

OUTCOMES OF A DEMENTIA RESOURCE AND EDUCATION PROGRAM IMBEDDED IN A HEALTH CARE SYSTEM

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- on behalf of our study team including Terry R Barclay, PhD, Anna Forsberg, Avis Thomas, Jean Crow & Heidi Haley-Franklin, MSW



Memory PREP

Patient Resource & Education Program

- Most families wait until a crisis to seek education and connection to resources, often years after a diagnosis
- Education and planning for the management of this chronic, progressive disease - imbedded in the health system, after a new diagnosis of dementia
- 2 Goals:
 - Understand the potential benefits of this program
 - Determine if meeting by phone could be as beneficial as meeting in-person

Memory PREP Curriculum

Visit Type	Visit	Task	Time (min)	Handouts	Homework
In-person Or By Phone	Week 0	<ul style="list-style-type: none"> - Introduction - Build rapport - Explain structure - Disease Education - Legal/Financial topics - Community Resources 	60-90	<ul style="list-style-type: none"> - Power of Attorney-Attachment #3 - Health Care Directive-Attachment #4 - Basics-Attachment #5 - Communication-Attachment #6 - Stages of AD-Attachment #7 - Living Well-Attachment #8 	<ul style="list-style-type: none"> - Complete power of attorney - Complete healthcare directive - Take 1 Action step
Phone	Week 2-3	<ul style="list-style-type: none"> - Review action steps - Identify barriers/successes - Living Well-Reduce Stress 	15-30		Ch. 5 Living Well
In-person Or By Phone	Week 4-6	<ul style="list-style-type: none"> - Review homework - Goals of care - Partnering with MD - Navigating healthcare system - Avoiding the potholes - Next steps 	60-90	<ul style="list-style-type: none"> - Medication Log-Attachment #9 - MASR-Attachment #10 - Driving Resources-Attachment #11 - Right Level of Care-Attachment #12 - Brain Tips-Attachment #21 	<ul style="list-style-type: none"> - MASR - Driving Evaluation - Take 1 action step
Phone	Week 8-10	<ul style="list-style-type: none"> - Review action steps - Living Well - Finding meaning and purpose 	15-30		Ch. 6 Living Well
Phone	Week 12-15	<ul style="list-style-type: none"> -Review action steps - Living Well - Establish a routine 	15-30		Ch. 9 Living Well
Ad-hoc	Week 0-32	Patient-initiated phone support	~15		

Research Measurement Visits @ 0, 4, and 8 months

Study Flow

Recruited 90 patients and their care partners

– Physician Referral

- 93 patients referred → consent 34

– Letters mailed to patients

- 2,427 patients contacted → consent 56

Randomized: 46 in-person and 44 phone-only

79 completed the program

– 4 death / terminal illness

– 7 voluntary withdrawals / loss to follow-up

Participation resulted in:

↑ Knowledge of Alzheimer's disease

Care partners, Alzheimer's Disease Knowledge Scale

↑ Feeling Emotionally Supported

Care partners, Medical Outcomes Study Social Support Survey

↑ Completion of Care Planning

e.g. power of attorney, driving and safety plans

↑ Use of Community Resources

Alzheimer's-related support groups, day programs, etc.

The program was equally effective when administered by phone as it was when administered in-person.

93% were likely to recommend this program to others

CARE-PARTNER COMMENTS

- Anyone going through this needs this program.
- It's been a relief to be asked “How are you doing?” for a change. Concern has been focused on [the patient] for years now. I also am aging!
- This program has been an invaluable resource.
- I don't know how it would have been possible to navigate all the concerns, issues with the information available. I feel very grateful to have had access to this program.

PATIENT COMMENTS

- I think anyone with dementia onset will benefit greatly from this program.
- Helped us communicate with family and friends. Provided a structure for having difficult conversations.
- Provided practical information