ACT on Alzheimer’s®
Dementia Capable Community:
Report on Progress
Cambridge, MN

Prepared by Paone & Associates, LLC
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This report

This report was written by Adine Stokes, LSW, Research Associate, and Deborah Paone, DrPH, MHSA, Principal of Paone & Associates, LLC to highlight one of the community action teams working as part of the ACT on Alzheimer’s initiative, toward becoming a dementia-capable community. The report is intended to capture the activities of this Cambridge community and share observations and lessons learned for others to use in their work.

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Executive Summary

Cambridge is a city of just over 8,200 residents located in Isanti County, in the central region of the state of Minnesota. Approximately 17.5% of the population is over age 65. This report captures highlights from the work of the Cambridge ACT on Alzheimer’s® community ACTion team from May 2013 to May 2014.

The Cambridge ACTion team launched its work in May 2013 with involvement of individuals representing many sectors of the community. The purpose of the work was to engage the community in an assessment and action planning process using the ACT on Alzheimer’s Dementia Capable Community Toolkit.

The group had two Coordinators: Julie Tooker, Community Relations Director, and Todd Klein, Housing Administrator, both of GracePointe Crossing of Presbyterian Homes and Services. The Cambridge community ACTion team included involvement and input from many sectors of the community and by more than 23 individuals. Sectors represented included: law enforcement and safety, social service agencies, home care providers, respite care providers, hospice providers, faith communities and parish nurse programs, additional senior housing providers, Isanti county and city offices, and secondary education and community education representatives.

This community ACTion team received technical support and assistance from the ACT on Alzheimer’s leadership team and from Kathy Gilbride Community Development Specialist from the region’s Area Agency on Aging which is the Central Minnesota Council on Aging (CMCoA). The ACTion team meetings not only worked through the process of conducting a community assessment, but also provided education about Alzheimer’s disease, facilitated discussion about the meaning of “dementia-capable,” and highlighted resources for individuals with the disease or for their caregivers that are available in or near Cambridge.

The Cambridge community ACTion team structured their work using sub-groups, including a sub-group of members who served as their Survey Team. These seven members met in July and August of 2013 to help coordinate the assessment (survey) process. The surveys were conducted September through November. A total of 67 surveys were completed, covering all of the sectors except adult day care (that service is not available in the city of Cambridge). This team also helped interpret and analyze the results and present findings to the full ACTion team.

The synthesis of the survey results was conducted from February through May 2014. Discussion focused on increasing public awareness of Alzheimer’s disease within the community. Additional action items included supporting first responders, and providing information and resources to health care providers so that they can offer information and support in a timely way immediately after diagnosis.
Background

ACT on Alzheimer’s®
ACT on Alzheimer’s® is a volunteer-driven statewide collaboration. It focuses on 5 goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer’s disease and related dementias (ADRD). The goals include: (1) sustain caregivers, (2) raise awareness and reduce stigma, (3) invest in promising approaches, (4) increase detection and improve care, and (5) equip communities. The initiative was launched in June 2011.

In 2012 a Dementia Capable Communities Toolkit was developed by one of the leadership groups and other participants involved in ACT on Alzheimer’s. The Toolkit provides a structured process for a community to assess its own dementia awareness and resources, as well as to determine priority areas for action. The process utilizing the ACT on Alzheimer’s Dementia Capable Communities Toolkit has been piloted by four communities in Minnesota and is now being used by additional communities. The ACT on Alzheimer’s website summarizes the focus of this work as follows: “Community by community, we can create a supportive environment for everyone touched by this disease.” Additional information about specific goals of dementia-capable communities is provided in Appendix1.

Alzheimer’s disease and related dementias are increasing in prevalence as the population ages. According to the ACT on Alzheimer’s website:

As more and more Minnesotans live with Alzheimer’s disease and other dementias, the costs and challenges can be overwhelming for them, their families, our communities and our state. Care costs for Americans age 65 and older with Alzheimer’s disease and other dementias are projected to increase from $203 billion in 2013 to $1.2 trillion by 2050 (in 2013 dollars).

Many individuals with Alzheimer’s live alone and are at greater risk for inadequate self-care, malnutrition, untreated medical conditions, falls, wandering and accidental deaths.

Nearly 250,000 Minnesotans care for family members with Alzheimer’s disease. These caregivers provide 277 million hours of unpaid care, valued at $3.4 million yearly. The physical and emotional impact on caregivers results in nearly $9 billion in increased healthcare costs annually, including $157 million for Minnesota caregivers.

Dementia-capable is defined as an “informed, safe and respectful of individuals with the disease, their families and caregivers, and providing supportive options that foster quality of life.”

There are four phases defined in the ACT on Alzheimer’s Dementia Capable Community Toolkit. They are:

- “Convene” – where stakeholders, key community leaders and community members at large are asked to come together as a coalition to work together and to begin to examine the implications of Alzheimer's disease on the defined community;

1 Source: www.ACTonAlz.org/realities accessed on December 20, 2013
2 Source: www.ACTonAlz.org accessed on December 20, 2013
• “Assess” – where the ACTion team members fan out into the community to conduct face to face or telephone surveys across community sectors in order to collect perspectives, information, and opinions about the community’s current capacity for meeting the needs that result from the disease and related dementias. The assess phase uses survey instruments from the ACT on Alzheimer’s Dementia Capable Community Toolkit;
• “Analyze/Synthesize” – where the results from the community assessments are reviewed and discussed to identify strengths and gaps and to determine the priority issues. This is done with stakeholders and community members in a facilitated process in order to obtain full participation;
• “Implement/ACT” – where the results and synthesis from the community surveys and the discussion are used to identify a specific action step that is high priority and is achievable within a defined timeframe.

Methods
Paone & Associates LLC provides strategic program development and evaluation. Paone & Associates was contracted to provide a qualitative snapshot of the Cambridge community ACTion team progress as part of the overall ACT on Alzheimer’s evaluation. Deborah Paone, DrPH, MHSA (Principal), and Adine Stokes, LSW (Research Associate), worked on this report. Using a key informant question set (Appendix 2), Adine conducted telephone interviews with the coordinators of the Cambridge ACTion team and two other team members who were actively involved in the effort. Interviews were conducted in February and March of 2014. Interviews were recorded and transcribed. Adine also reviewed Cambridge ACTion team meeting agendas and survey results.

The interviews focused on gathering information about how the community worked through the four phases of the process and about lessons learned. Each respondent was asked to comment and offer his or her personal observations and analysis about the ACTion team’s efforts and community activities. Additional information on the results of the community assessment and the synthesis of these results was obtained in April and May through a follow-up phone call with one of the community ACTion team coordinators and through review of the narrative comments offered by Cambridge community members during their survey interviews.

Cambridge ACTion Team

The City of Cambridge

Cambridge is located in Isanti County, approximately 47 miles east of St. Cloud, Minnesota, and 43 miles north of Minneapolis, Minnesota. The most recent population assessment by the U.S. Census (2012) estimates the population to be 8,217\(^4\), based on data collected from the 2010 U.S. Census. Most of the residents are White. Appendix 3 provides additional demographic and geographic information about Cambridge.


Accessed March 21, 2014
Residents over the age of 65 comprise 17.5% of the total city population (approximately 1,438 individuals).\textsuperscript{5} Using the estimate that one in nine people age 65+ have Alzheimer’s disease, approximately 159 Cambridge residents over age 65 have Alzheimer’s disease or a related dementia and about 22 of these individuals live along (Alzheimer’s Association: Facts and Figures, 2014).

\textit{Purpose/Drivers}

Cambridge is a close-knit community with a desire to serve and include all of its residents and a willingness to work together. When asked what the community hoped to gain from a grassroots change effort, respondents said they were interested in bringing attention to Alzheimer’s disease among the general public in Cambridge. They also wanted to create a dialogue among engaged stakeholders around Alzheimer’s disease and discuss/discern how residents of the community are impacted by it. They also talked about supporting residents living with the disease.

Members of the Cambridge ACTion team said that there are resources available in the city of Cambridge for people with Alzheimer’s disease or dementia—but not all residents know what the supports are or how to access them. Respondents expressed a belief that increasing awareness among the city as a whole will improve the community overall.

Excerpts from interviews with community ACTion team members include:\textsuperscript{6}

\textit{We want Cambridge to be proactive in addressing the issues faced by people living with dementia.}

\textit{We have close connections in Cambridge. We're small enough that people know each other. We not only work here, we live here.}

\textsuperscript{6}Source: Act on Alzheimer’s © Website. \url{http://www.actonalz.org/cambridge} Accessed March 31, 2014.
Groundwork and Convening

GracePointe Crossing is a senior residential community owned and operated by Presbyterian Homes and Services. It is one of the largest senior residential providers in the area. Its’ website reads: “At the heart of GracePointe Crossing is a commitment to high quality service as a ministry of compassion and fellowship.”

GracePointe was identified by interview subjects as the logical organization to convene an effort such as this, since it is viewed as a key resource in educating and supporting the community in senior issues including Alzheimer’s disease. In the past, GracePointe Crossing hosted educational events and served as a location for events offered by other organizations within the city of Cambridge.

Two staff members of GracePointe Crossing have served as coordinators of the Cambridge ACTion team: Julie Tooker, Community Relations Director, and Todd Klein, Housing Administrator.

Convening
The Cambridge community ACTion team convened its first meeting on May 23, 2013. Since that initial meeting, the team has attracted stakeholders from a variety of sectors including: law enforcement and safety, social service agencies, resource centers, home care agencies, respite and hospice care providers, faith community and parish nurse programs, additional senior housing providers, Isanti county and city offices, and secondary and community education representatives (see Appendix 4 for a full list of Cambridge ACTion team members).

The first meeting was organized as an invitational community-wide event. Each attendee received a personal invitation to this meeting—either in person, over the telephone, or via e-mail. The Cambridge ACTion team leads said that they were committed to recruiting a large base of participants for the initial meeting. Representatives from the city and the county were invited to participate (e.g., county commissioners, sheriff) as well as educators and journalists.

At the first meeting those in attendance were provided with sign-up sheets so that they could volunteer to be part of the ACTion team on an ongoing basis. They were asked to identify their preferences and indicate how they would be participating and when they were available. Members were also asked to personally invite colleagues and peers to future meetings. This strategy helped bring participants in from various sectors not initially represented, such as business owners. ACTion team members tapped into their personal as well as their professional networks. Making personal invitations was a strategy employed consistently within this ACTion team. This strategy is credited with widening the perspective of the group as a whole through adding individuals with diverse expertise from different sectors of the community.

Leadership
Several organizations took a leadership role in this initial phase of development for the Cambridge ACTion team, including:

Ms. Tooker was identified as the champion for the Cambridge ACTion team by members interviewed. Her style was described as “friendly,” and “approachable.” She maintained a positive working environment for the group. Respondents interviewed said that Julie has strong organizational and facilitation skills, which help keep momentum within the group. She was seen as effective at delegating activities and tasks evenly among group members. Team members said that Julie encouraged group cohesion by keeping in regular contact with members, building personal connections, and encouraging group members to contact each other outside of the meetings. Having a leader like Ms. Tooker was helpful in these early stages. One respondent commented that she was a “sensitive cheerleader who didn't give up.” A respondent offered the following observation:

*Julie is the heartbeat of the group. She took a leadership role, and she maintains that role, even during phases that are challenging. . . Julie knows when to assign a job, and when to ask for help. It’s a matter of knowing when and how, and that’s important.*

**ACTion Team Process & Structure**

As the ACTion team continued to grow and develop, members found that they needed to put some parameters around the effort and set realistic and attainable goals. Tasks that were more laborious or required more input were identified and were set as activities for smaller separate working groups. The smaller groups reported back to the larger ACTion team. Members found that when goals and steps were smaller, the tasks felt more manageable. Groups would report progress regularly. The ACTion team could then evaluate if they were meeting milestones. If an individual was struggling, other ACTion team members helped by troubleshooting or offering idea and other support.

Regarding challenges experienced in this early phase, team members interviewed admitted that it was easy to become overwhelmed. In part this was because “the problem of Alzheimer’s disease and its impact seemed too big to address” and the solutions difficult to conceptualize.

Several members stated that they did not know what was available in their own community to address needs of people or caregivers with this disease, and furthermore, they felt that they did not have sufficient knowledge about Alzheimer’s disease or its impact on those living with the disease. As a response, regular educational opportunities were offered to address these educational and informational needs. At each Cambridge ACTion group meeting, information on resources for people living with ADRD were offered by Kathy Gilbride, Community
Development Specialist, from Central Minnesota Council on Aging (CMCoA). Kathy brought information to each meeting and distributed relevant materials.

Overall, each respondent interviewed considered the early stages of building the Cambridge ACTion team to be very successful. People were engaged and excited to begin the community assessment process. The engagement of community leaders and those from many sectors of the community added to what the team feels was a very successful convening phase for the effort. Those from outside of the aging services sector helped bring attention to the need for education, information, and dialogue so that the whole group could have a common understanding of issues faced by people living with Alzheimer’s disease. This also encouraged team members to share their opinions and interpretations of the definition and vision for a “dementia-capable community,” as well as how to measure this concept.

Like other ACTion communities, Cambridge team members discovered that having wider representation from the community helped enhance community engagement and advance their goals of increasing awareness and fostering dialogue across community sectors. One respondent commented that having community leaders from the city and county, along with newspaper reporters, helped add credibility. This also increased visibility of the effort.
Assessing

The assessment phase began with a review of the *ACT on Alzheimer’s* Dementia Capable Communities Toolkit and involved all members of the ACTion team. Kathy Gilbride, Community Development Specialist from CMCoA, assisted the team by walking through the survey and assessment process. There are fourteen sectors defined by the ACT on Alzheimer’s Dementia Capable Community Toolkit. The community sectors are shown in Figure 1.

![ACT on Alzheimer’s Community Sectors](image)

**Figure 1. ACT on Alzheimer’s Community Sectors**

**Survey Team Created**

The ACTion team discussed ways to administer the community assessments (surveys) and identify potential interviewees. They decided to identify a specific Survey Team to facilitate the process. Thus, the Cambridge ACTion team defined a Survey Team comprised of seven members of the full group. These members met in July and August of 2013 and worked on the survey process through October. They also presented interim results to the full ACTion team in October 2013.

The format for the Survey Team meetings was: (see Appendix 5)

- Welcome/Introductions
- Review the concept of what a dementia-capable community means for your community

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The Survey Team prepared for administering surveys by conducting a 30-minute role playing exercise and practicing asking the survey questions. The group also continued to discuss how to present and talk about the concept of being “dementia-capable.” Survey Team members also took time to review the Toolkit. The respondents interviewed for this report indicated that it was easiest to download the Toolkit directly from the ACT on Alzheimer’s website. Each team member reviewed the survey questions and spent time becoming familiar with the content on their own. Survey Team meetings were used to ask questions and problem-solve with the group as a whole.

**Conducting the Community Assessments (Surveys) in Cambridge**

The protocol for administering the surveys in Cambridge was set as follows:

- Determine the sector
- Identify individual/s to survey and who would conduct the survey
- Make contact with the potential survey respondent to set up a face-to-face meeting (if possible)
- Email/mail a copy of the survey for the individual respondent to look over (and complete, if they wished). If a face-to-face or phone meeting was not possible, the respondent was asked to complete the survey and contact the ACT Survey Team member if the individual respondent had questions
- Re-read the survey questions to be prepared for the interview
- Be prepared for the interviewee to ask about the meaning of each question asked and about the ACT on Alzheimer’s initiative
- Conduct the in-person interview/assessment and take notes directly on the survey
- Offer a set of “leave behind” materials, including the Alzheimer’s Association “10 Warning Signs”
- Provide a thank-you note following the interview

The Cambridge ACT Survey Team agreed that having a personal connection to survey respondents was critical to getting people to agree to be interviewed. Having a personal connection also helped the Survey Team members feel more at ease. One respondent commented:

_We all got to choose who we wanted to interview or survey - we tried to get a representation . . . and this was helpful. You don't have to go through the formality - I wouldn't want to do this cold - it gets personal and most are affected by the disease. I think if I didn’t know the people I had personally interviewed it would have been more stressful and taken more time. All I had to do was call up, and I got a “absolutely, when_
do you want to do it?” response. It was fun. I don’t know if I would have liked calling someone out of the blue, though.

Allowing survey respondents to receive a copy of the questions prior to the meeting was considered helpful in preparing the individual for the survey. The Survey Team agreed that it was an important strategy. It allowed the survey respondent to prepare to talk about this difficult and possibly emotionally-charged topic. Also, if the respondent provided the Survey Team member with a completed survey to work from, this facilitated note-taking and allowed the team member to be more “present and in the moment” during the interview.

Some Survey Team members went in pairs with one person serving as “the scribe.” However others went alone. Some surveys were conducted over the telephone. In a few cases the survey was administered via email. Surveys took between 15 minutes and two hours to administer, with an average time to complete of about one hour. The Survey Team members would reserve between at least two hours to conduct each survey, in order to not rush the conversation.

Survey Team meetings focused on small, measurable goals, with regular reporting. The respondents interviewed for this report indicated these meetings helped keep the group on task, and allowed them to create and measure their progress. The regular meetings also allowed the group to problem-solve with one another. When a member identified a problem, team members informally brainstormed ideas or solutions and shared stories with one another about how they had addressed this issue. These opportunities helped increase the team’s cohesion and effectiveness, as they learned from one another and defined a workable process.

In total, 67 assessments were conducted in each sector (except Adult Day, because that service is not available in the city of Cambridge). The timeframe to complete all of the surveys was about 3 months. All surveys were printed out or kept in raw (handwritten on paper) form. This included the narrative comments provided during the assessments.9

Person needs to learn to listen – to help repeat as needed and take time to get response. People to not know how to react, afraid of unknown, may have denial.

Where do they refer persons now? What are the legal obligations... in making such a referral? Time limits on medical personnel to make referrals.

Findings

By far, the predominant theme identified throughout many of the 67 surveys (either as an opportunity or a barrier) was lack of knowledge in the community about Alzheimer’s disease and about resources to help. To address this issue, the community identified the primary solution for Cambridge is to increase awareness.

On March 26, 2014 following the community assessment process, team members began to create a list of potential action steps (Attachment 6). Each Survey Action Team member began

9 Synthesis of narrative comments was performed and is available.
generating ideas for solutions or approaches for addressing the need for greater awareness as well as other priority issues (especially how to increase awareness). Also, interviewees from the community had frequently offered ideas or comments during the survey process, and these were brought to the meeting. These included:

- Magnet with number to call on it for help.
- Refer by making brochures available.
- Can go through churches, schools, Rod and Gun Clubs. Could train several people in these groups who could teach others.
- Educate family members.
- The Community college might be able to help with promotion and teaching.
- Could incorporate Alzheimer’s disease teaching into training curriculum for organizations like support groups, rotary clubs, other support groups.
- Through schools – especially nursing classes who need to know how to deal with this population.
- Would be beneficial to have classes on Alzheimer’s for everyone. Have a central resource center especially for people with Alzheimer’s.
- Refer by making brochures available; we do have CMC at present.
- Use newspaper/media to build awareness.
- Encourage churches to use brochures available
- Have a meeting during National Alzheimer’s week for teaching.
- Clinics can have brochures.
- Health classes in high school can incorporate Alzheimer’s education.
- Buy groceries at Cub for fundraiser and hand out brochures.
- Youth groups can be involved, such as 4-H clubs.
- Schools can be a resource for education, especially high school.
- Groups like Family Pathways--would be good if more churches could have group meetings like that.
- Caregiver assistance.
- Day center.
- Gathering for caregivers and receivers.
- Respite.
- Apple a Day program has a meeting once a month of various subjects. It is free and open to the community . . . could address dementia/Alzheimer’s.
- Notification to employees through quarterly letter updates – like calling a “help line” for anything confidential.
- Suggestion for postcards with number for help line.
- Would not go first to Alzheimer’s Association. Would go to their family physician.
- Agree it should be priority as people would not know where to go, who to call. If you don’t know who to call, you may not do anything.
- People could be more helpful and respectful to people with dementia.
- Opportunities available for training – need to know where people are at.
Synthesis and Action Planning

Data Entry and Compiling

The next step for the ACTion team was to compile the data from the surveys and synthesize it in order to make it meaningful for preparing action steps. This step proved challenging. Ms. Tooker and Mr. Klein reported that the ACTion team considered several alternatives or approaches for compiling the data. However, after reviewing the materials and a video from the *ACT on Alzheimer’s* website, the group decided that bringing in Emily Farrah-Miller from the *ACT on Alzheimer’s* leadership would be the best option for them. Having an experienced outside stakeholder would facilitate compilation of the data, clarify if all necessary data had been captured or if more surveys were necessary to complete any missing data points, and help the ACTion team understand how to interpret results.

All respondents interviewed that this phase of the process was more difficult than anticipated, and this slowed down the momentum. However, this decrease in activity by the Cambridge ACT team was not viewed negatively. Respondents noted they maintained enthusiasm about moving into the ACTion phase that would identify priorities for the community.

The guided synthesis process was conducted in April and May, with the help of Emily Farrah-Miller from *ACT on Alzheimer’s*. This process began with one meeting lasting several hours, and was followed by work conducted by the two coordinator leads from the Cambridge ACTion team. On May 1, 2014, the ACT group convened to further discuss the data from the compiled surveys and to develop an Action Plan. Emily Farrah-Miller from *ACT on Alzheimer’s* provided technical assistance.

Rich discussions between and among the ACTion team members had followed the assessment process. Members had discussed how the city was not yet “dementia-capable.” The Survey Team had identified a few priority areas for action based on their review of the surveys. They believed the area most frequently mentioned by the community of Cambridge was the need for greater community education and awareness of Alzheimer’s disease and the identification of available resources in and around Cambridge.

Survey Team members felt that the following areas of emphasis should be the focus of the Action Plan:

1. increase early identification and diagnosis of people with ADRD
2. increase awareness
3. increase skills interacting with people with dementia
4. increase specialized services in the community - specifically caregiver support services

The ACTion team decided to discuss and offer feedback on each priority action area. This approach is unique—other communities in Minnesota (e.g., Saint Paul, St. Louis Park), worked to narrow the focus to one or two priority actions.

The group split into four small groups (by priority area). Each table had a facilitator. The facilitator generated notes on flipcharts reflecting the discussion of the group. The groups rotated
so that members could comment on more than one priority area. The group’s discussion for each table had the following assignment:

1. Review the Priority Area
2. Review the Possible Actions and Resources in your Priority Area
3. Discuss additional Actions and Resources
4. Add to flip chart

Upon arriving at a table, members would review the list of ideas already generated and add additional comments or ideas, building on themes offered by other team members. Discussion at each table convened for approximately ten minutes, then the group members would move on to another table/priority area discussion. The process continued until each group member weighed in on each priority area.

Next, the group summarized the discussion about the four priority areas using the notes recorded on the flipcharts. Team members collectively decided if anything was missing. Ideas that were similar were grouped together. The ACTion team further narrowed the list of ideas for action using the following criteria:

✓ The idea seems doable (we have the right people and resources to make it work in a year or less).
✓ It is a good fit for the Cambridge community.
✓ It would make a meaningful difference for the community.
✓ It is affordable (can be done on a limited budget).

A summary of the ideas generated is provided (See Appendix 7). Increasing awareness was identified by the survey team as a top priority area. This was also a priority in the narrative responses offered to the survey team by respondents. Furthermore, there were several specific target audiences and service sectors to target—particularly first responders and health care providers.

**Action Items**
The team selected several items for collective action:

1. **Offer training** for city staff members who interface with the public—police, sheriff, EMS—on Alzheimer’s disease and how to recognize the signs and communicate effectively with persons living with the disease.

2. **Increase awareness** of AD and caregiver supports through information and education. This would include:
   a. information in community education flyer
   b. newspaper articles
   c. resources/references (compiling links to existing articles to disseminate)
   d. placing articles in existing newsletters
   e. creating Notification Cards (http://www.actonalz.org/caregivers-families),
   f. creating an informational brochure for first responders,
g. offering an ongoing community education class,
h. offering presentations to community organizations, including information at county fair booth.

3. **Educate health care** providers on the resources available and provide them with a resource handout that they can give to patients and families at the end of a medical appointment when there is a diagnosis or as a follow-up.

At time of this report, the Cambridge ACTion team had begun to consider methods to increase awareness in Cambridge.

One issue the ACTion team discussed was barriers to raising awareness. A person interviewed for this report commented, “Barriers start with the individual person.” The ACTion team was working to identify solutions targeted to the individual and those at the community level. Those who had participated in the Cambridge community surveys also identified barriers to increasing awareness of the disease. These are offered below.

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**Voices from the Cambridge Community on Barriers:**

[There is] not enough exposure and information in our community [about Alzheimer’s disease and dementia]. If they had the knowledge of dementia they may have more patience for people . . . more empathy.

[A barrier is … that ] caregivers wanting it private – afraid to share.

*Thinking forgetfulness is normal and not seeking help. Not seeing early warning signs.*

*DENIAL – both in self and in family and friends. There is stigma that often goes with the disease, and fear.*

*We get comfortable with aging and not associating aging with dementia. That [may mean] we are comfortable with it [aging] and not seeking help for dementia.*

*It is not dealt with by professionals until something serious takes place.*

*I believe getting people to be really interested enough in need for awareness will be biggest hurdle. It costs money to provide education and I am not sure if there are enough resources for this.*

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Respondents also shared their concern about the decrease in available funding for dementia services in the community--which some believed had already negatively impacted the city of Cambridge.
Cutbacks in funding have caused closing of adult day centers for people with dementia in Cambridge. Also, cutbacks leave less time in nursing homes and other care centers as staff cut, leaving staff less time to listen.

Some described how, because of the lack of available services, dementia care and support services are perceived as more “risky” to offer. In addition, caregivers may have difficulty paying for services that are fee-based.

Employers were also identified by the Cambridge community as a possible entry point for changing the landscape of awareness and support for people living with dementia, primarily caregivers caring for someone diagnosed with Alzheimer’s. AARP’s 2012 report on the impact of family caregiving on workers describes caregivers’ increasing concern for missed work time, missed opportunities for advancement, and possible retaliation for missed time due to caregiving duties.\(^\text{10}\)

One survey respondent echoed this issue: “The overall cost of missed work, lower productivity, lack of flexibility [serves as a barrier]. There have been new efforts to engage with employers through employee assistance programs and human resources. Cambridge ACTion team members hoped that this effort will help employers fully understand the implications that caregiving has, and its effect on their employees. One challenge is how to respond given the limited social services available—that is, if demand for help increases through employer support, how will local agencies be able to increase their capacity?

Voices from the Cambridge Community on Information and Access to Services:

This ACT program we have now involved in Cambridge should lead to people knowing more about Alzheimer’s and hopefully have a central place people can go to for info and help.

Providing one place to find credible and current information and resources such as a web site.

If there could be education and awareness to employees, there would be great opportunities to reverse some of the cost to employers.

I think it takes employers who are willing to think outside the box and be creative to support their employees.

\(^{10}\) Source: Understanding the Impact of Family Caregiving on Work. Lynn Feinberg and Rita Choula. AARP Public Policy Institute. 2012
Lessons Learned, Advice

Respondents participating in the interviews for this report stated that the experience of working on this initiative has been fulfilling. They reported that the group was engaged, and it was rare that ACTion team members missed meetings. Benefits realized thus far from engaging in this community assessment and action-focused effort have included the strong identity as a “connected city,” with new connections being built between people and sectors within the community. This grassroots ACT on Alzheimer’s community effort has reinforced the positive relationship-based energy and capacity for action within the City of Cambridge. ACTion team respondents put it this way:

*We are here in the community - we have this unified thing - developing a relationship and discovering one another and we are all learning how much the community cares and wants to do this.*

*Other projects have grown out of this - professional and personal - because of this ACT. I facilitate a support group – [with] some of the contacts that I have made. . . I have a speaker to help the caregivers understand the resources in the community, and now they can put a face to the organization. It is so much more meaningful, even if they may not need it now. ”*

The small size of the community has been a benefit from a public relations perspective as well. Two local newspapers have been invited to each ACT meeting. The activities of the group are well publicized in local press, and greater participation from community members has occurred because of this. For example, following publication of an article, a family member caring for someone with memory loss called for information.

Successful Strategies

Several successful strategies were offered by the Cambridge ACTion team members. First, the Toolkit can seem overwhelming, and the entire process can be daunting. Managing this process by dividing the activities into reasonable tasks with small measurable goals has been effective. Having short-term small goals helped the group make and mark progress.

Second, group members said that it is important not to be too rigid in how to do the community assessment. Flexibility is important, as the community needs assessment can be overwhelming. Members pointed out that having “a good knowledge of the community and its members can help guide this process more than any Toolkit.” The Cambridge ACTion team also said that creating a separate Survey Team, specifically charged with the task of survey administration, was helpful. They felt having too many people involved in this task could have slowed momentum.

The encouragement and direction of technical support guides and experts, such as Emily Farrah-Miller, ACT on Alzheimer’s, and Kathy Gilbride from CMCoA facilitated progress. The leadership of the Coordinators was very important, particularly the positive style, openness, and inclusiveness of the leaders. Even when the group faced problems during the Analysis phase due to time-consuming data entry, the group was not discouraged.
Having stakeholders who understand the local resources and current services was also important to provide members with accurate information. Involving city and key civic stakeholders to participate provided benefit to the Cambridge team. The county commissioners and sheriff have helped the ACT team access new members and contacts in the community that the group may not have considered. These new contacts have been an asset during the early phases of the group’s community assessment. It is also hoped they will continue to support the group into the future as Action plans are developed.

The Cambridge ACTion team also identified the ACT on Alzheimer’s website as very useful. The Toolkit was easily accessible, and videos were seen as a method to learn more about each phase of the community needs assessment.

Another successful strategy has been to ensure that each team member who attends a meeting signs up for a job or task that will benefit the group. The philosophy is this: when members are asked to invest and participate in the activities of the group, those who are willing and able to invest the time will continue to attend. Regular attendance with modest work in between meetings helps the group accomplish its goals. Those who cannot or will not accept a role will self-select out.

Personal passion and commitment to the issue and to their community has also been a driver. One respondent commented:

Finding time is difficult. I had to make this a priority, but I did that because I know it’s important. My leadership understands the value of ACT, but I wouldn’t do it if I didn’t love it.

When asked about the future of other ACT on Alzheimer’s efforts, one respondent reflected:

Every community should do it. It is a fabulous thing; this is a prototype and this is what you implement into the community - each community is able to decide what makes sense to them. We are lucky, we have some really nice tools to make it happen and make it work!

Have fun! Honestly, don’t make it a chore. Be open to it, and make it a community event. Value everything that is being shared, your work is keeping people plugged in!
Impact to Date

Even though the city of Cambridge is a “small and tight-knit community,” Action team members said that regular meetings and participating in the ACTion community assessments have substantially increased their personal knowledge of the community and its resources. Participation has been a rich learning experience. Members described collaboration and cross-disciplinary connections.

The community engagement and survey/assessment process has generated interest in this disease and in working together as a community to help address some of the greatest needs. Those who participated in the surveys from the community have been eager to participate. The objectives and goals of this effort are considered important. New connections have been made and other connections deepened. The purposeful attempt to engage many stakeholders from various sectors has helped with visibility, community support, and has built enthusiasm for the future.

One member described an increase in knowledge around Alzheimer’s and a collective goal or vision:

“It’s a matter of the whole community coming together in a unified idea of what is Alzheimer’s disease and how does it affect - individuals, families and the entire community. This is where we touch people and make a difference - helping to pick someone up. Knowledge is power. Once you understand [it], great things can happen.

Prior to finalizing this report, the Cambridge ACTion team learned that the local/county newspaper would be including a dementia awareness update in their monthly guest column. The following information from Julie Tooker comes from the ACT on Alzheimer’s website which also includes an Isanti County News full feature story article about this Cambridge initiative (see Appendix 8).

Julie notes, “The local newspaper is setting aside a monthly guest column so we can include dementia awareness and support information for the entire Cambridge community.” Another priority is educating health care providers on the resources available and providing them a resource handout that they can give to a patient with dementia and/or their family caregiver at the end of the medical appointment.

What has made this work possible in Cambridge? Julie says, “Everyone works hand in hand rather than in silos. People in leadership positions in various Cambridge businesses understand the importance of working together on important issues.” Ensuring that people who have dementia are better served and that providers have the resources and tools they need to do a better job is the ultimate win-win outcome for the team’s work. “I’m hoping this is work that will never go away...that our work will be a model for other community issues that come up,” says Julie. “We are showing that when we all work together, we can do anything...and everyone wins.”

It seems Cambridge community is staged and ready for what this team has planned for the future.#
References

ACT on Alzheimer’s website:
Community Needs Assessment Dementia Capable Communities Toolkit:
http://www.actonalz.org/assess; Accessed March 29, 2014
www.ACTonAlz.org/realities; accessed December 20, 2013
www.ACTonAlz.org; accessed December 20, 2013
www.actonalz.org/elements-and-resources; accessed March 30, 2014


Appendix 1: Description of a Dementia-Capable Community

What is a dementia capable community?

A dementia capable community is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life. Every community can take action to become dementia capable.

Source: [www.ACTonAlz.org](http://www.ACTonAlz.org) see: [http://www.actonalz.org/node/111](http://www.actonalz.org/node/111)
Appendix 2: Key Informant Interview Question Set
(Prepared and conducted by Paone & Associates, LLC)

Activities and Progress
1. What was the incentive or impetus to be involved in ACT on Alzheimer’s?
2. What is the Community hoping to get out of this?

Groundwork & Convening
1. When did the effort using the ACT on Alzheimer’s Toolkit begin?
2. Did you conduct public awareness sessions and have an official “kick-off”? (Get details of when and who came, what done)
3. Who championed this effort?
4. What organization(s) or individuals took a leadership role? Why?
5. Why did you/your organization get involved?
6. How were others from your community invited to participate in the ACTion team work? Who was asked? Why?
7. Did you have a process to orient workgroup members to ACT on Alzheimer’s and the issues re: Alzheimer’s disease? What resources did you use?
8. How did you go about educating yourself or others about the Toolkit and how to use it? Who was involved in this? What resources were needed?
9. Was the convening effort successful, from your perspective?
10. What “lessons learned” do you have from the Convening phase of the process?

Assessing
1. Had your community/region ever done a community assessment (of this or another public issue)? How does this differ from that experience?
2. What resources were provided for the assessment process and how were they used?
3. Did people travel far?
4. How did they set up the surveys?
5. How many individual and organizations were involved in conducting assessments?
6. What are your observations from this assessment process regarding its: ease/difficulty, value, and the quality of the information gathered?
7. Did you get feedback from persons you were interviewing as you went along? What was that feedback?
8. How long did it take your “assessors” to conduct their surveys? What was the range of time and level of difficulty?
9. Did your assessors compile the results? How was that done?
10. What sectors were assessed? How many people were surveyed?
11. What did the assessments show in terms of the level of dementia capability and awareness at present?
12. Do you have any “lessons learned” from the assessment phase of this effort?
Analyzing
1. How did you handle the analysis part of the work – who collected the forms, compiled them, entered data, and organized the results to bring the information back to the ACTion team?
2. Did you use only the Toolkit instruments/tools for synthesizing or did you use other tools or methods?
3. How much time does this take? What are the constraints?
4. What are the facilitators? What makes this easier?
5. What emerged as top priority based on your analysis?
6. Do you have any “lessons learned” from the analysis phase of this effort?

Action Planning
1. What method was used for narrowing and focusing the priorities to choose one or a few top priorities for action? Did the ACTion team members and others involved come to consensus on these priorities?
2. As you prioritized what issues are most important to your community, what issue or action item rose to the top?
3. Have you created one or more action plans?
4. Do these written action plans have key activities, lead accountabilities, timeframes, and measures or milestones to gauge progress?
5. Who are the leads in this effort (organization and/or individual)? Is this different from those who led the assessment process?
6. Are there other stakeholders in the community that you intend to engage?
7. What is the measure and marker that will indicate your community is making progress toward its goals?
8. How visible is this effort in your community?

Lessons Learned, Overall Reflections, Advice
1. What were the major challenges?
2. Were there any barriers? What were they? Give an example of a barrier that your group experienced
3. What were the major successes in this effort? Were there “side benefits” that resulted from this effort?
4. What advice do you have for others who are starting this process?
5. Do you have tips or suggestions for making this go easier?
6. What were your lessons learned about the process?
7. What were your lessons learned about the Toolkit?
8. Do you have any other observations that would be helpful to the ACT on Alzheimer’s leadership regarding assessing and action planning by Communities to increase dementia capability?
Appendix 3: Population Facts about Cambridge

Source: U.S. Census Bureau

<table>
<thead>
<tr>
<th>People QuickFacts</th>
<th>Cambridge</th>
<th>Minnesota</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population, 2012 estimate</td>
<td>8,217</td>
<td>5,379,646</td>
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<tr>
<td>Persons under 5 years, percent, 2010</td>
<td>8.9%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Persons under 18 years, percent, 2010</td>
<td>26.6%</td>
<td>24.2%</td>
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<tr>
<td>Persons 65 years and over, percent, 2010</td>
<td>17.5%</td>
<td>12.9%</td>
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<tr>
<td>Female persons, percent, 2010</td>
<td>52.6%</td>
<td>50.4%</td>
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<tr>
<td>White alone, percent, 2010 (a)</td>
<td>94.5%</td>
<td>85.3%</td>
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<tr>
<td>Black or African American alone, percent, 2010 (a)</td>
<td>1.0%</td>
<td>5.2%</td>
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<tr>
<td>American Indian and Alaska Native alone, percent, 2010 (a)</td>
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<td>1.1%</td>
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<tr>
<td>Asian alone, percent, 2010 (a)</td>
<td>1.4%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander alone, percent, 2010 (a)</td>
<td>Z</td>
<td>0.0%</td>
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<tr>
<td>Two or More Races, percent, 2010</td>
<td>2.1%</td>
<td>2.4%</td>
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<td>Hispanic or Latino, percent, 2010 (b)</td>
<td>1.7%</td>
<td>4.7%</td>
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<td>Living in same house 1 year &amp; over, percent, 2008-2012</td>
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<td>85.5%</td>
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<td>Foreign born persons, percent, 2008-2012</td>
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<td>Language other than English spoken at home, pct age 5+, 2008-2012</td>
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<td>High school graduate or higher, percent of persons age 25+, 2008-2012</td>
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<td>Bachelor's degree or higher, percent of persons age 25+, 2008-2012</td>
<td>19.9%</td>
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<td>Veterans, 2008-2012</td>
<td>648</td>
<td>377,522</td>
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<td>Measure</td>
<td>Cambridge 2008-2012</td>
<td>Minnesota 2008-2012</td>
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<td>------------------------------------------------------------------------</td>
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<tr>
<td>Mean travel time to work (minutes), workers age 16+, 2008-2012</td>
<td>26.4</td>
<td>22.7</td>
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<td>Housing units, 2010</td>
<td>3,426</td>
<td>2,347,201</td>
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<td>Homeownership rate, 2008-2012</td>
<td>64.5%</td>
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<td>Housing units in multi-unit structures, percent, 2008-2012</td>
<td>27.8%</td>
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<td>Median value of owner-occupied housing units, 2008-2012</td>
<td>$150,500</td>
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<td>Households, 2008-2012</td>
<td>3,076</td>
<td>2,101,875</td>
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<td>Persons per household, 2008-2012</td>
<td>2.49</td>
<td>2.46</td>
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<td>Per capita money income in past 12 months (2012 dollars), 2008-2012</td>
<td>$23,329</td>
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<td>Median household income, 2008-2012</td>
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<td>Persons below poverty level, percent, 2008-2012</td>
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<td>Geography QuickFacts</td>
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<td>Land area in square miles, 2010</td>
<td>7.46</td>
<td>79,626.74</td>
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<tr>
<td>Persons per square mile, 2010</td>
<td>1,087.4</td>
<td>66.6</td>
</tr>
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</table>
Appendix 4: Cambridge Team Members

**Survey Team** – conducted all of the one-on-one surveys

**Action Team** – Input, feedback and updates provided to this group

**Events Team** – will organize our community event to provide an update to our entire community about survey findings and next steps

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greg Anderson</td>
<td>Isanti County Commissioner</td>
<td>Action</td>
</tr>
<tr>
<td>Barb Bergwall</td>
<td>Director Cambridge, Senior Activity Center</td>
<td>Action</td>
</tr>
<tr>
<td>Lisa Budnick</td>
<td>Volunteer, Family Pathways</td>
<td>Survey</td>
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<tr>
<td></td>
<td></td>
<td>Action</td>
</tr>
<tr>
<td>Marge Burns</td>
<td>Retired, Co-Founder of New Pathways</td>
<td>Action</td>
</tr>
<tr>
<td>Chris Caulk</td>
<td>Deputy Sheriff, Isanti County</td>
<td>Action</td>
</tr>
<tr>
<td>Alicia Chapman</td>
<td>Editor, Isanti County Star</td>
<td>Action</td>
</tr>
<tr>
<td>Collette Colucci</td>
<td>Senior Services Coordinator, Family Pathways</td>
<td>Action</td>
</tr>
<tr>
<td>Judy Foster</td>
<td>RN Parish Nurse, Karmel Covenant Church</td>
<td>Survey</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Action</td>
</tr>
<tr>
<td>Bruce Hildebrandt</td>
<td>Director, Emergency Medical Services</td>
<td>Action</td>
</tr>
<tr>
<td>Shirley Karstens</td>
<td>Volunteer, Cambridge Medical Center</td>
<td>Survey</td>
</tr>
<tr>
<td>Jayne Mund</td>
<td>Caregiver Consultant, East Central Senior Resource Center</td>
<td>Survey</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>Name</td>
<td>Role/Position</td>
<td>Action Type</td>
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<td>-------------------------------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Craig Rempp</td>
<td>Director, Heartland Express</td>
<td>ACtion</td>
</tr>
<tr>
<td>Diane Sibley</td>
<td>Director of Wellness, Anoka Ramsey Community College</td>
<td>Survey Action</td>
</tr>
<tr>
<td>Julie Tooker</td>
<td>Community Relations Director, GracePointe Crossing</td>
<td>Survey Action</td>
</tr>
<tr>
<td>Lynda Woulfe</td>
<td>City Administrator for Cambridge</td>
<td>Action</td>
</tr>
<tr>
<td>Karen Muhlhauser</td>
<td>Volunteer, Cambridge-Isanti Rotary</td>
<td>Action</td>
</tr>
<tr>
<td>Karen Carlson,</td>
<td>Visiting Angels</td>
<td>Action</td>
</tr>
<tr>
<td>Julie Keller</td>
<td>LPN St. Croix Hospice</td>
<td>Action</td>
</tr>
<tr>
<td>Marcia Westover,</td>
<td>City Planner for the City of Cambridge</td>
<td>Survey Action</td>
</tr>
<tr>
<td>Jim Rostberg,</td>
<td>Veterans Service Officer for Isanti County</td>
<td>Action</td>
</tr>
<tr>
<td>J. Scott Ken,</td>
<td>CEO Haven House</td>
<td>Action</td>
</tr>
<tr>
<td>Heidi Vandermey,</td>
<td>Social Worker, Guardian Angels Elim Hospice</td>
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<tr>
<td>Gina Henchen, S</td>
<td>Social Worker, Isanti County Family Services</td>
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</tr>
<tr>
<td>Name</td>
<td>Organization</td>
<td>Role</td>
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<tr>
<td>Earl Lassen</td>
<td>Pastor, First Baptist Church</td>
<td>Action</td>
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<tr>
<td>Rachel Kytonen</td>
<td>Isanti County News Editor</td>
<td>Action</td>
</tr>
<tr>
<td>Mary Sarault</td>
<td>Isanti County Commission on Aging</td>
<td>Action</td>
</tr>
<tr>
<td>Martha Ahlschlager</td>
<td>Home Instead</td>
<td>Action</td>
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<tr>
<td>Shirley Karstens</td>
<td>Volunteer, Cambridge Medical Center</td>
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<tr>
<td>Marge Burns</td>
<td>Retired, Co-Founder of New Pathways</td>
<td>Action</td>
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<tr>
<td>Nicki Klanderud</td>
<td>Community Engagement Manager, AllinaHealth</td>
<td>Action Events*</td>
</tr>
<tr>
<td>Tricia O’Donovan</td>
<td>Pharmacist at Walgreens</td>
<td>Action</td>
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<tr>
<td>Tony Smaby</td>
<td>Haven House</td>
<td>Action</td>
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<tr>
<td>Todd Klein</td>
<td>Housing Administrator, GracePointe Crossing</td>
<td>Action</td>
</tr>
<tr>
<td>Susan Morris</td>
<td>Isanti County Commissioner</td>
<td>Action</td>
</tr>
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</table>
### Appendix 5: Sample Agenda of Survey Team

**Cambridge ACT Survey Team Agenda**

<table>
<thead>
<tr>
<th>Time</th>
<th>Action</th>
<th>Materials Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 min.</td>
<td>Welcome/Introductions Review the concept of what a dementia capable community means for your community</td>
<td>Agenda</td>
</tr>
</tbody>
</table>
| 10 min | The Assessment Phase  
  Process  
  Timeline  
  Job Responsibilities | Work Plan  
  Job Descriptions                  |
| 30 min | Identify the Sectors  
  Potential Interviewees  
  Assigning Interviewers | Worksheet                            |
| 30 min | Survey Preparations  
  Review the Survey Instructions and questions  
  Contacting and Scheduling an appointment  
  Leave behind materials  
  Thank you letter | Sector Surveys  
  Call Script  
  10 Warning Signs  
  Thank you letter |
| 30 min | Role Play  
  Interview Process |                                      |
| 15 min | Next Steps  
  Communication Tools  
  Task – Complete and report out on one survey |                                      |
|        | Next meeting information  
  Date ________________________  
  Time _______________________  
  Location____________________ |                                      |
## Attachment 6: Early Identification of Cambridge Priority Areas and Possible Actions/Resources

<table>
<thead>
<tr>
<th>Priority Area (from 3/26/14 meeting)</th>
<th>Possible Actions and Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>indicates proposed action items by Survey team members</em> Remaining items are proposed by ACT.</td>
<td></td>
</tr>
</tbody>
</table>

### Caregiver Supports

- **Increase awareness and provide education about available caregiver supports and resources for community members and family caregivers**
  - *Write a series of monthly articles for the Guest Column section for the local paper, the Isanti County News. The topics would range from: Introducing the ACT on Alz to our community to the 10 Warning Signs of Alzheimer's and to a number of other options as it pertains to the Cambridge ACT on Alz's group. Each sector would take a month to write an article.*

- **Increase awareness among professional organizations and service providers including identifying strategies in how to work together and refer when appropriate**
  - ACT Cambridge sponsors community resource sharing events and/or electronic forums with representation from local organizations that offer services for people with dementia and their families

- **Lack of respite and adult day**
  - *Identify resources to create an adult day program*

### Local Government

- **Increase awareness of AD among local government staff.**
  - *Offer training for City staff, Police, Sheriff, EMS on Alzheimer’s disease and how to communicate with persons living with the disease*
  - *Display brochures at the police office*
  - *Provide bracelets (500) for individuals that may wander*
  - *Become involved in Project Lifesaver [http://www.projectlifesaver.org/]*
  - For city planners include planning best practices i.e. disaster planning for persons with dementia.
| Increase dementia awareness and knowledge in the community | *Create a website, a one-stop shop for dementia information for citizens of Cambridge*  
- Cambridge ACT works with the Alzheimer’s Association or other partners to sponsor a dementia “friendly” initiative offering forums and trainings to businesses and other community service organizations regarding dementia friendly skills (e.g., banks, stores, hair stylists/barbers, faith communities, legal and financial planning profession) |
| Health Care Community | Cambridge ACT hosts on ACT on Alzheimer’s training to health care providers and community based organizations  
- Provide training in early detection, assessment and treatment |
| Employer | Cambridge ACT works with the Alzheimer’s Association or other partners to sponsor a dementia “friendly” initiative offering forums and trainings to businesses and other community service organizations regarding dementia friendly skills (e.g., banks, stores, hair stylists/barbers, faith communities, legal and financial planning profession)  
- Disseminate ACT on Alzheimer’s employer resources  
- Increase business owners/employees knowledge about the warning signs of dementia  
- Raise awareness of services and organizations that can support persons with AD and caregivers  
- Increase business owners/employees skills for interacting with people with dementia |
Attachment 7: ACTion Team Full Group Discussion of Priority Areas and Ideas

(With Team Tally)

Summary of local government priority area discussion:

Selected as a priority action item (13 votes)

- Offer training for city staff (staff who interface with the public), police, sheriff, EMS on Alzheimer's disease how to recognize the signs and how to communicate effectively with persons living with the disease.

- Develop a registry and alert system for people with Alzheimer's. (4 votes)
  - Police currently have a registry system used for a number of other issues such as conceal and carry, offenders, etc. This potentially could be modified to accommodate an Alz registry.
  - Police currently have a Code Red system (reverse 911) that can put out a call to all phones within a given radius to alert residents to issues. This could be used for a wandering adult with Alz. This could be used kind of like an Amber Alert.
  - Explore other registry options
    - Database companies like those for deaf/hearing impaired
      - Project Lifesaver, http://projectlifesaver.org
      - ID bracelets ($500?) are an option but many people with Alz are stressed by wearing bracelets

- Alz friendly restrooms and signage to indicate

Summary of caregiver support priority area discussion:

Selected as a priority action item (12 votes)

- Increase awareness of AD and caregiver supports through information and education
  - Includes: information in community education flyer, newspaper articles, compiling links to existing articles to disseminate, placing articles in existing newsletters, creating Notification Cards (http://www.actonalz.org/caregivers-families), create informational brochure for first responders, offer an ongoing community education class, offer presentations to community organizations, include information at county fair booth.

- Offer an annual symposium (1 vote)
- Offer training to local businesses (1 vote)
Summary of employer priority area discussion:

- Develop training for employers to offer employees. Training would include 10 warning signs and how to communicate/interact with those with AD. Training may also include information on Notification Cards (http://www.actonalz.org/caregivers-families), how to create an DF environment e.g. fitting rooms, family restrooms, etc. (4 votes)
  - Training considerations: business size (small employers may have part time employees, large employers may have full time employees), types of employees (education level and lower/middle income).
  - Method: short YouTube videos to supplement workshops (with survey to gauge learning), on-site, ½ hour
  - Delivery: new employee orientation
  - Audience: BNI, Rotary (meets weekly), community development, chamber. These groups would be used as a means to connect with employers.

- Develop training for employers on employees with cognitive impairment and education on the stages of AD.

- Make Notification Cards (http://www.actonalz.org/caregivers-families) available to the public

- Create an employee advocate – a person an employee could go to if they had concerns in their workplace

- Increase awareness among employers about working caregivers (http://www.actonalz.org/workplaces) and supports that could assist employees http://fyi.uwex.edu/balancingcare/guide-for-educators/

- Increase awareness among human resource staff about AD, supporting working caregivers. Encourage HR to include information in company newsletters.

- Develop a campaign to increase awareness of federal and state policies (e.g. FMLA, statutory requirements for leave, etc.) that could support working caregivers. Target employers – this is what you need to know. Target employees – this is what you can ask for.

- FYI – any outreach to large employers/chains will need to go through their corporate office and will take a long time.
Appendix 8: Local media coverage - *Isanti County News*


**ACT on Alzheimer’s full steam ahead in Cambridge**

By [Jon Tatting](http://isanticountynews.com/2014/07/09/act-on-alzheimers-full-steam-ahead-in-cambridge/)

July 9, 2014 at 12:07 pm

Meet the Cambridge ACT on Alzheimer’s Action Team, starting with the front row, from left: Craig Rempp, Heartland Express; Chris Caulk, Cambridge City Council and Isanti County Sheriff’s Office; Bruce Hildebrandt, Allina EMS; and Todd Klein, GracePointe Crossing. Second row: Judy Foster, parish nurse; Karen Muhlhauser, volunteer; Julie Tooker, GracePointe Crossing; Earl Lassen, First Baptist Church; Karen Carlson, Visiting Angels; Vicki Ostrom, volunteer; and Nicki Klanderud, Allina Health. Back row: Mary Sarault, Isanti County Commission on Aging; Susan Morris, Isanti County Board of Commissioners; Barb Bergwall, SAC’s; Marcia Westover, city of Cambridge; Lisa Budnick, volunteer; Martha Aschlaager, volunteer; Peggy Carpenter, volunteer; Heidi Vandermey, Guardian Angels Elim Hospice;
The Cambridge ACT on Alzheimer’s group held an informative community event Wednesday, June 25, at the new SAC’s Senior Enrichment Center in Cambridge.

People receive an update on the Cambridge ACT on Alzheimer’s effort at the new SAC’s Senior Enrichment Center in Cambridge. Presenting in the background is Diane Sibley of Anoka-Ramsey Community College.

Photo by Jon Tatting

Giving an update on the effort were Debbie Richman from the Alzheimer’s Association, Lori Vrolson of the Central Minnesota Council on Aging and several local community leaders and volunteers who said they are personally aware of those affected by dementia and the importance of educating the community.

Members of the ACT on Alzheimer’s Action Team were introduced. They invited people to hear the message on enhancing the lives of and better servicing those with dementia and their caregivers. It was about a year ago when key members of Cambridge committed their support to become a dementia-friendly community.

Richman noted Minnesota has almost 30 communities involved with ACT on Alzheimer’s, which is a statewide, volunteer-driven effort that was born from a working group called Prepare Minnesota for Alzheimer’s 2020.

“It’s been incredibly exciting to see how it’s defined in each community,” she said. “What does Cambridge need?”

Others presenting at the community meeting were Todd Klein, of GracePointe Crossing; Lynda Woulfe, city administrator for the city of Cambridge; and Isanti County Commissioner Susan Morris. Chris Caulk, chief deputy with the Isanti County Sheriff’s Office, also discussed the need for ongoing training so officers know how to handle dementia-related incidents.
Diane Sibley, from Anoka-Ramsey Community College, helped define a dementia-friendly community through a handout. Her points included early diagnosis and quality care and support, specialized memory loss services, dementia-aware and responsive client services and customer service, a welcoming and supportive spiritual environment, independent living and quality of life support emergency preparedness and response and suitable transportation and public spaces.

She went over the steps in becoming a dementia-friendly community, as well. The steps start with convening, which is happening now, and continue with assessing the current strengths, gaps and barriers in the community, analyzing those findings and acting together.

“We live in a great community that works very well together. That in itself is worth celebrating,” said Julie Tooker, community relations director for GracePointe Crossing, who is leading the cause.

For more information about the Cambridge ACT on Alzheimer’s effort, call Tooker at 763-691-6192.