9	8	4
20	11	11	10	9	8	7	4
15	10	10	9	9	7	6	3
10	9	9	8	8	6	5	1
5	8	8	7	6	4	4	0

Chair Stand Test Scoring (Men)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	23	23	21	21	19	19	16
90	22	21	20	20	17	17	15
85	21	20	19	18	16	16	14
80	20	19	18	18	16	15	13
75	19	18	17	17	15	14	12
70	19	18	17	16	14	13	12
65	18	17	16	16	14	13	11
60	17	16	16	15	13	12	11
55	17	16	15	15	13	12	10
50	16	15	14	14	12	11	10
45	16	15	14	13	12	11	9
40	15	14	13	13	11	10	9
35	15	13	13	12	11	9	8
30	14	13	12	12	10	9	8
25	14	12	12	11	10	8	7
20	13	11	11	10	9	7	7
15	12	11	10	10	8	6	6
10	11	9	9	8	7	5	5
5	9	8	8	7	6	4	3

Arm Curl Test Scoring (Women)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	24	22	22	21	20	18	17
90	22	21	20	20	18	17	16
85	21	20	19	19	17	16	15
80	20	19	18	18	16	15	14
75	19	18	17	17	16	15	13
70	18	17	17	16	15	14	13
65	18	17	16	16	15	14	12
60	17	16	16	15	14	13	12
55	17	16	15	15	14	13	11
50	16	15	14	14	13	12	11
45	16	15	14	13	12	12	10
40	15	14	13	13	12	11	10
35	14	14	13	12	11	11	9
30	14	13	12	12	11	10	9
25	13	12	12	11	10	10	8
20	12	12	11	10	10	9	8
15	11	11	10	9	9	8	7
10	10	10	9	8	8	7	6
5	9	8	8	7	6	6	5

Arm Curl Test Scoring (Men)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	27	27	26	24	23	21	18
90	25	25	24	22	22	19	16
85	24	24	23	21	20	18	16
80	23	23	22	20	20	17	15
75	22	21	21	19	19	17	14
70	21	21	20	19	18	16	14
65	21	20	19	18	18	15	13
60	20	20	19	17	17	15	13
55	20	19	18	17	17	14	12
50	19	18	17	16	16	14	12
45	18	18	17	16	15	13	12
40	18	17	16	15	15	13	11
35	17	16	15	14	14	12	11
30	17	16	15	14	14	11	10
25	16	15	14	13	13	11	10
20	15	14	13	12	12	10	9
15	14	13	12	11	12	9	9
10	13	12	11	10	10	8	8
5	11	10	9	9	9	7	6

8-Foot Up-and-Go Test Scoring (Women)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	3.2	3.6	3.8	4.0	4.0	4.5	5.0
90	3.7	4.1	4.0	4.3	4.4	4.7	5.3
85	4.0	4.4	4.3	4.6	4.9	5.3	6.1
80	4.2	4.6	4.7	5.0	5.4	5.8	6.7
75	4.4	4.8	4.9	5.2	5.7	6.2	7.3
70	4.6	5.0	5.2	5.5	6.1	6.6	7.7
65	4.7	5.1	5.4	5.7	6.3	6.9	8.2
60	4.9	5.3	5.6	5.9	6.7	7.3	8.6
55	5.0	5.4	5.8	6.1	6.9	7.6	9.0
50	5.2	5.6	6.0	6.3	7.2	7.9	9.4
45	5.4	5.8	6.2	6.5	7.5	8.2	9.8
40	5.5	5.9	6.4	6.7	7.8	8.5	10.2
35	5.7	6.1	6.6	6.9	8.1	8.9	10.6
30	5.8	6.2	6.8	7.1	8.3	9.2	11.1
25	6.0	6.4	7.1	7.4	8.7	9.6	11.5
20	6.2	6.6	7.3	7.6	9.0	10.0	12.1
15	6.4	6.8	7.7	8.0	9.5	10.5	12.7
10	6.7	7.1	8.0	8.3	10.0	11.1	13.5
5	7.2	7.6	8.6	8.9	10.8	12.0	14.6

8-Foot Up-and-Go Test Scoring (Men)

Percentile Rank	60-64	65-69	70-74	75-79	80-84	85-89	90-94
95	3.0	3.1	3.2	3.3	4.0	4.0	4.3
90	3.0	3.6	3.6	3.5	4.1	4.3	4.5
85	3.3	3.9	3.9	3.9	4.5	4.5	5.1
80	3.6	4.1	4.2	4.3	4.9	5.0	5.7
75	3.8	4.3	4.4	4.6	5.2	5.5	6.2
70	4.0	4.5	4.6	4.9	5.5	5.8	6.6
65	4.2	4.6	4.8	5.2	5.7	6.2	7.0
60	4.4	4.8	5.0	5.4	6.0	6.5	7.4
55	4.5	4.9	5.1	5.7	6.2	6.9	7.7
50	4.7	5.1	5.3	5.9	6.4	7.2	8.1
45	4.9	5.3	5.5	6.1	6.6	7.5	8.5
40	5.0	5.4	5.6	6.4	6.9	7.9	8.8
35	5.2	5.6	5.8	6.6	7.1	8.2	9.2
30	5.4	5.7	6.0	6.9	7.3	8.6	9.6
25	5.6	5.9	6.2	7.2	7.6	8.9	10.0
20	5.8	6.1	6.4	7.5	7.9	9.4	10.5
15	6.1	6.3	6.7	7.9	8.3	9.9	11.1
10	6.4	6.6	7.0	8.3	8.7	10.5	11.8
5	6.8	7.1	7.4	9.0	9.4	11.5	12.9

Adapted from Rikli & Jones 1999.

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LIVING WELL PROGRAM: Assessment & Testing

NAME (PWD): _____ NAME (CP): _____

T1-PRE T2-POST T1-PRE T2-POST

DATE:				
AGE:				
BLOOD PRESSURE:				
8 FT. UP & GO:	_____	_____	N/A	N/A
_____ %				
CHAIR STAND:	_____	_____	N/A	N/A
_____ %				
ARM CURL:	_____	_____	N/A	N/A
_____ %				
NOTES:				

Signature & Initials _____



Appendix I: Participant and care partner information

Demographic characteristics

	Participant (N=20)	Care partner (N=17)
Average age	71 years	69 years
Male	60%	24%
White	95%	100%
Married	80%	100%
Some college or more	100%	100%
Live with care partner	80%	100%

Test scores

	Pre- to Post- Change
Chair Stand	Improvement
Arm Curl	Improvement
Life Balance	No change
Perceived stress	Improvement