



The University of Texas at Austin
Dell Medical School

Dementia Caregiver Roadmap

Transforming Health Care Systems
Through the Implementation of the
RAISE Act for Dementia Family Caregivers

by Alyssa Aguirre, LCSW



Executive Summary

This Dementia Caregiver Roadmap is a comprehensive guide for health care administrators and clinician providers. It offers innovative strategies for planning, developing, and implementing policies and procedures aimed at supporting family caregivers of individuals living with dementia in healthcare settings nationwide.

Recognizing the urgent need for a public health approach to dementia care, the roadmap fills a critical gap by providing a practical framework for integrating family caregivers into healthcare systems. It examines 10 core strategies for engaging family caregivers, drawing from real-world implementation experiences at the Comprehensive Memory Center, an outpatient, interprofessional dementia specialty practice at UT Health Austin (the clinical enterprise of Dell Medical School at The University of Texas at Austin).

Each section of the Dementia Caregiver Roadmap includes practical examples from the CMC model on how to implement the core strategies, showcasing how they facilitate the development of coordinated, comprehensive care with family caregivers. With a focus on engaging family caregivers within healthcare systems, this roadmap is a vital resource for healthcare administrators and clinician providers dedicated to dementia care excellence.



“ This roadmap is an absolute game-changer for administrators and clinicians looking to raise the bar in dementia care. The guide’s tangible recommendations for including caregivers at the center of care is truly a blueprint for optimizing the treatment and well-being of our patients and those who support them.”

Terry R Barclay, PhD


Clinical Director, HealthPartners Neuropsychology

Adjunct Associate Professor, Department of Neurology, University of Minnesota

“ Everyone’s path through the forest of Alzheimer’s and dementia is unique. The Dementia Caregiver Roadmap provides clinicians with proven strategies to engage with patients and caregivers throughout the journey, thus helping to smooth and widen the path. The road map advises the clinical team on what patients and caregivers might need, when they might need it, and possible ways to provide it, resulting in a quality experience for all parties involved.”

Elise Passy, MPH, MAEd, CDP

Director of Health Care Systems, Alzheimer’s Association



Background: In January 2018, Congress passed the RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act, which established the RAISE Family Caregiving Advisory Council. In September 2021, the council provided an initial report to Congress with 26 recommendations to establish a national approach to address the needs of family caregivers. The five priority areas of the recommendations were:

- Increased awareness of family caregiving
- Increased emphasis on integrating caregivers into processes and systems from which they have been traditionally excluded
- Increased access to services and supports to assist family caregivers
- Increased financial and workplace protections for caregivers
- Better and more consistent research and data collection

A related resource is the RAISE Act State Policy Roadmap for Family Caregivers, developed by the National Academy for State Health Policy and designed in response to the RAISE Act Advisory Council's Report to Congress. The roadmap's six sections guide states in developing and expanding supports for family caregivers in practical ways by providing resources on implementing innovative policy and programmatic strategies.

While the State Roadmap provides tools and resources for states, there is currently no implementation guide for health care systems. Providing practical tools and resources for health care systems to support dementia family caregivers is still in its infancy. The purpose of this Dementia Caregiver Roadmap is to offer practical strategies and resources for health care administrators and clinician providers to implement the recommendations of the State Policy Roadmap "Section 2: Engagement of Family Caregivers in Health Care Services."

Contact: For questions or to express interest in collaborating with the Comprehensive Memory Center, please reach out to alyssa.aguirre@austin.utexas.edu.

Acknowledgments and Funding: This Dementia Caregiver Roadmap: Transforming Health Care Systems Through the Implementation of the RAISE Act for Dementia Family Caregivers was made possible by generous support from the Cambia Health Foundation. I would like to acknowledge the entire Comprehensive Memory Center team at UT Health Austin, who are passionate and dedicated to providing exceptional, person-centered care. Thank you to the Mulva family, who generously supported the Comprehensive Memory Center, which was recognized as a 2018 Innovator in Aging from the Texas Department of Health and Human Services as well as an Age-Friendly Health System Committed to Care Excellence. I extend my heartfelt thanks to Jared Benge, Sue Fielder, Anna Finger, and Andrea Taurins for their invaluable guidance in shaping the content of this Roadmap. Finally, I extend my deepest gratitude to the individuals living with dementia and their caregivers, whose input shaped the Comprehensive Memory Center. Their stories continue to inspire me to seek excellence in dementia care.

“ I liked that the visit was thorough and explained every step of processes. I like that they not only cared for the patient but the caregivers.”

— a CMC family caregiver

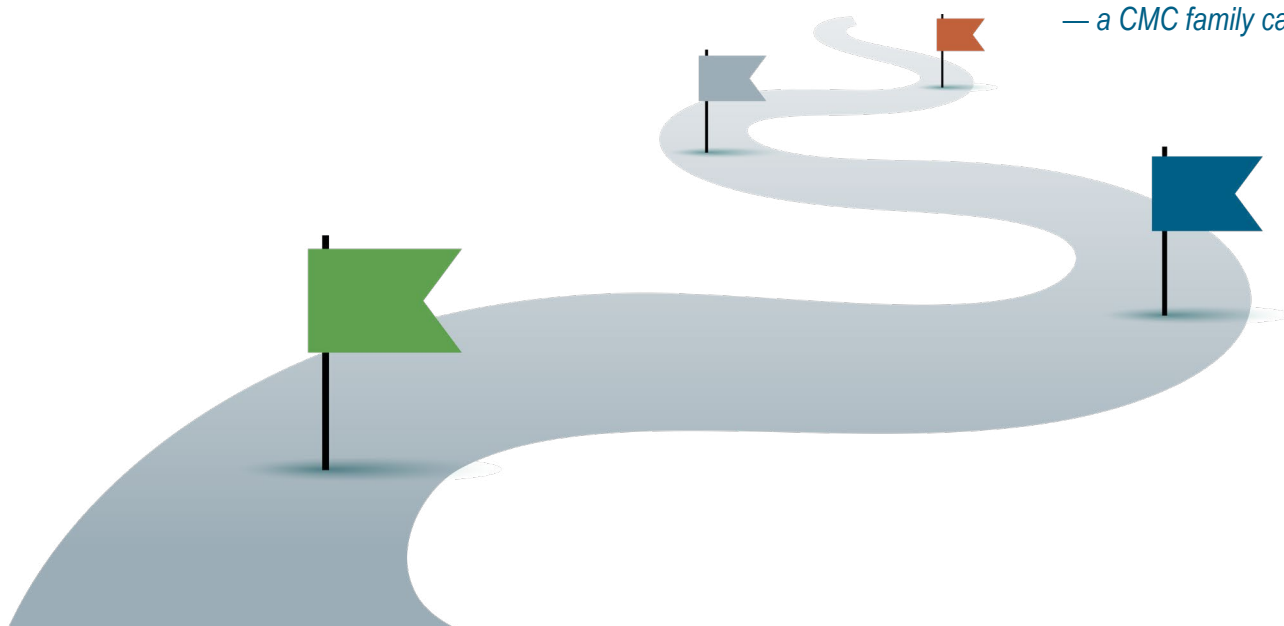


Table of Contents

The roadmap's 10 core strategies are designed to be dynamic and adaptable for use in diverse health care settings. They are meant to be non-linear and flexible, empowering organizations to consider creative ways of engaging family caregivers. Rather than offering a rigid, one-size-fits all approach, the core strategies can serve as a catalyst to ignite innovative approaches to engage family caregivers, fostering comprehensive support that can be tailored to the diverse needs of healthcare systems.

Core Strategies

1	Foster caregivers' inclusion on the care team.....	1
2	Build identification and assessment of family caregivers in the electronic health record.....	3
3	Ensure that family caregivers receive the information necessary to coordinate care.....	5
4	Offer billable mental health counseling, support, education and evidence-based services to family caregivers.....	7
5	Ensure providers and other members of the care team know how to effectively engage family caregivers.....	9
6	Measure and document family caregiver well-being at critical transition points.....	11
7	Use an interprofessional team approach to support family caregivers.....	13
8	Utilize qualitative research methods to inform care.....	15
9	Increase family caregiver access to research.....	17
10	Provide family caregivers access to community resources and educational programs.....	19

Foster Caregivers' Inclusion on the Health Care Team

Family caregivers of individuals living with dementia have multifaceted responsibilities. They play an integral role in diverse activities such as scheduling appointments, transportation to the clinic, active participation during medical encounters and arranging follow-up action steps (i.e., arranging lab tests, scheduling brain imaging, managing medications and finances, and coordinating future appointments). Caregivers are instrumental in ensuring the continuity of care. Including them as a member of the care team is vital to providing comprehensive dementia care.

@CMC

The CMC team understands the importance of including family caregivers as essential members of the patient's healthcare team, and employs deliberate strategies to engage and include them in the following ways:

Consent to Disclose Health Information: Patients are provided documents at their first visit to decide whether they want to share health information with their family members and/or caregivers. All consents are then scanned into the electronic health record (EHR).

Website: Specific sections describe the caregiver counseling program and dementia caregiver support, such as local resources and organizations, and general tips on caregiver stress and burnout.

E-Mail Communication: Appointment reminders and instructions are sent to both the patient and the caregiver for seamless communication. Written instructions are scripted to be inclusive of the patient and their caregiver.

Phone Reminders: Attempts are made to contact the patient and the caregiver if the patient misses an appointment or if there are re-scheduling needs.

Assessment: Caregivers complete mental health questionnaires about their own emotional well-being on clinic tablets prior to the initial diagnostic medical appointment for the patient (see core strategy #6 for a list of assessments).

Individualized Care: Caregivers have their own 30-minute appointment scheduled with a clinical social worker to complete a biopsychosocial assessment of their individualized needs and goals.

Documentation: Results of caregiver mental health assessments and identified caregiver goals and needs are recorded in the patient's medical chart by a clinical social worker and communicated with the patient's medical providers as part of the weekly interprofessional consensus team meetings.

Inclusivity: At each appointment, clinicians invite the caregiver to share observations, ask questions, and identify their own needs and preferences pertaining to their caregiving role. Recommendations in the patient's care plan are specific to caregiver needs and goals.

Engagement: During the first few years of development, CMC had an executive council that consulted on clinical operations and strategic planning. A family caregiver joined the council to provide the perspective of having first-hand experience caring for someone living with dementia (Appendix A).

LESSON LEARNED

Training the receptionist/check-in team has been essential to CMC's success. Each time a new team member is hired, training is provided to explain how the CMC serves both patients and caregivers. For example, they are responsible for completing the electronic check-in for caregivers at social work visits scheduled under the patient's name in our electronic medical record. They also provide the tablet and instructions for the caregiver mental health questionnaires. The check-in team explains that the caregiver should answer the questionnaires regarding their own emotional well-being, not the patient's.

Build identification and assessment of family caregivers in the patient's electronic health record

For years, caregiving organizations have advocated for enhanced integration of caregiver identification within healthcare systems in electronic health records (EHR). There is a critical need to standardize methods to capture caregiver contact information in EHRs, as current practices often involve entering data as free text, leading to significant challenges for health care providers to locate and utilize this information effectively. The implications of this fragmented approach are vast, including sub-optimal coordination of appointments, diminished caregiver involvement in care planning, and delayed communication of discharge plans. Despite existing regulations such as those in the CARE Act, which mandates documentation of caregiver information in inpatient settings, outpatient settings lack a standardized framework for capturing caregiver information.

..... @CMC

Identifying a Caregiver: When the CMC team calls patients to schedule an initial appointment, they are strongly encouraged to bring a family member or friend to their appointment. Their name and contact information are collected, and this information goes on the EHR facesheet in a yellow box that pops up when a provider opens the patient's medical record. Caregivers are also asked to attend all follow-up appointments.

Training: All new team members and call center operators get a brief orientation on how we partner with family caregivers to schedule appointments, making it easier to reschedule or reach the patient and caregiver. For example, when patients receive the automated appointment reminder phone calls, texts, or e-mails, they often don't recall scheduling the appointment or assume their family caregiver scheduled it on their behalf. Occasionally they will call back to cancel an appointment that may have been scheduled for months. If a patient calls to cancel an appointment, it is our general practice to reach the family caregiver to confirm.



Quality Assurance: Since the family caregiver is also a recipient of our health care services, having their e-mail and phone number is important so they can receive satisfaction and feedback surveys that our EHR automatically sends out.

Caregiver Assessment: When a patient is checked in for an appointment, the family caregiver completes mental health questionnaires on a tablet about their own well-being (see core strategy #6 for list of assessments). Having the caregiver's information readily available in the EHR ensures a smooth process for the reception team to identify the patient and the caregiver when they arrive for their appointment.

LESSON LEARNED

More than just an emergency contact: Identifying the full name and contact information of the family caregiver in the EHR has been critical for the coordination of care services. Many patients with cognitive impairment rely on a caregiver to manage their appointments and schedule.

Ensure that family caregivers receive the information necessary to coordinate care

Family caregivers serve as the cornerstone of support for people living with dementia, often navigating complex healthcare journeys and shouldering a diverse range of responsibilities. Caregivers have a pivotal role in ensuring the seamless coordination of patient care, sometimes across several healthcare settings. Access to comprehensive and time-sensitive information is paramount for family caregivers to fulfill their roles effectively. From understanding treatment plans and medication regimens to navigating daily tasks and coordinating appointments, family caregivers require access to accurate and easily understandable information. Equipped with this knowledge, they can actively participate in care planning discussions and advocate for their loved ones' needs with confidence. Informed caregivers are better positioned to recognize potential issues, address emerging concerns promptly, and collaborate more effectively with healthcare providers, thereby enhancing the overall quality of care and patient outcomes.

LESSON LEARNED

One of the challenges the CMC had faced was confusion about logging into the patient electronic medical record system. When a caregiver was also a patient in the healthcare system, they would often use their own log-in and password instead of the patient's and message the care team using their own portal instead of the patient's. The solution was creating a shared email account that clinicians can use to send both patients and family caregivers links for virtual appointments, care instructions, and reminders.

Before the Appointment: Prior to their initial appointment, patients and caregivers receive a phone call and a welcome e-mail with instructions on what to bring, where to park, and what to expect for their appointment (Appendix B). The goal is to set expectations and help family caregivers prepare to get the most out of the appointment. At the end of this appointment, patients and family caregivers are given a printed checklist of next steps, including information on obtaining lab work, brain imaging, and a social work appointment (Appendix C).

Feedback Appointment: After all diagnostic assessments are complete, the patient and caregiver attend a feedback appointment to review the diagnosis. Family caregivers and patients are sent an e-mail that includes a copy of their individualized care plan. The plan might include referrals for a driving assessment, caregiver counseling services, medication instructions, and related referrals (Appendix D). The CMC team adapted a document that helps family caregivers consider what level and types of services they currently need (Appendix E).



Offer billable mental health counseling, support, education and evidence-based services to family caregivers

As highlighted in the Alzheimer’s Association’s 2023 Facts and Figures Report, caregiving for individuals with Alzheimer’s disease or other dementias places significant emotional strain on family caregivers, with a striking 59 percent reporting high to very high levels of emotional stress. This burden often translates into increased feelings of social isolation, anxiety, and depression among caregivers. Recognizing the diverse needs of caregivers and developing targeted interventions tailored to their circumstances is essential for enhancing their access to high-quality care. By understanding the complexities of caregiving dynamics and providing personalized interventions to address them, we can better support and empower dementia caregivers in their crucial role.

@CMC

In the CMC, family caregivers complete mental health questionnaires on a tablet about their own well-being at the initial visit (see core strategy #6 for a list of assessments). If scores are elevated, the social worker recommends scheduling caregiver counseling sessions. Sessions are available in-person or by telehealth and accepted by most insurance plans.

Counselors take a person-centered approach to help caregivers establish personally significant goals within their caregiving role. Evidence-based interventions, such as cognitive behavioral therapy, motivational interviewing, solution-focused and mindfulness techniques are used. For topics typically covered in caregiver counseling, see Appendix F.

LESSON LEARNED

One challenge was that caregivers wanted the information they shared about themselves with the social worker to stay private. They voiced concerns about caregiver counseling session notes being recorded in the patient's electronic medical record. To alleviate these concerns, family caregivers are now asked to sign an informed consent form and have the opportunity to create their own patient chart so they may receive caregiver counseling services as patients themselves. In these instances, the family caregiver becomes a patient of the healthcare system, and their own insurance is billed for mental health appointments with the social worker.

NOTE: TYPICAL CPT CODES

90791 (Diagnostic Interview)

90846 (Psychotherapy without Patient Present)

90834/90837 (45-60 minute Psychotherapy Codes)

90847 (Family Psychotherapy with Patient Present)



Ensure providers and other members of the care team know how to effectively engage family caregivers

Not all healthcare degree programs emphasize the significance of family-centered care and the integral role caregivers should have on the healthcare team. Consequently, caregivers frequently encounter challenges in navigating the healthcare system, describing the experience as fragmented and convoluted. However, fostering enhanced communication and collaboration between healthcare providers and family caregivers can yield significant advantages for patient care. By recognizing caregivers as essential partners in the care journey and prioritizing their inclusion and involvement, healthcare systems can optimize outcomes for both persons living with dementia and their family caregivers.

@CMC

In-Service Training: Periodically, local service agencies are invited to meet with the CMC team and describe services they provide to individuals living with dementia and their family caregivers. This helps our interprofessional team stay up-to-date on community resources and build collaborations for services that can further support our patients and their family caregivers. Examples of topics include hospice and palliative care, elder law, adult day programs, home health agencies, adult day services, driving assessment resources, and nutrition.

Annual Retreat: Each year, the CMC clinical team meets for an all-day, off-site retreat to reflect on our successes and participate in vision planning for the clinic. This is also an opportunity to introduce new team members into our culture of interprofessional practice and strategize new ways to support family caregivers.

LESSON LEARNED

When clinical team members or medical residents join the CMC professional team, they are oriented to our patient/family caregiver-centered practice in several ways:

- *Educational articles that inform CMC's unique approach to care (Appendix G)*
 - *History of the clinic, which was developed with input from patient and family caregivers through local experience groups*
 - *Training on where to find caregiver information in the EHR*
 - *Education on the purpose of caregivers having individual appointments scheduled with the clinical social work team and where to find caregiver assessment results in the patient's EHR*
-

CONSENSUS MEETING

Each week, the CMC team discusses patients who will receive diagnosis the following week. Relevant medical history, labs, imaging, the clinical interview, neuropsychological testing, and caregiver well-being are reviewed. Together, the interdisciplinary team determines the diagnosis, stage of dementia and a care plan. The plan is e-mailed to the patient and caregiver after the feedback appointment and includes the diagnosis and stage as well as action steps and resources for both the patient and family caregiver based on their individualized needs (Appendix D). Consistently discussing the needs and goals of family caregivers during team consensus meetings helps trainees, providers, and other team members to regularly engage family caregivers as part of their usual practice.

Measure and document family caregiver well-being at critical transition points

Navigating care transitions presents significant challenges for both persons living with dementia and their family caregivers, often placing immense strain on their well-being. It is imperative to prioritize the reassessment of family caregivers at the patient's critical transition points, including the initial visit, emergence of new behavior symptoms, post-hospitalization, move to residential care, and death. By recognizing and proactively addressing the evolving needs of caregivers throughout these critical stages, healthcare providers can better support their resilience and effectiveness in providing care, ultimately enhancing the overall quality of patient outcomes.

@CMC

Assessments: Questionnaires in the CMC are always completed prior to the initial patient appointment, as well as before the initial and final counseling sessions. The caregiver completes mental health assessments of their own well-being via a link to the survey in the e-mailed appointment reminder. The surveys are captured in REDCap, a HIPAA-compliant database. A social worker is responsible for reviewing the responses and making recommendations for follow-up support and care. The raw scores are captured in the patient's medical record by the social worker so that the patient's medical providers have access to objective assessments of caregiver well-being. Social workers also relay caregiver needs and goals in weekly interprofessional consensus meetings.

Initial Visit: Collected on a tablet in-person or in advance with an online survey:

- Demographics
- Health Needs Assessment (agency created, see Appendix H)
- Depression (GDS-15 or PHQ-9)
- Anxiety (GAD-7)
- Burden (ZARIT-4)



Initial and Final Counseling Sessions: An online survey is used to collect:

- Demographics
- GDS-15 or PHQ-9
- GAD-7
- Zarit-12
- COPE-ING (agency created, see Appendix I)

LESSON LEARNED

Caregiver outcome measurements are used to guide and direct counseling sessions to establish baseline goals and monitor progress over time. There is a lack of assessment tools that adequately capture information on the caregivers' needs and goals. Thus, CMC developed several of its own assessment tools.

Use an interprofessional team approach to support family caregivers

While healthcare providers typically collaborate in interdisciplinary teams, it is common for them to complete training and advanced degree programs within silos. This compartmentalization can inadvertently foster biases and misconceptions among healthcare professionals regarding each other's care approaches, ethical codes, and practice philosophies. Therefore, it is crucial to cultivate teams that actively engage in learning about interprofessional values, fostering traits such as trust, mutual respect, and effective communication. By prioritizing the development of these values on healthcare teams, we can ensure that patients receive comprehensive and cohesive care delivery, ultimately optimizing outcomes through collaborative efforts.

@CMC

There are several strategies the CMC team uses to develop interprofessional skills:

Internal Training: Each discipline is invited to give a presentation on their professional values, educational training process, licensure requirements, scope of practice, billing codes and general expertise. By understanding each other's professions better, they are able to communicate about each other's services to patients and increase trust among team members. A summary of the learnings is shared with new team members.

Assessment: Objectively measuring strengths and areas for growth as a team is critical, especially in the first few years of working together. To evaluate this, the CMC uses a Team Fitness Survey (Appendix J). The results are shared with the team, and priorities to work on together in the following year are identified.

Meetings: Once a month, the CMC team meets for “Outcomes and Processes,” where there are discussions about clinic workflow, outcome measurements, marketing, managing trainees, referral process, staff transitions and research projects. Relevant institutional information, kudos, and announcements are also shared. These meetings help provide consistency across disciplines.

Journal Club: The CMC has an optional journal club where clinicians take turns choosing relevant research articles for group discussion.

Social Events: CMC team members conduct outreach at community events, participate in panels and guest lectures together, and volunteer for the Walk to End Alzheimer’s.



Utilize qualitative research methods to inform care

Through qualitative research, researchers and clinicians gain a better understanding of the nuances of experiences, perceptions, and preferences of family caregivers. Qualitative findings not only shed light on the psychosocial and cultural factors shaping caregiving dynamics, but also pave the way for the development of person-centered interventions tailored to meet individual needs. By leveraging qualitative research methodologies with family caregivers, healthcare professionals are empowered to adopt a more comprehensive and tailored approach to care delivery. Qualitative research methods can transcend statistical data and foster a healthcare environment where the needs of both patients and caregivers are prioritized and addressed effectively.

@CMC

Examples of how the CMC team uses qualitative research methods to engage family caregivers:

Experience Groups: The CMC team partners with local nonprofit agencies that serve individuals living with dementia and their caregivers to conduct “experience groups.” The goal is to understand real-world perspectives of barriers to getting a diagnosis, finding information about disease stage, coordinating care, and receiving appropriate referrals, as well as what is meaningful to families before, during, and after a diagnosis. When conducting the groups, a representative from executive administrative leadership is invited to attend to hear the perspectives of individuals living with dementia and their caregivers.

Visit Satisfaction Surveys: To evaluate the CMC model, short satisfaction surveys were administered (Appendix L) after initial and feedback appointments between February and October 2019. There were three open-ended items and four multiple choice items, and data was collected from 180 patients and 173 caregivers. Their responses helped inform changes made to the practice.

Health Needs Assessment: The CMC team developed an 11-item person-centered assessment to measure the benefits of care — not just satisfaction with services — assessing elements of comfort, capability, and calm. It is given prior to the initial medical appointment and reviewed by the team’s social worker (Appendix H). This assessment addresses topics such as hopefulness, confidence in caregiving abilities, caregiver physical health, and perceived availability of support network.

LESSON LEARNED

Open-ended questions did not yield useful information from the initial experience groups, because individuals with cognitive impairment had difficulty following long discussions and were less likely to be able to answer the interviewers’ questions on-the-spot with succinct responses. For subsequent experience groups, questions to be answered were provided in advance. Many came with written responses that were collected by the CMC team. A checklist of potential topics of importance was also handed out. Finally, there were open-ended questions if individuals wanted to provide more written information (Appendix K).



Increase family caregiver access to research

Expanding access to opportunities for family caregivers to participate in research is crucial, especially as identification and recruitment of caregivers into clinical trials remains a challenge. Efforts to increase accessibility may encompass various strategies, including targeted outreach, community collaborations, culturally relevant research materials, and the establishment of caregiver-focused research networks. Fostering partnerships among researchers, healthcare institutions, and caregiving organizations can lead to the co-creation of research projects that directly address the needs and concerns of caregivers. Through these concentrated efforts, caregivers can be empowered as active participants in the research process, contributing their unique perspectives and expertise to the advancement of knowledge and the development of more effective support services and interventions.

@CMC

Feedback from caregivers during the experience groups (see core strategy #8) was consistent with the recommendations from the RAISE Family Caregiving Advisory Council. The overall interest in research participation was very high, and the CMC team developed several innovative strategies to inform family caregivers about local and national research opportunities:

Consensus Meetings: A research assistant (RA) attends weekly virtual team consensus meetings. While clinicians review patient medical records, the RA looks at inclusion/exclusion criteria to see if the patients or caregivers are eligible to participate in any active research studies. If any are identified, the physician provides more information at the feedback appointment.

Marketing: Research flyers are posted in clinical exam rooms as well as on the Dell Medical School website. An RA is available to talk to patients and family caregivers directly after their initial medical appointment. At that time, they can be screened and may consent to participate in available research studies.



Community Events: The CMC team regularly sponsors booths at local caregiver conferences that are organized by agencies in the community. At these events, flyers on available research studies and clinical services are provided to conference attendees.

Trial Match: Information about opportunities to be matched with worldwide clinical trials through programs such as TrialMatch and clinicaltrials.gov is provided.

Demographics Survey: Prior to the initial appointment, the identified family caregiver completes questionnaires, including demographic information. The last question on the demographic survey is “Can we contact you about future research opportunities?”

Provide family caregivers with community resources and educational programs

Offering caregivers access to tailored community resources and educational programs is critical to equip them with the support and knowledge necessary to navigate their caregiving journey effectively. Resources may include support groups, respite care services, counseling services, and informational workshops tailored to address the specific needs and challenges faced by caregivers. Educational programs can cover a wide range of topics, such as disease management, caregiving techniques, stress management, and self-care strategies. By connecting caregivers with resources and knowledge, they can feel more informed and better equipped to provide quality care while also maintaining their own well-being. Additionally, these initiatives can foster a sense of belonging and connection within the caregiving community, providing invaluable emotional support and solidarity.

@CMC

The CMC team extends support to caregivers beyond the doors of the clinic in several ways:

Website: The CMC website lists national and local services and agencies that support family caregivers of individuals living with dementia.

Clinician Resources: An online collection of resources is available on CMC's intranet so clinicians can quickly search for relevant community resources to print or e-mail patients and their caregivers before, during, or after appointments.

Resource Library: A designated room in the clinic holds brochures from local community organizations, such as home health agencies, support groups, hospice and palliative care, driving resource programs and upcoming events. There are also information booklets from the National Institutes of Health, Mayo Clinic, and other organizations on topics such as brain health and different types of dementia.

Flyers: Clinical exam rooms display flyers detailing pertinent upcoming events including caregiver conferences, research study opportunities, brain health information, and frequently asked questions about dementia.

In-Service Trainings: To ensure the clinical teams remain informed about community agencies and services, multiple in-service trainings are hosted annually. Representatives from agencies are invited to educate teams about the services available to patients and their family caregivers (see core strategy #5).

Community Education: CMC providers frequently give educational talks in the areas of brain health, dementia research, family caregiving, clinical practices and more. The CMC team collaborates with agencies to provide information to the community at support groups, staff training sessions, senior housing facilities, faith-based communities, caregiver conferences, and similar events.



Appendix A

Executive Committee Invitation Letter for Care Partner

Invitation to Become a Member of the Comprehensive Memory Center (CMC) Executive Committee

The CMC has an executive committee that meets quarterly to consult on clinic operations and strategic planning to ensure we are meeting the needs of our patients and care partners. The committee believes that a care partner who has experienced our clinical services first-hand and has cared for a person with dementia would be an important perspective to add to the committee. This committee is purely an advisory committee and no extra time commitments are required. The only expectation would be for you to attend the quarterly meetings, either in person or by phone, which are scheduled on Fridays from 9-10 a.m., and offer your perspective. The meetings take place at the Comprehensive Memory Center at UT Health Austin. Other committee members include our clinic director, a physician, a social worker, a speech and language pathologist and a representative from our operations team. Would you be interested in this opportunity to provide advice and insights for future development of the CMC?

Appendix B

Phone Call and Welcome Email Scripts

Phone Call Script:

- Hello, my name is _____, and I'm calling from the Comprehensive Memory Center to schedule an appointment for _____.
- We take a team approach to investigate your concerns; you will meet more than one provider.
- We consider family members an important part of the team and would like a family member or someone who knows you well to be at the appointment. Who will be coming with you?
 - Modify as needed if scheduling with the caregiver instead of patient (put caregiver name and contact information on the facesheet)
- In order to get the answers you are looking for efficiently, we try to collect as much information as possible at this first visit.
 - There will be an interview followed by a comprehensive evaluation which will take a couple of hours.
 - While you are doing the evaluation, your family member will meet with a social work counselor.
 - You will need a brain scan. We can do the brain scan before the interview or right after lunch. Which do you prefer? Do you have any metal implants?
- Verify the following if unclear/unknown:
 - Primary language
 - Prior appointment with neurologist or neuropsychologist (if yes, find out who, when, and request records, including neuropsych report, if appropriate)
- We will send a confirmation email with appointment date/time, location and parking, and what to bring, such as a list of your current medications. There is also a link to a survey for the family member to complete. What is the best email address for them?
- On the day of your appointment, please come 15-20 minutes early to complete paperwork.
- Any questions?

Appendix B

Phone Call and Email Welcome Scripts

Welcome E-mail Script:

Welcome to the Comprehensive Memory Center, thank you for choosing us for your healthcare needs. We look forward to meeting you and your family/friends at your upcoming appointment.

Please arrive 30 minutes before your scheduled appointment time to complete consent, privacy and health history forms. You may also complete some of your forms online before your appointment through your patient portal.

Please complete the Family Questionnaire (link) before your visit. This questionnaire is intended for the family member (or primary caregiver) to complete regarding their own well-being. Our aim with this survey is to focus on how the family member (not the patient) is doing.

WHAT TO BRING

Family Member or Friend – we provide a comprehensive team-based, family-based approach to our visits, and due to the nature of the conditions we treat, we encourage all of our patients to have a family member or friend attend the appointments with them.

Insurance card and Driver's license or Identification card – you will not be seen without your insurance or identification and must have the original copy.

- Glasses and/or hearing aids (with fresh batteries)
- List of medications, including over-the-counter medications
- A list of questions, concerns and goals for the appointment
- Credit card for any co-payment charges
- Lunch or snacks
- Any medical records you may think will be helpful
- Power of attorney paperwork and any other advance directive paperwork

WHAT TO EXPECT:

- Friendly and welcoming staff
- New and clean environment
- Meeting with a team of providers (most appointment types)

LOGISTICS/PARKING:

- We are located at 1601 Trinity, 78712 (the corner of 15th and Trinity)
- Park in the Health Center Parking Garage and take the elevators to 7th floor
- We are NOT located in Dell Seton Hospital
- If you need a wheelchair, please call 833-882-2737 to request and wait in the Patient drop off zone before entering gates.

If you have any questions, please do not hesitate to call us at 1-833-882-2737. For any Financial or insurance coverage questions please call 512-471-3434.

Appendix C

Initial Appointment Next Steps



The University of Texas at Austin
UT Health Austin

Mulva Clinic for the Neurosciences
Comprehensive Memory Center
Health Transformation Building
1601 Trinity Street
Austin, Texas 78712
1-833-UT-CARES | www.uthealthaustin.org

PATIENT NAME: _____

TODAY'S DATE: _____

NEXT STEPS:

1. BRAIN IMAGING (MRI or CT) – please complete within 10 days

- UT Health Austin Imaging
The order is attached – Imaging center will call you to schedule the appointment
512-495-5300
- Austin Radiological Association (ARA)
The order is attached– Imaging center will call you to schedule the appointment
512-458-9098

2. LAB WORK – please complete within 10 days

- Clinical Pathology Laboratory (CPL)
The order is attached
Located in our building, on the 9th floor, Suite 9.705 *or*
Call 512-339-1275 to find a location near you and to schedule an appointment

3. NEXT APPOINTMENT

- Care Partner/ Family Assessment _____
- Neuropsychological Testing _____
- Follow-Up Appointment _____
- Feedback Session _____

4. OTHER

YOUR TREATMENT TEAM TODAY

- | | |
|---|--|
| <input type="checkbox"/> Ra'Aana Brown CMA | <input type="checkbox"/> Alyssa Aguirre LCSW, Social Work Counselor |
| <input type="checkbox"/> Yasmin Zambrano CMA | <input type="checkbox"/> Jess Ambiee LCSW, Social Work Counselor |
| <input type="checkbox"/> John Bertelson MD, Neurologist | <input type="checkbox"/> Anna Finger LCSW, Social Work Counselor |
| <input type="checkbox"/> Steve Steffensen MD, Neurologist | <input type="checkbox"/> Lindsey Wineholt CCC-SLP, Speech Language Pathologist |
| <input type="checkbox"/> Megan Klein PA | <input type="checkbox"/> Bertha Ortiz, Psychometrist |
| <input type="checkbox"/> Jared Benge PhD ABPP, Neuropsychologist | <input type="checkbox"/> Illyana Runnels BA, Psychometrist |
| <input type="checkbox"/> Bonnie Scott PhD ABPP, Neuropsychologist | |

Appendix D

Sample Care Plan



The University of Texas at Austin
UT Health Austin

Mulva Clinic for the Neurosciences
Comprehensive Memory Center
Health Transformation Building
1601 Trinity Street
Austin, Texas 78712
1-833-UT-CARES | www.uthealthaustin.org

Care Plan for (Patient Name)

Date of Visit:

Care Partners:

Comprehensive Memory Center Team:

- John Bertelson, MD- Neurologist
- Alyssa Aguirre, LCSW – Social Worker
- Megan Klein, PA – Physician Assistant
- Jared Benge, PhD- Neuropsychologist

Diagnosis: Mixed Dementia (Mild) likely Alzheimer's & Vascular disease

Recommendations:

- **Information About Your Diagnosis** – see printed information
 - Alzheimer's Association Website and Help Line (www.alz.org, 800-272-3900)
- **Medications:** Begin Aricept in 2 weeks. Check her heart rate, it needs to be more than 60 bpm prior to starting. If it is less than 60 bpm, do not take the medication.
- **Speech Language Therapy:** We recommend beginning cognitive communication therapy with our speech language pathologist
- **Family Support** –
 - Counseling with one of our social workers is available in this clinic
 - Attend a caregiver support group in the community (see list provided)
 - Online information for family care partners at www.caregiver.org
- **Brain Healthy Lifestyle for You and Your Family**
 - Six Pillars of Brain Health (information provided)
 - AARP Global Council on Brain Health www.aarp.org/health/brain-health/

Questions: Call 1-833-882-2737 (1-833-UT-CARES)

Care plan follow-up: Return in 6 weeks to discuss the care plan on _____

At the Comprehensive Memory Center, our team specializes in determining the cause of your memory or thinking problems and providing a diagnosis and initial care plan. Once your care has been stabilized, you will return to your primary care physician for ongoing medical management. We recognize that as your disease progresses you may have questions and additional needs, and our team is available to consult with you and your family members to determine a path forward.

Appendix E

Care Level Definitions

CHOOSE THE RIGHT CARE AT THE RIGHT PLACE

PRIMARY CARE PROVIDER

Your PCP is a physician with whom you have an established relationship and who is taking care of your ongoing medical needs as well as providing continuity of care.

Routine and annual checkups • Basic medical tests, lab work • Preventative care • Medications – prescriptions, dosage changes, refills • Treatment for common/non-life-threatening medical issues • Ongoing health management for chronic conditions • Referral to and care coordination with specialists (cardiology, pulmonology, gastroenterology, pain management, etc.) • Assistance in developing a long-term health plan

CALL YOUR PCP FIRST, SAME-DAY URGENT APPOINTMENTS MAY BE AVAILABLE

URGENT CARE

Care for conditions that require care within 24 hours, but are not life threatening.

Accidents • Falls • Minor wound care - cuts that require stitches • Mild to moderate asthma • Fever • Flu • Minor broken bones / fractures • Severe sore throat and cough • Skin rash • Sprains / strains • Vomiting, diarrhea, constipation.

EMERGENCY DEPARTMENT

Care for conditions that are life threatening.

Sudden tightness / pressure in the chest • Difficulty breathing • Loss of consciousness • Stroke symptoms: vision loss, slurred speech / difficulty speaking, numbness, weakness • Convulsions, seizures • Sudden confusion • Severe abdominal pain • Heavy, uncontrollable bleeding • Trauma / deep wounds • Severe head / neck / back injury • Major bone fracture

PHARMACY

Questions or concerns regarding prescriptions

Prescription refills • Specific questions regarding medication side effects • Clarification on dosage / frequency / administration method • Clarification on compatibility with medical issues and/or other medications

COMPREHENSIVE MEMORY CENTER

Questions or concerns regarding your dementia diagnosis, treatment plan, new or worsening symptoms or behaviors, side effects of medications we have prescribed

Our team specializes in determining the cause of your memory or thinking problems and providing a diagnosis and initial care plan. Once your care has been stabilized, you will return to your primary care physician for ongoing management. We recognize that as your disease progresses you may have questions and additional needs, and our team is available to consult with you. We provide time-limited counseling and speech-language therapy services following your diagnosis.

Appendix F

Topics Covered in Counseling

TOPICS THAT COME UP IN THERAPY

- Experience getting a diagnosis
- Telling family and friends about the diagnosis
- Accepting the diagnosis
- Legal questions, avoiding scams, long-term care insurance
- Communication tips
- Safety: driving, falls, cooking, supervision of finances and medications
- Emotional strain
- Identifying a support network
- Spirituality, faith, and hope
- Creating routine and structure
- Long term housing planning
- Identifying ways to pay for long-term care
- Long distance caregiving
- Grief and loss
- Intimacy
- Managing challenging behaviors such as wandering, aggression, sleep
- Caregiver identity
- Brain health strategies
- Feelings towards accepting help
- Identifying relevant community resources
- Understanding what to expect as the disease progresses
- Reducing depression, anxiety, burden, strain
- Caregiver self-care
- Using technology to support caregiving responsibilities

Appendix G

Recommended Articles

Aguirre*, A., Hilsabeck*, R.C., O' Mahar, K., Carberry, K., Ayers, G., Bertelson, J., Rousseau, J., Paydarfar, D. (2022) Designing an Interprofessional Dementia Specialty Clinic: Conceptualization and Evaluation of a Patient-Centered Model. *Journal of Interprofessional Care* (37) 2. <https://doi.org/10.1080/13561820.2022.2060194>

Aguirre, A., Benge, J.F., Finger, A.H. et al. (2024) The Caregiver Outcomes of Psychotherapy Evaluation (COPE): Development of a Social Work Assessment Tool. *Clinical Social Work Journal*. <https://doi.org/10.1007/s10615-024-00925-2>

Borson, S., & Chodosh, J. (2014). Developing dementia-capable health care systems. *Clinics in Geriatric Medicine*, 30(3), 395–420. <https://doi.org/10.1016/j.cger.2014.05.001>

Callahan, C. M., Sachs, G. A., LaMantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs*, 33 (4), 626–632. <https://doi.org/10.1377/hlthaff.2013.1260>

Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (2018). Alzheimer's Association dementia care practice recommendations. *The Gerontologist*, 58 (suppl_1), S1–S9. <https://doi.org/10.1093/geront/gnx182>

Galvin, J. E., Valois, L., & Zweig, Y. (2014). Collaborative transdisciplinary team approach for dementia care. *Neurodegenerative Disease Management*, 4 (6), 455–469. <https://doi.org/10.2217/nmt.14.47>

Gaugler, J. E., Bain, L. J., Mitchell, L., Finlay, J., Fazio, S., Jutkowitz, E., Banerjee, S., Butrum, K., Fazio, S., Gaugler, J., Gitlin, L., Hodgson, N., Kallmyer, B., Meyer, O. L., Logsdon, R., Maslow, K., & Zimmerman, S. (2019). Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 5 (1), 388–397. <https://doi.org/10.1016/j.trci.2019.02.008>

Appendix G

Recommended Articles

National Academies of Sciences, Engineering, and Medicine. (2021). *Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: A way forward*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26026>

Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health care experiences of people with dementia and their caregivers: A meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal*, 185 (14), E669–E680. <https://doi.org/10.1503/cmaj.121795>

Reuben, D. B., Tan, Z. S., Romero, T., Wenger, N. S., Keeler, E., & Jennings, L. A. (2019). Patient and caregiver benefit from a comprehensive dementia care program: 1-year results from the UCLA Alzheimer's and Dementia Care Program. *Journal of the American Geriatrics Society*, 67 (11), 2267–2273. <https://doi.org/10.1111/jgs.16085>

Appendix H

Health Needs Assessment

Our clinic takes a comprehensive family-based approach to care. This questionnaire is intended for the family member (or primary care partner) to complete regarding their own well-being. Our aim with this particular survey is to focus on how the family member (not the patient) is doing. Thank you!

1. Today I am _____ .
 - a. Enjoying life
 - b. Doing okay
 - c. Struggling
 - d. Suffering

2. I do things I enjoy.
 - a. Every day of the week
 - b. Most days (4-6 days of the week)
 - c. Some days (1-3 days of the week)
 - d. Never (0 days of the week)

3. My physical health is _____ .
 - a. Excellent
 - b. Good
 - c. Fair
 - d. Poor

4. My loved one has memory or thinking problems. Yes / No
 - a. If yes: I know how to manage (or cope with) my loved one's memory or thinking problems. Yes / No

5. My loved one has emotional or behavioral problems. Yes / No
 - a. If yes: I know how to manage (or cope with) my loved one's emotional or behavioral problems. Yes / No

6. I have supportive social relationships. Yes / No

7. I feel confident in my ability to care for my loved one. Yes / No

8. I feel hopeful. Yes / No

9. I am interested in learning more about (check all that apply):
 - a. My loved one's symptoms/condition
 - b. Support groups
 - c. Help in the home
 - d. Long-term care

10. Is there anything else you would like us to know about your health or care?

Appendix I

Caregiver Outcomes of Psychotherapy Evaluation (COPE)

Answer the statements below by marking which option choice you most agree with.

1. I am knowledgeable about dementia (symptoms, stages, behaviors):
Strongly Agree Agree Neutral Disagree Strongly Disagree
2. I am confident in my caregiving skills:
Strongly Agree Agree Neutral Disagree Strongly Disagree
3. I have communication strategies that are effective with my loved one:
Strongly Agree Agree Neutral Disagree Strongly Disagree
4. I feel able to manage my emotional well-being:
Strongly Agree Agree Neutral Disagree Strongly Disagree
5. I have a network of people who provide me with practical and emotional support:
Strongly Agree Agree Neutral Disagree Strongly Disagree
6. I am equipped to make a decision about keeping my loved one at home or moving to a long-term care community:
Strongly Agree Agree Neutral Disagree Strongly Disagree
7. I enjoy life:
Strongly Agree Agree Neutral Disagree Strongly Disagree
8. I am confident in facing challenges ahead:
Strongly Agree Agree Neutral Disagree Strongly Disagree

Please notify alyssa.aguirre@austin.utexas.edu of use.

Use the citation below when appropriate. No other permissions required.

Aguirre, A., Benge, J.F., Finger, A., Ambiee, J., Runnels, I., Hilsabeck, R. (2024) The Caregiver Outcomes of Psychotherapy Evaluation (COPE): Development of a Social Work Assessment Tool. *Clinical Social Work Journal*. <https://doi.org/10.1007/s10615-024-00925-2>

Appendix I

Caregiver Outcomes of Psychotherapy Evaluation (COPE)

1= not at all
5= very important to me

Caregiver Needs and Goals	This is important to me	This is a top priority for me right now
I want to understand more about dementia, memory or thinking problems and what to expect as things change in the future		
I want help finding meaningful activities at home or community programs for the person I care for, such as senior centers, adult day care, respite and support groups		
I want help finding caregiver programs, such as education, trainings, classes or support groups		
I want to learn about brain health for myself and the person I care for, such as exercise, nutrition, or tips for getting good sleep		
I want to learn better ways to reduce my own stress, depression, frustration or anxiety		
I want information on how to find and pay for caregivers in the home		
I want help understanding the cost and types of housing options for right now or in the future, such as independent living, assisted living and memory care		
I want help with legal, medical, or financial questions such as medical power of attorney, long-term care insurance, disability paperwork or medical insurance		
I want to learn about transportation options for me or the person I care for		
I want to learn about research studies or clinical trials for me or the person I care for		
I want to discuss topics related to safety, such as driving, preventing falls, cooking, supervision of finances, medication oversight or avoiding scams		

Appendix I

Caregiver Outcomes of Psychotherapy Evaluation (COPE)

I want to learn how to manage and respond to behaviors such as repetitive questioning, wandering, aggression, shouting or personality changes		
I want to learn communication strategies that will be helpful for me to use with the person I care for		
I want information on ways to meet our basic needs, such as paying utilities, finding rides to medical appointments, paying for medications or groceries		
I would like to know how apps and technology can help with my caregiving, such as in-home cameras, fall risk alerts or auto pill dispensers		

Appendix J

Team Fitness Test¹

Rate each of the following statements as it applies to your team using the following rating scale:

- 4 This statement **definitely** applies to our team.
- 3 This statement applies to our team **most of the time**.
- 2 This statement is **occasionally** true for our team.
- 1 This statement **does not describe** our team at all.

Enter the score you believe appropriate for each statement beside the statement number on the scoring sheet.

- ___ 1. Each team member has an equal voice.
- ___ 2. Members make team meetings a priority.
- ___ 3. Team members know they can depend on one another.
- ___ 4. Our mandate, goals, and objectives are clear and agreed upon.
- ___ 5. Team members fulfill their commitments.
- ___ 6. Team members see participation as a responsibility.
- ___ 7. Our meetings produce excellent outcomes.
- ___ 8. There is a feeling of openness and trust in our team.
- ___ 9. We have strong, agreed upon beliefs about how to achieve success.
- ___ 10. Each team member demonstrates a sense of shared responsibility for the success of the team.
- ___ 11. Input from team members is used whenever possible.
- ___ 12. We all participate fully in team meetings.
- ___ 13. Team members do not allow personal priorities/agendas to hinder team effectiveness.
- ___ 14. Our roles are clearly defined and accepted as defined by all team members.

Appendix J

Team Fitness Test

- ___ 15. Team members keep each other well informed.
- ___ 16. We involve the right people in decisions.
- ___ 17. In team meetings we stay on track and time.
- ___ 18. Team members feel free to give their honest opinions.
- ___ 19. If we were asked to list team priorities, our lists would be very similar.
- ___ 20. Team members take initiative to put forth ideas and concerns.
- ___ 21. Team members are kept well informed.
- ___ 22. We are skilled in reaching consensus.
- ___ 23. Team members respect each other.
- ___ 24. When making decisions, we agree on priorities.
- ___ 25. Each team member pulls his or her own weight.

Appendix K

Experience Group Sample Questions

Please check the items are important to you and share any thoughts you have:

- Participating in clinical trials

- Support for my family/ care partner

- Participating in art therapy (sharing your story/writing a book, guided museum tours)

- Participating in performance art (choir, dancing, theater)

- Meeting with a counselor to talk about my mood, anxiety, depression, grief, memory loss

- Finding solutions to help me live more independently

- Someone to help me get around town (go to a movie, out to lunch, etc.)

- Communicating with my health team on the computer, phone or iPad

- Talking with a health provider about my end-of-life wishes and preferences

- Legal counsel to put estate and financial affairs in order

- Volunteering with project or group that interests me

Appendix K

Experience Group Sample Questions

What would you like to improve or change in your life?

What are your personal goals?

Is there something you have not done in your life that you would still like to do?

What things help you manage your stress?

If you could take a class, what would it be? (cooking, arts, exercise, history etc.)

Please feel free to write down your diagnosis story.

Appendix K

Experience Group Sample Questions

Imagine you could create a new dementia clinic. What would be the most important things to you?

FOR CARE PARTNERS:

- What did it feel like when you were going through the diagnosis process? (length of time until a diagnosis, specialty vs. primary care)
- What could be done differently at your clinic to support you and your family? (what is being measured at their visits)
- Who would you call if you have questions about memory loss, medications, or if there were an emergency? (how available, strength of relationship)
- If you could wave a magic wand and create the ideal experience with the dementia healthcare team and clinic - what would that look like?
- Describe what a 'good day' is like from your perspective. (quality of life)
- Describe a difficult day
- What outcomes are important to you? (living at home longer, number of medications, timeliness of appointments, caregiver health etc.)

Appendix L

Satisfaction Survey

FOR OFFICE USE ONLY: Care Partner version

Date: _____

Clinicians: _____

Visit Type: Initial Feedback Follow Up

Your feedback is important to us. Please take a few minutes to complete this questionnaire.

Did we help you today? YES/NO

If yes, how? _____

If no, why not? _____

What did you like about today's visit? _____

What can we do better? _____

1) My concerns were heard.

<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>None of the time</i>
------------------------	-------------------------	-------------------------	-------------------------

2) My questions were answered.

<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>None of the time</i>
------------------------	-------------------------	-------------------------	-------------------------

3) The information I received today was explained clearly.

<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>None of the time</i>
------------------------	-------------------------	-------------------------	-------------------------

4) I feel informed about the next steps.

<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>None of the time</i>
------------------------	-------------------------	-------------------------	-------------------------

If you would like to provide additional feedback about today's visit, please email CMCFeedback@austin.utexas.edu.

Thanks in advance for your feedback!