



Dementia Friendly
DECATUR
Task Force

Report of Community Wide Needs Assessment

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By

Sheila M. Greuel, MA, ECIAAA Community Liaison Consultant

Director, Covenant Transitions

History

The Dementia Friendly Decatur Task Force was created in September 2021 for the purpose of exploring the feasibility of establishing Decatur IL as the first Dementia Friendly Community in the East Central Illinois Area Agency on Aging service area. The reporter, an independent consultant contracted by the East Central Illinois Area Agency on Aging. The Consultant has developed groups under the guidelines set forth by the Dementia Friendly America Toolkit to explore the need, interest, and willingness of the community to take on the responsibility of becoming a member of the Dementia Friendly America Network. Membership entails an ongoing commitment to strive to improve support for persons living with dementia and their caregivers so that they remain active engaged members of the community as long as possible.

Julie Walker, Executive Director of CHELP contacted Susan Real in November 2020 to request Decatur be considered as becoming a Dementia Friendly Community. Ms. Walker then reported to Ms. Greuel that the Macon County 708 Board committed \$10,000 towards the work of Decatur becoming a Dementia Friendly Community.

A group of Key Community Leaders were upon recommendation of Ms. Walker, invited to participate in the first phase to determine if there would be enough interest and if the need was present coupled with desire to commit to the work of **making** and **keeping** Decatur Dementia Friendly. The committee met in September 2021 and agreed wholeheartedly the time was NOW. The Dementia Friendly Decatur Task Force (DFDTF) was developed. The DFDTF members would eventually include key community leaders, community-based organization members, business owners, government representatives, caregivers of persons living with dementia, and older adults. They were tasked with helping to identify members for an Action Team that would advise and assist with the development and implementation of a community-wide assessment. The purpose of the assessment was to inform the Dementia Friendly Decatur Task Force as to the needs of and for the community to support persons living with dementia and their caregivers.

The assessment process which started in December 2021 and ended in May 2022 was delivered by both the consultant and Action Team members conducting focus groups and delivering individual surveys to those willing to participate. The report below is the result of those combined efforts. This was an informal survey process that employed a combination of surveys supplied by the Dementia Friendly America Toolkit and Focus Group questionnaires developed to gather the needed information. The analysis was completed solely by the ECIAAA Community Liaison.

Population Sample

The information was gathered utilizing individual surveys and one-hour Focus groups as small as 5 and large as 27 participants. Individual surveys were designed for the particular sector group being questioned such as hospital or community caregiver. A summary of the sample is as follows:

Individual Surveys

31 hospital professionals

18 older adult caregivers

49 = Total Sample Size of Individual Surveys

Focus Groups

Sector	Organization	# of Participants
Clinical	Hospital	5
Residential Older Adults	Oxford House	7
Residential Older Adults	The Woods	5
CBO	CICN	14
CBO	Sr. Center Staff	6
CBO	Catholic Charities Staff	12
CBO	Starting Point Staff	4
Community	Old Kings Orchard	27
Community Older Adults	Senior Center	14
Business	Table for 10	12
Government	EMS	12
		114 Total Participants

Total Sample for Community Wide Assessment

49 Individual Surveys

114 Focus Group Participants

163=*n* Sample

Encounters

Ten people from the individual surveys indicated they had been involved with persons living with dementia prior to their current role. 74 professionals from the focus groups and 15 older adults reported having personal encounters with persons living with dementia.

Descriptions of the encounters of persons living with dementia that were shared included the following:

Type of encounter	Frequency
Work Patient	2
Work Client	5
Parent Caregiver Change in Roles	6
Repeat questions	2
Financial Exploitation	1
Meals on Wheel deliveries	1
Spouse	1
Early Onset	1
Sundowning experience at work, I knew the individual and the situation and I knew who to call for help, only because I knew them.	1
Lady on the bus by herself confused with no assistance.	1
During Customer Service Interactions	1
Confusion	1

There were many comments during the focus group discussions related to the necessity for patience and understanding of the disease in order to help the person.

Knowledge of Services Available

The focus group questions captured this information through the question:

What services and supports are already present in Decatur for addressing the needs of people living with dementia and their families?

The responses to the services available to help a person living with dementia and their caregiver revealed very different pictures between the professionals and the older adults. There was a general response that both professionals and older adults are unaware of the specifics of services offered by agencies. It was also telling that the older adults did not list specific programs available to help and very few community-based organizations. The following charts identify services names and the frequency.

Professional Knowledge of Services Available

Name of Service or Provider	Frequency
CHELP	5
Starting Point/Macon Co. Health Dept.	3
Memory Café	1
Catholic Charities	1
Memory Care Facilities Carriage Crossing (Unsure)	1

The Loft (Unsure)	
Alzheimer's Association	1
SAIL	1
DORS	1
Synergy	1
State's Attorney	1

Older Adult Knowledge of Services Available

Name of Service or Provider	Frequency
CHELP	2
Dove	2
Sr. Center	1
In Home Care	1
Medical Doctor	1
Nursing Homes	1
Adult Day	1

There was no indication the person was aware Adult Day Services are no longer available.

Older Adult (Case Management Clients) Knowledge of Services Available

Name of Service or Provider	Frequency
Unaware/Not Sure	5
Private Pay Day	1
Memory Care Facility	1
Memory Café	1
Starting Point	1
Respite	1
Nursing Home	1
Private Pay HCA	1

The individual surveys did not request services to be listed but rather asked the following 2 questions:

1. Indicate your level of agreement with this statement: *Our community currently has adequate awareness of the resources that can help support people with dementia and their families.* Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree, Do not know
2. Indicate your level of agreement with this statement: *Raising community awareness of the resources that can help support people with dementia and their families should be a*

priority for action in our community. Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree, Do Not Know

Five individuals’ responses to the individual surveys indicated they were unaware of services available in the community of Decatur.

Twenty of the 31 hospital staff that completed the individual surveys disagree or strongly disagree that awareness of resources is adequate and agree or strongly agree raising community awareness of resources should be a priority for action.

Missing Resources

The focus groups were asked the question *What do you believe is missing in Decatur for addressing the needs of people living with dementia and their families?*

Professional responses

What is missing in Decatur	Frequency of Responses
Adult Day Care	2
Respite	2
Early Detection	2
Screening Options/Diagnostic Resources	2
Prompt Assessments	1
Nearness of family facility	
Companionship assistance to access services	1
Companionship	
Education: Awareness of the illness/symptoms Public Transit Staff Family Members Early Intervention Education-End of Life, POA	4
Caregiver Support	1
Support Groups	1
Informal needs meetings	1
Information online/website	1

Older Adult Responses

What is missing in Decatur	Frequency of Responses
Adult Day Care	3
Earlier testing and detection	1
More Education	1
Training needs identified:	1

Training to know symptoms	1
Training for Caregiver (Fall Risk Awareness)	1
Training for Supportive Nursing Staff & CNAs	1
Training for Home Care Aids working with PLWD	2
Training for Caregivers unfamiliar with dementia	1
Training for Specialized Memory Care Staff/Agitation and Aggression	1
Support Groups	1
Additional Respite	1
Outreach awareness of Available Caregiver Assistance/Access to care	1
Affordable Memory Care for PLWD	1
Shortage of Primary Care Physicians	1
Repeat experiences to develop familiarity	1
Outings to nature reserves	1
Facilities strictly for Dementia	1
Companionship	1
Supervision with assistance to do basic things	1

Respondents from the individual professional surveys did not have the opportunity to identify what is missing. They were asked a different question:

Indicate your level of agreement with this statement: *Increasing dementia-related resources tailored to our diverse and underserved population should be a priority for action in our community.*

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither agree or disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>	<i>Do not Know</i>
		4	13	10	4

Resources Participants Believe Will Help a Caregiver for A Person Living with Dementia

The focus groups were not as robust in their remarks regarding this question. The professionals identified the following potential helpful ideas for family caregivers

- Standard follow-up practices with physicians that identify potential cases
- More training for staff and family caregivers
- More assessment practitioners and options for having an assessment completed.

The older adults had the following recommendations:

- More education for home care staff (2)
- Agency Resource list (document) for Caregivers
- Starting Point/CCP/Memory Café
- Senior Center? (Unsure)
- Assisted Living
- Alzheimer’s Association
- Unsure of any help (3)

What Participants Believe Will Make Decatur More Dementia Friendly

The professional responses were somewhat different than the responses of the older adults. It is noteworthy that most of the individual surveys were completed by hospital staff.

Professional response:

Response	Frequency
Training	1
Online training	1
Training to identify symptoms	2
Better signage in the hospital	1
Change in the Senior Rama Platform to include workshop sessions/presentations of service providers	1
Day respite program	1
Frequent education/trainings for community members	1
Education Training should start at an early age	1
Easy access to trainings	1
Nontraditional training means/ video playing in hospital library, cafeteria, waiting area.	1
Snippets of education that is frequent and available often	1
Color coded bands to identify hospital patients with dementia	1
Dementia Friendly Unit for patients living with dementia	1

Older adult response:

Response	Frequency
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Teach more patience	1
Training for Law enforcement& Fire	1
More simplified better explanation of health care instructions	1
Easier access to Dr and Scheduling	1
Money management services	1
On site congregate meals in housing authority buildings	
Sign-up sheet when trainings are held	1
Better information what staff to go to for what help in residential buildings	1
Training how to interact and communicate with PLWD	1
Increase family education and involvement	1
Increase family education of disease process	1

An additional survey section gave participants the opportunity to identify which agencies should be involved/invited to Dementia Friendly Decatur Work. The list is as follows (Please note agencies mentioned currently involved are identified with an *):

- School Systems
- *St Mary's Hospital
- Centers for Assisted Living *(Some are currently involved)
- *Mental Health (2)
- *Case Management (Starting Point, hospitals were surveyed)
- Directors of ER and Nursing
- Shelters (2)
- Faith Groups (5)
- Northeast Community
- *Police (2)
- Fire
- Physicians
- *Macon County Health Dept.
- *Senior Center (2)
- Salvation Army (3)
- Food Pantries (2)
- *United Way
- *St. Mary's Physicians
- *Memory Care Facilities (2) (Some are)
- *City Council

- *Catholic Charities (2)
- Oasis Day Center
- IL AARP
- Public Volunteers
- Macon Resources
- *EMS
- Psychiatry
- *Hospitals (HSHS & Memorial Medical)
- Neurology

Those that participated in the Focus Group/Community Conversation questions were given the following scenario appropriate to their organization and asked to respond.

Pretend you are the caregiver or family member of a person living with dementia. Now imagine you are patronizing your (hospital, business, agency) and the person living with dementia is with you. What do you think would be helpful for you to best support the person living with dementia while in your establishment?

- People trained to interact with a patient living with dementia.
- Adult Day Care
- Awareness of Symptoms
- Knowing where to go for help
- Need information
- Offer a nutrition site
- Understand be able to identify what stage they are in

The Need for Training

The following were responses from individual surveys. Not all surveys included this question.

Training topic	Indicate whether training is provided			
	Never	At hire	Periodically	Not applicable
Identification of Dementia	6	1	5	6
Behavior as Communication	6	1	6	4
End of Life Care	5	2	7	4
Individual Patient Needs	3	1	10	4
Medications	3	1	8	4
Supporting Family Caregivers	4	1	8	3

The individual responses to training for those that completed a different survey included

- 4 people have experienced dementia training and education (Three through work when they were employed).
- 7 People have had no training and education related to dementia.

- 1 person did not know if they had experienced any training and education related to dementia.
- One person had attended the Savvy Caregiver program provided by a Caregiver Advisor.
- The others had experienced training in the work setting and one at graduate school.
- One individual reported that they felt the personal experience had been their training.

Recommendations

Reviewing the responses indicate there are four main actions/responses that came up consistently in the focus groups and reflected in the individual survey responses.

- The need for training within the community, among family caregivers and for professionals in all sectors.
- The need for Adult Day Services.
- The need for expanded local assessment/diagnostic capabilities.
- The need for marketing of existing services.