



# IT TAKES A VILLAGE

Living with Dementia:  
An Environmental Scan  
of Current Practices



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## FOREWARD FROM THE RESEARCHERS

The purpose of this work is to search and identify current practices in providing care for older adults with dementia who live at home. We aim to provide Design Sprint participants with a list of current practices of dementia care at home so that they are able to develop more innovative solutions that will meet the needs of people with dementia and close current gaps.

Multiple literature review methods were combined and research conducted in the following five steps.

First, a broad academic literature search was conducted using four sets of keywords in 10 academic databases through the library of the University of Toronto. The sets of keywords refer to four themes of (1) dementia, (2) home, (3) care, and (4) outcomes. Each theme includes multiple keywords which were generated by Medical Subjects Headings and frequently used keywords in the database. For instance, for the theme of dementia, “dementia\*”, “Alzheimer\*”, and “neurocognitive disorder” were identified. The databases are MEDLINE, PsycINFO, CINAHL, AgeLine, Social Sciences Abstracts, Compendex, Library Science and Technology Abstracts, Communications Abstracts, Businesses Abstracts Premier, and Web of Science. The search generated more than 40,000 academic papers. Due to the large volume of the literature, it was decided to narrow down the search.

Second, based on the large pool of literature generated by the first round of search, a review was conducted of literature reviews. Comparing and evaluating existing works, literature reviews often report current states, issues, and gaps in research in specific fields. This method was used to identify the specific topics related to the broader framework of providing care for people with dementia at home.

The results of the evaluation were verified in the literature reviews by tracing down empirical studies to related websites, reports, and other sources of information to assess whether they are still current practices or outdated instead. Meanwhile, gaps discussed in the exiting literature reviews related to each topic were also identified.

Third, by reviewing the literature reviews, a preliminary list of topics was generated. However, this list may not represent all aspects of providing care for people with dementia at home. By consulting with subject matter experts for their expertise in the field, the list of topics was refined and eleven topics were identified: (1) Dementia Journey, (2) Environment & Housing, (3) Independent Living & Self-Care Skills, (4) Safety & Security, (5) Physical Health, (6) Mobility & Transportation, (7) Social Connectedness, (8) Communication, (9) Meaningful Activities, (10) Caregiver Support, and (11) Challenging Stigma.

Fourth, an extended grey literature search was conducted with latest news stories and reports from a variety of organizations, such as Alzheimer’s Societies, government organizations, and community centres. This search was considered important and necessary because some latest innovation and current practices being adopted are yet to be evaluated by academic research. They could be extremely inspiring and useful for the participants to the Design Sprint. Therefore, it was decided to include such information.

Following the above steps, the current practices related to each topic were searched, assessed, and selected. Gaps reported in various sources were also cited and integrated into a list for each topic.

# THE DEMENTIA JOURNEY

A person's experience of dementia is embedded within their identity as an individual, their social connections, their interactions with the social and healthcare system, and broader society. Thinking about dementia as a journey, with interconnected aspects of a person's experience, helps one to understand the challenges, positive aspects, and diversity of experiences for each person with dementia and their care partners. A person's needs will vary according to where they are in the dementia journey (Wiersma, Sameshima, Dupuis, Caffery, & Harvey, 2014).



In partnership with the Alzheimer Society of Ontario, Wiersma et al. (2014) conducted focus groups and interviews with people with dementia, informal caregivers, and health professionals. Through their analysis, Wiersma et al. (2014) identified different aspects of the "Dementia Journey", which they divide into four different pathways, as seen in the diagram below and explained on the following pages.

## MAPPING THE DEMENTIA JOURNEY



Figure from Wiersma, E. C., Sameshima, P., Dupuis, S., Caffery, P., & Harvey, D. (2014). *Mapping the Dementia Journey*. <http://ondri.ca/sites/default/files/Alzheimer%20Society%20Dementia%20Journey.pdf>



**THE SYSTEM JOURNEY** describes interactions with the healthcare and social service system. (Wiersma et al., 2014)

#### > **Testing and assessment**

- Challenge: not a clear pathway for assessment
- Current practices: See “Promoting earlier diagnosis and access to information” in Challenging Stigma topic

#### > **Diagnosis**

- Challenges: sometimes takes years to receive a diagnosis; lack of information provided by healthcare provider; people may experience a diversity of responses (e.g., surprise, relief) to diagnosis

#### > **Finding out more**

- Challenge: need for information, awareness, and education (needs to be appropriate, not sugar-coated)
- Current practice: See “Promoting earlier diagnosis and access to information” in Challenging Stigma topic

#### > **Planning ahead**

- Challenges: getting a will, looking after future finances, funeral arrangements, planning for long-term care, home care, or future physical care needs.
- Current practice: see “Advance Care Planning” in Physical Health topic

#### > **Connecting with services**

- Current practices: See “Promoting earlier diagnosis and access to information” in Challenging Stigma topic, “Concierge services and time-sharing” and “Home care service coordination” in Independent Living and Self-Care Skills topic, and “Case management and care coordination” in Physical Health topic.

#### > **Giving up driving**

- Challenge: loss of autonomy, changes in roles for care partners
- Current practices: see Mobility and Transportation topic

#### > **Navigating the system**

- Challenge: surviving crises (e.g., responsive behaviours, infections, physical health concerns, care partner exhaustion), having appropriate care at the time of need
- Current practices: See Physical Health topic

#### > **Staying at home**

- Challenges: recognizing when help is needed; caregiver’s difficulty adapting to the change when their family member can’t be left home alone any longer
- Current practices: See Independent Living and Self-Care Skills, Safety & Security topics

#### > **Alternative living arrangements**

- Challenges: sometimes needed in a crisis; there is a lack of available places when they are needed

#### > **Palliative care**

#### > **Leaving a legacy**

- A positive aspect of their dementia journey: advocating and championing better services for people with dementia
- Current practices: See Challenging Stigma topic

**CHANGING AND ADAPTING** refers to the kinds of changes that people may encounter during their journey and how they react and adapt to these changes. (Wiersma et al., 2014)

- > **Crystallizing moments of awareness:** Moments of awareness as signs and symptoms become more frequent, leaving the person to wonder if they are experiencing dementia.
- > **Catalyst:** it often takes something more dramatic to trigger people to seek help from a health service provider.
- > **Response to a diagnosis:** Varied responses (e.g., relief, validation of concerns, shock, anger, disbelief, fear, wondering about the future, sadness and grief, anger), which can occur at any time point and shift over time. A person can respond with acceptance or fight a diagnosis so that they can live as well as possible.
- > **Adjusting to a new normal:** Normal is always changing, this is a constant process.
- > **Reconstruct the future:** First step is acceptance that the future will be different from one's original plans. This also involves dealing with uncertainty and lack of control over the future.
- > **Live for today:** People living with dementia tended not to focus on the future but instead live for today and enjoy the moment.
- > **Changing identity and sense of self:** Learning to give up self-sufficiency and accept help. Changing roles for both people with dementia and care partners. Positive changes in becoming an advocate for people with dementia. Changes in care partners' roles within marriages, partnerships, and families.

**RELATIONSHIPS IN THE COMMUNITY** encompasses interactions with family, friends, and the community. (Wiersma et al., 2014)

- > **Telling others about the diagnosis:** A very difficult decision, with some people choosing not to share their diagnosis with family members and friends, some choosing to share the information with a select group of trusted people, and others sharing with everyone to let others know why they were forgetting things.
- > **Changing relationships**
  - Changing roles between spouses: e.g., one spouse now has to do the driving or cooking when the other did these tasks before.
  - Managing personality changes in the person with dementia, e.g., if they are angry or hurtful when they wouldn't have been before.
  - Loss of intimacy in relationships. Sometimes positive changes as well: becoming more grateful for each other, new closeness, different friendships.
- > **Building circles of support:** Gaining support and involvement of family members and friends and learning to let them help. Partnering with others going through a similar experience in a support group.
- > **Challenging stigma:** Negative stereotypes pervade many people's perceptions of dementia. The behaviours of a person living with dementia are viewed through the lens of dementia. Negative jokes are often casually made about dementia. Many people with dementia and their care partners can choose to challenge this stigma in their daily interactions.

## CARING FOR MYSELF AND FOCUSING ON ME (Wiersma et al., 2014)

- > **Keeping a positive attitude:** Having a sense of humour.
  - > **Coping with emotions, stress, and anxiety:** Opportunities to “vent”, deal with feelings of grief and anger. Guilt in care partners.
  - > **Engaging in meaningful activity:**
    - Continuing to engage in previously enjoyed activities and participating in new ones.
    - Challenge: Disengaging from social circles as they try to hide the diagnosis.
    - Finding purpose and meaning: Individuals who have to give up work following a dementia diagnosis, find new purpose and meaning. Potential sources of meaning include advocacy work and bolstered relationships with family members.
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## ENVIRONMENT & HOUSING

The quality of living environment has been considered as a substantial determinant of health. Many studies confirmed the effects of community environment and living environment / housing on physical activity, and mobility in people with dementia. Community environment refers to built environment (presence of stores, and amenities, transport, health and community services, physical infrastructure) and social environment (community networks, organizations, traffic, crime rate) in communities. People with dementia and family ask for living environments that support independence, compensate for declining vitality, and lower the burden of family care (Keady et al., 2012; Singelenberg, Stolarz, & McCall, 2014).

### Current Practices

#### > Integrated Service Areas (ISA)

in Germany, the Netherlands, Switzerland, Denmark, Sweden, the US, Japan (Singelenberg et al., 2014)

<http://isa-platform.eu/news.html>

- Implementation components: (1) full participation of people with dementia and local stakeholders in shaping the housing and services offered; (2) cooperation between stakeholders, especially formal caregivers and local governments, is prioritized.
- Provisional components: (1) free or low barrier apartments close to easily accessible public spaces; (2) adaptable levels of assistance provided by health care professionals as well as neighbors; (3) multiple care options, with an emphasis on small-scale home care; (4) multiple social meeting places.
- Eching, Germany: Intergenerational programs, low barrier dementia unit in the building with age-integrated open apartments.

#### > Cohousing: Beacon Hill Village, Boston (60)

(Singelenberg et al., 2014)

- Members pay an annual fee that averages \$600/person.
- Members are part of an extended network that provides social activities, discussion groups, fitness classes, field trips, etc. while staying in their own homes.
- Villages provide members with a “one-stop shop” phone number for everything they could need, e.g., a ride to the grocery store, help changing a light-bulb, plumber services, help with paperwork, a daily check-in, help navigating different pre-screened service providers.
- Villages pre-screen vendors, organize volunteers, arrange group discounts and manage appointments and bill-pay for those who have concerns about money matters. They use a “members-helping-members” approach to connect vetted service providers with seniors.

<http://www.shareable.net/blog/Seniors-Reinventing-Aging-Through-Cohousing-Senior-Villages>

[http://www.vtvnetwork.org/content.aspx?page\\_id=0&club\\_id=691012](http://www.vtvnetwork.org/content.aspx?page_id=0&club_id=691012)



> **Cohousing: Harbourside Seniors Cohousing in Sooke, B.C.** (Singelenberg et al., 2014)

- Members live in 31 private apartments, with a shared common house (guest bedrooms, library and community space for meals, meetings, and social activities). An additional studio apartment can be used if residents need more advanced care. The goal is to provide affordable, environmentally friendly and socially supportive housing and community to members.

[www.harbourside.ca/index.html](http://www.harbourside.ca/index.html)

<http://canadianseniorcohousing.com/>

- Other cohousing communities in the U.S. and Canada include people of all ages, e.g., <https://vancouvercohousing.com/>

> **Dementia-Friendly Community, the UK**

(Poncy, Twaddell, Lynott, & AARP, 2011)

[http://www.housinglin.org.uk/\\_library/Resources/Housing/Support\\_materials/Viewpoints/Viewpoint25\\_Dementia\\_Friendly\\_Communities.pdf](http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Viewpoints/Viewpoint25_Dementia_Friendly_Communities.pdf)

- Care homes: (1) Familiar environments, (2) Legible environments (avoiding corridors, simple and clear color coding), (3) Distinctive environments (separate distinctive rooms, visual access), (4) Accessible environments (closeness to services, large windows and curtains), (5) Safe environment (no trip hazards, flat), (6) Comfortable environment (soft furnishing, quietness)

> **Dementia Friendly Neighbourhoods**

(Poncy et al., 2011)

Design features include:

- wide, flat sidewalks free of bicycles
- accessible drop off points outside important venues
- shops clustered together
- non-slip, non-reflective paving
- ample seating with arm and back rests
- good lighting
- dementia-friendly signs and symbols
- sheltered bus stops
- frequent pedestrian crossings
- handrails at street crossings, safety islands, etc.

> **A case: Sheffield, the UK**

(Mitchell, 2012)

Planners use a checklist for designing dementia friendly neighbourhood and consult with:

- local people who often interact with people with dementia, such as staff in shops.
- The community often holds dementia awareness events and training sessions (see details in Awareness Campaigns in Challenging Stigma topic).

[http://www.innovationsindementia.org.uk/projects\\_communities.htm#communities](http://www.innovationsindementia.org.uk/projects_communities.htm#communities)

<http://dementiawithoutwalls.org.uk/dementia-friendly-communities/>

> **Low-Speed Vehicles and Golf Carts in Community Transportation Networks.**

(Poncy et al., 2011)

<http://assets.aarp.org/rqcenter/ppi/liv-com/insight54.pdf>

- Special design of roads (see details in Mobility & Transportation topic)



### > Dwelling design for older adults with dementia

(van Hoof, van Waarde, & Blom, 2010)

- Open and accessible floor plans (toilet easier found, large windows, privacy for family members, limited use of clutter, storage for assistive devices)
- Interior design (familiarity for the patients, avoid confusion, reducing falling, temporal orientation, independence or assisted use of bathroom and toilet, height of mirrors, position for roll-in shower with shower seat etc.)
- Physical indoor environment (odours, thermal climate, lighting and sound)
- Supportive technology (robust, rapid responses to perceived technological difficulties)

### > Dementia-Friendly Home app from Alzheimer's

**Australia Vic:** An app that helps caregivers to adapt a home for people with dementia. They explore 3D rooms in a home with interactive objects that help them see or hear how simple modifications can help facilitate independence and safety.

*Trials have tested its usability, but efficacy has not been formally evaluated.*



Image from <http://www.dailymail.co.uk/sciencetech/article-3494917/Virtual-home-app-help-Alzheimer-s-stay-homelonger.html>

### > ADLife System in Denmark: An Activities of Daily Living Monitoring; Preventative sensor technology (See Safety & Security topic) (van Hoof et al., 2010)

<http://www.tunstall.co.uk/Uploads/Documents/ADLife%20solution%20sheet%2002.01.13.pdf>

### > Howz in the UK

<http://inteleasant.com/products/howz/>

(see Safety & Security topic)

### Gaps, Limitations and Opportunities

- > Informal social contacts and activities (in shopping areas, medical centres, cafes, or on the street) are more valued than activities offered by social workers in purpose-built activity centres. Preferences of older adults must be taken into account.
- > Local culture has to be considered for planning.
- > A research study found that older adults reported poor traffic conditions and lack of benches/trees/ places as barriers to exploring their communities. Proximity to parks and access to shops enabled their walking. People in suburban neighbourhoods reported that poor sidewalk quality, absence of street lights and personal safety concerns were major barriers to walking (Mitra, Siva, & Kehler, 2015).
- > It is unclear whether cooperative and cohousing communities are inclusive to people with dementia. Members of cooperative communities may unexpectedly become informal caregivers.
- > Some older adults may not like the reduced privacy and need to make new social connections that come with cohousing initiatives. They may instead wish to strengthen their existing friendships.

### Stakeholders

- > People with dementia
- > Informal caregivers
- > Local stakeholders (city, community centre, stores, police)
- > Urban planners / interior designers
- > Health agencies
- > Churches / synagogues
- > Vendors

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<http://www.tunstall.co.uk/Uploads/Documents/ADLife%20solution%20sheet%2002.01.13.pdf>



## INDEPENDENT LIVING & SELF-CARE SKILLS

The complex skills needed to live independently are known clinically as instrumental activities of daily living or iADLs. They include shopping, cooking, cleaning, managing finances and schedule, getting around (driving or taking public transportation), and taking medication. People earlier in their dementia journey (with mild dementia) require assistance with some or all of these activities, while people further on (with more severe dementia) require assistance with all of them. Self-care skills are routine activities, referred to clinically as activities of daily living (ADLs). They include transferring (walking), self-feeding, bathing, dressing, grooming, and toilet hygiene. People in the later stages of dementia need help with some or all of these activities. Providing appropriate assistance, adapted according to a person's current ability level and making use of their own skills is crucial to help people with dementia optimally age in place.

### Current Practices

#### > Concierge services and time exchange

(also see "Cohousing" in Environment and Housing topic)

- Cohousing model, Beacon Hill Village, Boston (Singelenberg et al., 2014): With payment of an annual fee, membership provides "one stop shopping" for a range of services from providers who have been vetted by staff (e.g., handymen, computer experts, meal delivery, housekeepers, tax experts).
- Partners in Care "neighbours helping neighbours" model in Maryland: Members and family volunteers receive services (e.g., transportation, home repairs) in exchange for a contribution of their time or talents. This way people with dementia can also volunteer their time and talents.

<http://www.partnersincare.org/>

#### > Home care service coordination

(also see "Integrated Services Areas" in Environment and Housing topic)  
(Singelenberg et al. 2014)

- 24-hour home care through integrated service areas in Denmark (Stuart & Weinrich, 2001): For example, in Aarhus a referral coordinator conducts a needs assessment and decides which home care services (e.g., cleaning, cooking, personal care) will be provided free of charge by the municipality. The recipient decides between different private and public providers.
- District service team in De Bilt, Netherlands (Singelenberg et al. 2014): Team includes a small number of staff, volunteers, and people who do small jobs in exchange for social allowances. A digital service catalogue provides information on services available. A counselor helps find the right package of services for each citizen.

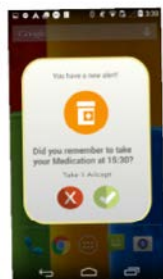
#### > Training and education to empower people with dementia in long-term care to complete self-care activities

(Schoberer et al., 2016)

- Physical and cognitive capacities of residents are evaluated. Short- and long-term goals for residents (e.g., walking to the dining room, engaging in personal care activities) are individually set based on residents' needs and motivation levels. Motivational posters are placed in rooms, and motivational interventions reward and recognize staff and residents for moving towards their goals.

> **Assistive technologies for cognition**

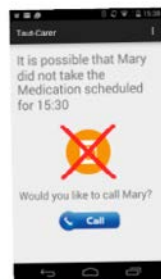
- Reminder systems (Geissbühler, Demongeot, Mokhtari, Abdulrazak, & Aloulou, 2015; Mokhtari et al., 2012): A smartphone or smart TV app for person with dementia or their caregiver to enter and edit reminders based on their daily routine and needs. A voice or visual prompt is displayed at the scheduled time with relevant details. Environmental sensors can be used to determine whether the person adhered to the reminder (e.g., contact switch on medicine cupboard door). Data is sent to a cloud-based system and alerts of missed actions are sent to the caregiver’s smartphone. They can then call or send a repeat reminder.



A Reminder prompt displayed on PwD's smartphone



B Repeat reminder prompt displayed on PwD's smartphone



C Alert displayed on a registered carer's smartphone

> **COACH assistive technology system**

- System makes decisions about the user’s progress through a task (i.e., hand washing) and offers audiovisual prompts to provide assistance, similar to a caregiver. (Czarnuch, Cohen, Parameswaran, & Mihailidis, 2013)

> **MedMinder automatic pill dispenser**

(Global Council on Alzheimer’s Disease, 2016)

- Visual cues and recorded messages remind person to take their pills. If the pill is not taken, a caregiver is alerted and the unused pill box is locked to avoid overdosing.



> **Smart home technologies**

(Liu, Stroulia, Nikolaidis, Miguel-Cruz, & Rincon, 2016)

- Commercially available kits (e.g., X10 ActiveHome kit) were given to frail older adults living alone, including remote controls for lamps and appliances and the software to provide centralized and automated control of electric devices, as well as door and window sensors, motion sensors, security system and alarms (Tomita, Mann, Stanton, Tomita, & Sundar, 2007)
- Sensors monitoring activities of daily living (See “ADLife System” and “Howz” in the Safety & Security topic)
- Smart Patch: a sensor outside of an adult diaper that tracks moisture levels alerts caregivers if the diaper needs to be changed.

<https://www.thestar.com/life/2015/07/07/toronto-entrepreneurs-look-for-success-in-seniors-home.html>



### > Meal preparation and eating

- Food delivery programs (Meals on Wheels) provide nutrition and food security to individuals unable to prepare their own food. Food may be prepared and delivered by volunteers or paid employees of commercial catering companies. Innovative Models (Winterton, Warburton, & Oppenheimer, 2013):
  - Santropol Roulant in Montreal: Actively recruit young people as volunteers to prepare and deliver food with intergenerational activities, opportunities to learn about urban agriculture, and alternate modes of delivery (e.g., via bicycle).
  - Eating with Friends initiative in Australia: Designed to better address social needs by providing meals outside of the home. Volunteers organize and host a meal, groups visit restaurants together, or student groups organize and host a meal.
- Smart utensils: Liftware level is a spoon that corrects for uncontrolled hand movements (i.e., tremors) by keeping the food level

<http://nht.org.au/projects/eating-with-friends/>

<http://www.digitaltrends.com/cool-tech/liftware-level-smart-eating-utensil/#ixzz4TObuVt4N>

### > Financial management and monitoring

(See Safety & Security topic)

### > Transportation needs (See Mobility and Transportation topic)

## Gaps, Limitations and Opportunities

- > Providing too much assistance can cause a person to lose independence prematurely. This is often seen in long-term care facilities, where people are not allowed to do tasks themselves for which they are entirely capable. The appropriate level of assistance has to be adapted constantly as changes occur on the dementia journey.
- > Existing solutions are not usually adaptable according to where a person is on the dementia journey
- > Some interventions may affect the privacy of the individual with dementia. Data security is critical.
- > Some of these models also meet social needs of isolated people with dementia (e.g., Meals on Wheels).
- > Balancing individual choice of services (private funded models) versus accessibility for all (publicly funded models)
- > Technology based solutions are often not evaluated in people with dementia

## Stakeholders

- > Persons with dementia
- > Family members and other care partners
- > Community members and volunteers
- > Technology companies and providers
- > Nonprofit organizations and charities



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- <http://www.partnersincare.org/>
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## SAFETY & SECURITY

Safety risks for older adults with dementia include falls, getting lost due to wandering, medication misses or overdoses, and fires from electrical appliances. One in three adults aged 65 and older experiences one or more falls every year. Injuries related to these falls can be a significant threat to older adults' health and independence, and can even lead to death (Chaudhuri, Thompson, & Demiris, 2014).

### Current Practices

#### > Personal Emergency Response Systems

(Stokke, 2016)

- Philips LifeLine call button: wireless push-button-activated automatic alarm system that summons emergency assistance in case of a fall or medical emergency. Provides 24/7 monitoring within a person's home

#### > Fall detectors (Li, Zeng, Popescu, & Ho, 2010)

- An acoustic fall detection system called FADE automatically detects a fall through a microphone system with 3D sound source localization and can report it to the caregiver.

#### > Fall prevention interior design

(van Hoof, Demiris, & Wouters, 2017)

- Open floor etc. (See Environment & Housing topic)

#### > Sensor Systems (van Hoof et al., 2017)

- ADLife System in Denmark: An Activities of Daily Living Monitoring; Preventative sensor technology
  - ADLife is an early warning system that provides detailed information on the client's activities of daily living at home (e.g. their usage of doors, food cupboards, electrical appliances such as kettles and ovens, and the time spent in bed or sitting on a chair)
  - Caregivers can access this information online to help them recognize any emerging problems.



Image from <http://www.tunstall.co.uk/Uploads/Documents/ADLife%20solution%20sheet%2002.01.13.pdf>

<http://www.tunstall.co.uk/Uploads/Documents/ADLife%20solution%20sheet%2002.01.13.pdf>

- Howz in the UK
  - Affordable system (£100)
  - Record visits of regular contacts
  - Track daily patterns of activity, spot anomalies and send alerts to the family
  - Individuals can control who is able to join their network of care and who can see their information

<http://intelesant.com/products/howz/>

#### Wandering prevention technologies

- Audible alarms: Alarms that play sound tones with different intensities if the person with dementia leaves the monitored setting.
- Lockout systems: Can inactivate whatever devices the resident might use to exit or wander.
- Optically activated alarms: Infrared or other types of light beams are used to monitor people with dementia. When he/she crosses the light, the alarm is activated.
- Pressure activated alarms: These alarms, placed under a mattress or chair, monitor changes in pressure. If the person with dementia gets out of bed or the chair, the alarm is activated.

- Pull tab alarms: A pin is affixed to the person with dementia's clothing via a cord. It is attached to a magnet, which is in turn connected to a monitoring device. Whenever the cord is pulled the alarm is activated.
- Visual deterrents: Physical barriers are placed in the person's path to prevent them exiting a door or entering a restricted area. The door may be camouflaged with a photograph or there may be a physical barrier without camouflage.
- Advanced systems: Combine different features that are frequently customizable to each facility.

[www.visn8.va.gov/patientsafetycenter/resguide/wanderingtechguide.doc](http://www.visn8.va.gov/patientsafetycenter/resguide/wanderingtechguide.doc)

### > Other locating devices

- Anchor Wandering Protection System: alarm on unscheduled departures



Image from <https://safetylabs.org/b2c/alzheimers>

### > Protection against abuse and neglect

(Pillemer, Burnes, Riffin, & Lachs, 2016)

- Caregiver interventions that relieve caring burden (see Caregiver Support topic): When these are targeted towards abusive caregivers they can prevent revictimization.
- Helplines: Allow people to call for advice or assistance from volunteers or professionals. Helplines facilitate early intervention and are often anonymous to avoid shame by people who are victims about the abusive situation.
- Emergency shelters: Specially developed for elder abuse victims, these include temporary relocation in a safe and medically appropriate environment.

- Multidisciplinary teams: Help to coordinate care and reduce fragmentation in the response to abuse across criminal justice, legal, health care, adult protective, financial, and long-term care services.

- Information for law enforcement

- 368+ app: A "cheat sheet" for police in California about signs of elder abuse and the relevant legislation. <http://www.centeronelderabuse.org/368ElderAbuseCA.asp>

### > Financial management and monitoring

- Money management programs (Pillemer et al., 2016) can include help with paying bills, making deposits, and negotiating with creditors.
- True Link: Allows caregivers to see spending habits, prevent transactions with certain types of businesses, and notifies them when their family member is attempting a transaction with a fraudulent entity. Prepaid debit cards can be provided to the person with dementia (Global Council on Alzheimer's Disease, 2016)

## Gaps, Limitations and Opportunities

- > Smart homes and related technologies can provide a variety of benefits.
- > Technologies need to be reliable and fit into householders' lifestyles.
- > Public concerns relate to cost, control and privacy.
- > Trust in energy companies and government is important (Balta-Ozkan, Davidson, Bicket, & Whitmarsh, 2013).

## Stakeholders

- > Persons with dementia
- > Family members and other care partners
- > Emergency services
- > Health care professionals
- > Technology companies and providers
- > Lawyers and the legal system

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<http://cnpea.ca/en/>

<http://www.advocacycentreelderly.org/>







## PHYSICAL HEALTH

A key aspect of maintaining health of people with dementia relates to managing multiple chronic conditions (e.g., diabetes, congestive heart failure); these conditions commonly co-occur in individuals with dementia and problems controlling them can lead to hospitalization. Additional causes of hospitalization in people with dementia include unintentional injuries (e.g., falls, burns), acute infections (e.g., urinary tract infections, pneumonia), and dehydration (Phelan, Debnam, Anderson, & Owens, 2015). Hospitalization rates and emergency room visits are consistently higher in people with dementia, and people with dementia are at greater risk of complications of hospitalization, such as delirium and falls, which increase the likelihood of being moved to residential long-term care. Initiatives to maintain physical health in people with dementia therefore need to address management of multiple chronic conditions and reduce risk of acute health problems. Planning for future health decisions is also important.

### Current Practices

#### > **Case management and care coordination:**

involves a case manager or case management team, who make an assessment of the individual's specific needs, provides information about possible care options, develops and implements a care plan, coordinates services from different agencies, and monitors, reassesses and revises care plans. Often undertaken by a nurse or social worker. Can be done by telephone and/or in-person, sometimes including structured home assessment and economic assessment. *Strong supportive research evidence that it is effective in dementia and other chronic conditions* (Barlow et al., 2007; Reilly et al., 2015)

- In dementia, strong evidence for reducing admittance to nursing homes, increasing use of community services, and lower overall healthcare costs. Some benefits in carer burden (Reilly et al., 2015). Limited evidence for reduction in hospitalization (Phelan et al., 2015; Reilly et al., 2015).

- Case management by telephone has reduced symptoms and improved clinical outcomes in depression, heart disease, diabetes, asthma, chronic obstructive pulmonary disease (COPD), and frail elderly people (Barlow et al., 2007).
- “Decide Guide” web-based system (see Communication topic)

> **Vital signs monitoring:** Monitoring vital signs, such as blood glucose in diabetes or blood pressure control in hypertension. Data can be automatically transmitted to health care providers, and in some cases, a nurse follows up with the patient. Can also be used for asthma, COPD. *Systematic review shows benefits in reducing hospital admissions and costs* (Barlow et al., 2007).

- I-Team intervention: Patients with chronic illness (congestive heart failure, COPD) and comorbid depression were given a small in-home monitor that measured their weight, blood pressure, pulse, oxygen saturation, and temperature daily. A nurse contacted people with abnormal results, and also provided telehealth counselling (Gellis, Kenaley, & Have, 2014).
- BlueStar: FDA-approved, prescription mobile therapy for diabetes that provides support to patients with exercise and diet tips, and 24/7 support with coaching. Patients enter their blood glucose levels and this information is sent directly to their physician.

<https://www.bluestardiabetes.com/>

- Smart clothing (wearables):

- Fabrics that measure physiological data and send it to a computer or smartphone are under development

<http://www.digitaltrends.com/wearables/smart-clothing-is-the-future-of-wearables/>

- Tattoo-like silicon sensors: still at the conceptual stage

<https://www.technologyreview.com/s/538826/what-are-the-prospects-for-flexible-biosensors/>

- Biostamp: Soft stamp sticks to your body and shares physiological data (surface electromyography or sEMG and as electrocardiography or ECG) wirelessly with a computer or smartphone. Used for research now, with a clinical application to be developed in the future.



Image from <https://www.mc10inc.com/our-products#BioStampMD>

- > **Advance care planning:** One aspect of the dementia journey is readjusting one's plans for the future. An important way to deal with uncertainty is to solidify one's wishes for future health care decisions and end-of-life care while the person with dementia can still make their wishes known.
  - Speak Up Advance Care Workbook from the Canadian National Advance Care Planning Task Group: An online interactive workbook that walks a person through different questions to consider what is important to them, document their beliefs and wishes, and develop an advance care plan. Once completed, it can be downloaded and shared with loved ones.
  - My Directives app by ADVault, Inc. in the U.S. (Fine, Yang, Spivey, Boardman, & Courtney, 2016): An app that allows a person to create, store, locate, and retrieve advance care planning and advance directives on their smartphone with minimal need for physician involvement. It can be integrated into a person's electronic health record.

#### > **The ACE (acute care for elders) Strategy by Mount Sinai Hospital**

emphasizes on low-tech innovations. (The Globe and Mail, Dec. 23, 2016)

- Encourages seniors to sit up in a chair for meals
- Provides no-slip socks
- Lowers beds to decrease falls
- Empowers geriatric-emergency-management nurses at the entrance to the hospital
- The ACE strategy has been adopted by 17 hospitals and health-care organizations in Canada and one in Iceland.

#### > **Fall detection and sensor systems**

(see Safety & Security topic)

### Gaps, Limitations and Opportunities

- > Costs associated with technology used for vital signs monitoring
- > Data security and privacy
- > Existing services and technologies can be difficult to use and are not designed for people with cognitive difficulties.

### Stakeholders

- > Person with dementia
- > Caregiver
- > Family members who may be called upon to make health decisions
- > Health care professionals
- > Lawyers

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<https://www.technologyreview.com/s/538826/what-are-the-prospects-for-flexible-biosensors/>

<https://www.mc10inc.com/our-products#BioStampMD>

<https://www.bluestardiabetes.com/>



## MOBILITY & TRANSPORTATION

Mobility refers to “moving by changing position or location or by transferring from one place to another” (WHO, 2001). Accessible transportation and mobility options are essential to the health and well-being of older adults and the overall livability of a community. In many cities, public transportation became more accessible with a large share of low-floor city buses. In addition, special transportation services are provided to older adults.

Nevertheless, high cost of special transportation is always an issue. Eligibility for special services is being increasingly restricted. Meanwhile, older adults may not consider themselves handicapped, however many do have trouble accessing regular public transit (Alzheimer’s Association, 2016).

In addition, many older adults live in rural areas where public transit has less stops and less frequent services. People who have traveled in automobiles in their lives would prefer to travel in automobiles, and they would not mind to pay for it (Freund, K., & McKnight, 1997).

### Current Practices

#### > Public transportation

- Public transportation in Sweden (Wretstrand, Svensson, Fristedt, & Falkmer, 2010)
  - Planning implemented covering all types of traffic, offering a wide range of services. Swedish Government Bill “From patient to citizen: a national action plan for disability policy” (1999/2000)
  - Combination of mainstream bus transit, Special Transportation Services, hospital transit,
  - Service Route Traffic specially designed for mobility-impaired users and offering a high degree of service
  - Barrier-free pedestrian zones and tactile surface

- Public transportation in Vancouver (Fitzgerald & Harbour, 2009)
- Go Bus in Vancouver: Seniors’ shuttle service

Figure 8 Inside Go Bus.



#### > Community bus

- Community bus in Vancouver (Fitzgerald & Harbour, 2009)
  - Community buses that are smaller and more flexible than regular transit buses can be a lifeline to independence.
  - Routes are designed to include senior-oriented origins and destinations, and a senior-oriented schedule
  - Specifically aimed at seniors and people with disabilities
  - A slower pace allows the driver to assist with boarding



- Enhanced customer service
- Ample space on bus for mobility aids and shopping bags
- Service is marketed through collaboration with community centres, community health service providers, etc.
- Low-Speed Vehicles and Golf Carts in Community Transportation Networks <http://assets.aarp.org/rgcenter/ppi/liv-com/insight54.pdf>
  - Low-Speed Vehicles (LSV), particularly Neighbourhood electric vehicles (NEVs) (Poncy et al., 2011)
  - LSV designed for 1-2 passengers, greater safety than golf carts
  - The Western Riverside Council of Governments, representing 16 cities in CA; the Villages, retirement community in FL, etc.
    - Designated on-road facilities and shared traffic lanes (e.g. special cart exiting areas)
    - Safety enforcement and education
- Volunteer drivers in communities (Freund & Vine, 2010)
  - Volunteer Driver Program in the US <http://www.beverlyfoundation.org/volunteer-driver-turnkey-kit/>
  - Independent Transportation Network, a US nationally affiliated volunteer transportation service for seniors, also in Canada and Australia <http://www.itnamerica.org/> <http://www2.gnb.ca/content/dam/gnb/Departments/esic/pdf/KatherineFreundITNLocalSolutionNationalSystem.pdf>
- EZRide Community Cars program for older adults <http://www.ezride.org/3-1-0-CommunityCars.asp>
  - Register with \$15 annual membership fees
  - Ride 24 hours in advance by calling
  - Fare deducted from the account and no money exchange with driver
  - Only runs Monday to Friday
  - Drives are volunteers
- Car-sharing model: people do not have to worry about car upkeep (Freund & Vine, 2010)
  - Zipcar
- Concierge system (see Environment & Housing and Independent Living and Self-Care Skills topics)

## Gaps, Limitations and Opportunities

- > Public transportation (i.e. buses) need a more reliable schedule, comfortable and accessible stops, a seniors information line, accessible seating, “bus buddy programs”, and training for providers about the needs of older adults (Fitzgerald et al., 2009).
- > Boarding and alighting buses are the most challenging issue (Wretstrand et al., 2010).
  - This suggests that the lower floor of vehicles and adjusted pavement are not sufficient accessibility affordances. Some research has identified other obstacles related to bus stops: cycle-ways conflicting with pedestrian environments, narrowness, poor weather protection, many buses at the same time, poor or incorrect information signs.
- > BLSVs and NEVs
  - Vehicle safety features
  - Licensing
  - Safety enforcement and education
  - Planning and designing safe facilities
- > Reduce traffic volume, speed, and density <http://cordis.europa.eu/pub/life/docs/mollenkopf.pdf>
- > Cognitive difficulties impact navigation of public transit systems and people with dementia may get lost.

## Stakeholders

- > City / Policy makers
- > Planners
- > People with dementia
- > Families
- > Volunteers
- > Public transportation
- > Private transportation
- > Vehicle manufacturers
- > Police



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## SOCIAL CONNECTEDNESS

Social connectedness is associated with cognitive functioning and mental health. Roughly 90% of people with dementia experience negative emotional symptoms. These symptoms can be improved by providing a sense of companionship and connection. Social connectedness can be fostered in person and online.

### Current Practices

> **“Dementia-Friendly Cities”** in the UK: Croft House is a Somerset Care home collaborating with Reminiscence Learning to raise awareness of dementia through intergenerational engagement.

- School children come to the care home to share in meals and activities
- School teachers are provided with dementia teaching packs
- Local citizens, shops, businesses and services can attend training workshops
- ‘Kitemark’ concept: After attending a workshop, businesses display a “kitemark” window sticker to indicate that they are a dementia friendly location. .

[http://www.innovationsindementia.org.uk/projects\\_communities.htm](http://www.innovationsindementia.org.uk/projects_communities.htm)

> **App “Care and Find”**, developed by a community as part of a research project at Newcastle University (see details in iADL topic). (Mitchell, 2012)  
<http://appcrawlr.com/ios/care-and-connect-dementia-frien#authors-description>

**Aging in Place** in the US, encouraging social connections. (Stafford, 2010). The Helen Andrus Benedict Foundation provided grants in Yonkers and Westchester County, New York, to help older learn and practice leadership skills, tutor school children, advocate for grandparents raising grandchildren, help other adults find jobs, learn about starting new businesses, teach others about Medicare rights and benefits and how to navigate a hospital stay.

> The Center for Aging in Place Support, in Westchester County, New York provides training and technical assistance, information on organizing community meetings and assessing neighbourhood needs, monthly “Village Council” meetings. It also makes small grants to aging in place initiatives, screens and “vets” service providers and negotiates fees for all member groups.

<http://www.centerforaginginplace.org/>

> **Intergenerational connection**

- University students live for free at Residential and Care Center Humanitas, a nursing home in the Netherlands, in exchange for 30 hours of volunteer work per month.
- Students teach residents new skills, e.g., using email, social media, and Skype, and even graffiti art.

<http://www.citylab.com/housing/2015/10/the-nursing-home-thats-also-a-dorm/408424/>

- The Exeter Care Homes Reading Project, in the UK.
- University students visit residents regularly, reading them poetry, plays, and short stories, and talking with them.

<http://readingproject.exeter.ac.uk/>

[https://www.weforum.org/agenda/2016/11/some-dutch-university-students-are-living-in-nursing-homes-this-is-why?utm\\_content=buffer07075&utm\\_medium=social&utm\\_source=twitter.com&utm\\_campaign=buffer](https://www.weforum.org/agenda/2016/11/some-dutch-university-students-are-living-in-nursing-homes-this-is-why?utm_content=buffer07075&utm_medium=social&utm_source=twitter.com&utm_campaign=buffer)

> **Social spaces**

- Dementia Cafés (see details in Challenging Stigma topic)
- Eating with Friends Initiative (see details in Meal delivery in Independent Living and Self-Care Skills topic)
- Talking Point (see details in Caregiver Support topic)

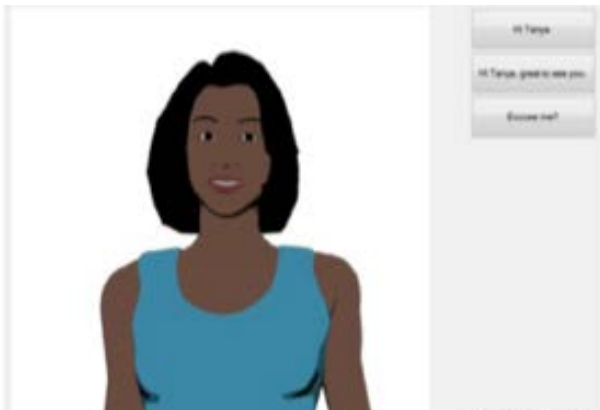
## › Technology

- General ICT: computer and internet (e.g. email) use provide new way of communication with family and friends. (Vichitvanichphong, Talaei-Khoei, Kerr, & Ghapanchi, 2014)
- Pet robot, PARO Therapeutic Robot: A seal-Shapea Robot that uses sensors and programming to respond to a user's actions, creating a sense of connection. (Khosravi, Rezvani, & Wiewiora, 2016)



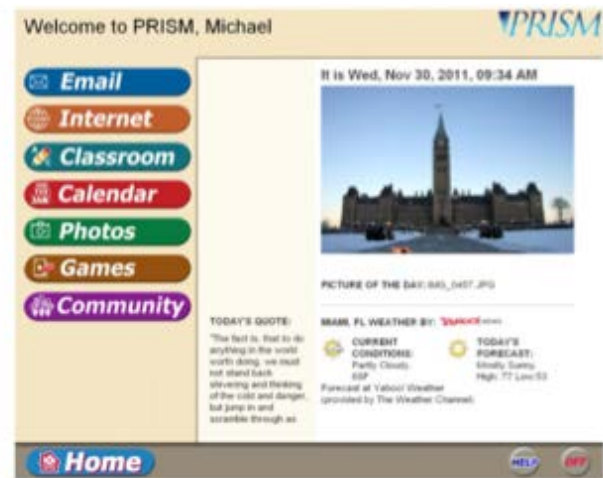
Image from <http://tombatney.com/design/case-study-paro/>

- Conversational agent: talk therapy; Wizard-of-Oz experiment (Ring, Shi, Totzke, & Bickmore, 2015)



- Video games can have a positive effect on cognitive and physical stimulation. One study using the Wii found improvements to social interaction and decreases in loneliness (Vichitvanichphong et al., 2014).

- PRISMS (Personal Reminder Information and Social Management system): Women-to-Women experiment in the U.S. (Czaja et al., 2015)



- Online forum: ALZConnected ([alzconnected.org](http://alzconnected.org))
  - Provided by the Alzheimer's Association in the US, people affected by dementia can discuss issues as part of a free online community <https://www.alzconnected.org/>

## Gaps, Limitations and Opportunities

- › Robots /technologies cannot and should not serve as a substitute for human contact
- › Significant expenses for robots
- › People with dementia and caregivers are often seen as two different groups. Social interaction platform both online and offline tend to facilitate communication within each group rather than between the groups (e.g. a forum for caregivers and a forum for patients).

## Stakeholders

- › People with dementia
- › Caregivers
- › Engineers
- › Local community centres
- › Local government
- › Schools
- › Libraries
- › Volunteers
- › IT companies

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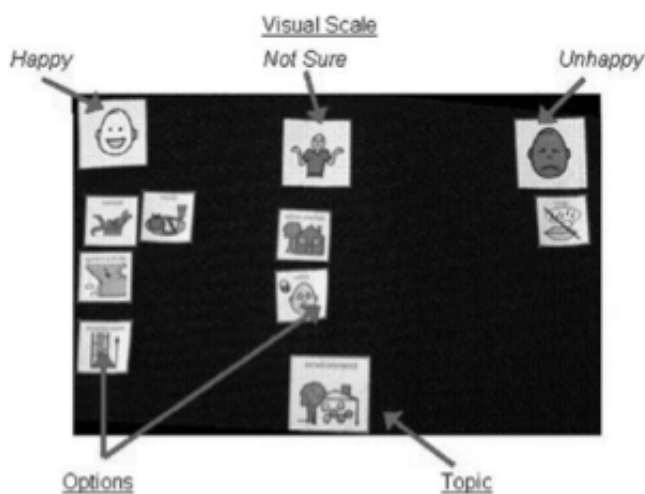


## COMMUNICATION

Many people with dementia experience a deterioration in communication, which may occur in the early stages of the illness. The variation in communication ability means that people with dementia may be challenged to express their needs to a wide range of caregivers, including family members, personal support workers, and physicians. When patients are unable to voice their opinion, their “personhood” might be easily ignored. A person with dementia can become disempowered if caregivers lower their expectations and reinforce dependency (Murphy, Gray, & Cox, 2007).

### Current Practices

› **Talking mats in the UK** (Murphy et al., 2017): Picture symbols can be placed on a textured mat during a conversation. Picture symbols can represent the topics being discussed, options related to each topic, and a visual scale to indicate someone’s feelings about each option.



› **NAO (a humanoid robot)** (Soler et al., 2015)

- A white, two foot tall humanoid robot that has sensors for movement, touch, sonar, sound, and vision. It can talk and sing, as well as move its neck and arms, walk, and dance.
- The robot can also act out a script for therapy sessions, including effects like speech, music and movements. The therapist can control the activation of the script using a remote control. Research shows that using the robot improved in apathy.



Images from <http://www.telegraph.co.uk/education/educationnews/10923190/Welcome-to-Nao-your-robot-teacher.html>

> **The DecideGuide:** an interactive Web-based system that can support shared decision-making in care networks. People with dementia, informal caregivers, case managers and other relevant professionals can communicate in order to make shared decisions about the person's care (Span et al., 2015).

### > **Communication training for caregivers**

- The Montessori Approach for Dementia  
<https://www.saintelizabeth.com/getmedia/a1d8aef1-14c3-4fdd-a8d7-9abd065d1782/montessori-approach-for-dementia.pdf.aspx?ext=.pdf>
  - The environment is tailored to the person's unique needs.
  - Persons with dementia maintain or learn a skill with repetition.
  - Demonstrate each activity to ensure the person understands what he/she is expected to do.
  - Activities should enable individuals to be as independent as possible.
  - People need high self-esteem and the chance to make meaningful contributions to their community.
- Educational programs for commination for caregivers (see "Information and Education Programs" in Caregiver Support topic). (Eggenberger, Heimerl, & Bennett, 2013)
- Dementia Advisor app (see details in Caregiver Support topic)

### Gaps, Limitations and Opportunities

- > People with dementia want to participate in the communication and decision making processes with physicians. In many cases, patients feel that they are objectified, and their patients' wishes are not taken into consideration.
- > Patients are concerns about the common language between themselves and physicians. They are afraid to express themselves because they do not know if they have the "right words".
- > A feedback culture should be developed for educational programs for caregivers.

### Stakeholders

- > People with dementia
- > Caregivers
- > IT companies
- > Health care professionals
- > Health agencies





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<http://www.telegraph.co.uk/education/educationnews/10923190/Welcome-to-Nao-your-robot-teacher.html>



## MEANINGFUL ACTIVITIES

Meaningful occupation is defined as any task or activity which is important and meaningful to the person with dementia, and hence includes a wide range of activities and interventions (Travers et al., 2015). Activities that are meaningful to a person with dementia are similar to those for people without dementia, and can include the full spectrum of one's daily activities, including a variety of leisure, social and recreational activities, household tasks, and work-related activities. When recreational activities are personalized and take into account previous interests and current skills, engagement can reduce agitation and improve well-being in people with dementia (Travers et al., 2015). Engagement in cognitively stimulating activities has been shown to reduce the risk of dementia (Stern & Munn, 2010).

### Current Practices

#### > Programming approaches

- The Butterfly Approach in the UK: a model of person-centred care used in nursing homes.
- Building on 5 key principles, staff are trained to increase their positive interactions with residents. The dementia care environment is filled with stimulating objects such as busy sensory items, domestic objects, dolls, musical items, spiritual items, and art.

<http://www.dementiacarematters.com/pdf/OT-news2010.pdf>

#### > Arts Interventions

- Ladder to the Moon: a theatre charity that uses staff coaching and interactive theatre to improve quality of life for people with dementia.
- Using "relationship theatre", professional actors and coaches work with care home staff to improve the enjoyment of people with dementia.

[http://www.innovationsindementia.org.uk/projects\\_communities.htm](http://www.innovationsindementia.org.uk/projects_communities.htm)

#### > Identity specific activities

Constructing a family tree for grandchildren, for a person who stated importance of the family-social role (Cohen-Mansfield, Parpura-Gill, & Golander, 2006).

#### > Exercise and outdoor activity

(Forbes, Thiessen, Blake, Forbes, & Forbes, 2013)

- Exercise interventions: e.g., 30 min programs of exercise 2-3 times per week
- Dementia Adventure in the U.K.: As dementia progresses, people are more likely to have difficulty accessing the outdoors. This program leads short park walks, sailing trips and holidays for people with dementia and their caregivers. Trips are designed with the needs of people with dementia in mind (Dementia Adventure, 2016)

#### > Music therapy

- iPod programs from the Alzheimer Society of Ontario
- Playlist for Life: App that explores the impact of music on people living with dementia

#### > Reminiscence therapy

- RemindMeCare: App that automatically pulls images of events, favourite places, films and music from the web to create a detailed multimedia profile of the person. Helps to stimulate conversation with carers. Can also help people identify shared interests in group settings. Designed primarily for use in long-term care settings.
- Book of You app with the National Health Service and Nesta innovation lab in the UK: Digital memory book of images, sounds, and comments  
*Research is currently being conducted*

> **Social contacts and active participation in Integrated Service Areas** is associated with the sense of meaningfulness. (See Environment & Housing topic) (Singelenberg, Stolarz, & McCall, 2014)

> **Activity intervention**

<http://www.ambientactivity.com/>

- The activities provide those who live with moderate to severe levels of cognitive impairments, opportunities to engage and interact with purposeful activity.
- AAT activities are available in the environment for easy access and augment existing activity programming, by providing self-accessed interactions that may be engaged with at any time. Ambient Activities help to promote and facilitate a 'state of calm' and 'well-being' in the resident to address disruptive behaviors.

> **Other enjoyable activities** designed to improve social connectedness (see "Aging in Place", "Conversational agent" and "Video game" in Social Connectedness topic)

> **Volunteer programs** (see "Aging in Place" in Social Connectedness and "Concierge services and time sharing" in Independent Living and Self-Care Skills topic)

## Gaps, Limitations and Opportunities

- > Personalized interventions (e.g., reminiscence interventions) are costly and time-consuming to put together.
- > The meaningfulness of activities is connected to a person's background, his/her motives, lifestyle and identity, and the contextuality of activities (Kuosa, Elstad, & Normann, 2014).

## Stakeholders

- > People with dementia
- > Caregivers
- > Local community centres
- > Local government
- > Schools
- > Libraries
- > Volunteers



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## CAREGIVER SUPPORT

Most people receiving care for dementia while living at home have at least one informal caregiver. More than 50% of informal caregivers are caring for a parent with dementia and 28% are caring for a spouse (Sabine et al., 2014). Caregivers experience physical discomfort and health problems as a result of caring. Over half of caregivers suffer emotional stress, especially when caring for individuals with responsive behaviors (e.g., verbal or physical aggression, screaming) or when they have cared for a long period of time with little outside support.

### Current Practices

#### > Information and education programs

- 10/66 Caregiver Intervention: Developed in India to deliver packages of dementia care in low and middle income countries with resource-limited health care systems. Multipurpose community healthcare workers deliver manualized education on dementia and training on managing responsive behaviours over five 30 min sessions to the main caregivers of people with dementia. Now being tested in Venezuela, Peru, Dominican Republic, China, Chile, Argentina, and Mexico (Dias et al., 2008; Gavrilova et al., 2009).
- Educational programs for communication (Eggenberger, Heimerl, & Bennett, 2013)
  - Verbal skills (skills at different phases of dementia)
  - Nonverbal and emotional skills (eye contact, etc.)
  - Attitudes towards people with dementia (take patients perspective, etc.)
  - Behavioural management skills (responding to disturbance, etc.)
  - Usage of tools (memory book, etc.)
  - Self experience
  - Theoretical knowledge
  - Cultural and ethical knowledge
  - Knowledge on communication issues (hearing and visual impairment)
- MIRELA: A Spanish-language webnovela for Latino families dealing with dementia in California and Nevada. The goal is to teach caregiving skills to cope with stressful situations and improve quality of life by showing the story of a family dealing with dementia.
- iSupport app: WHO-developed app to provide education, skills training and social support in low and middle income countries. After it has been piloted, it will be open-source, free of charge and allow individual tailoring of language and culturally-specific information. - *Project is being piloted in India.*
- Dementia Advisor app: Under development at Mt. Sinai Hospital, this app uses scenario-based training and expert coaching to improve communication and problem solving skills.
- Training in Montessori approach (see Communication topic)

#### > Counselling and support groups

- Telephone counselling sessions with a trained nurse or psychotherapist (Sabine et al., 2014).
- Talking Point, UK Alzheimer's Society: An online forum for caregivers of people with dementia that allows people to ask advice, share information, discuss issues, and get peer support. (McKechnie, Barker, & Stott, 2014)

#### > Share the Care model

- A step-by-step system that helps people create a "caregiving family" of friends, relatives, neighbours, co-workers, and acquaintances involved in sharing care. The goal is to identify the talents of each caregiver, make sure that no individual has too large of a burden, and navigate issues around teamwork. *Non-peer reviewed research has been conducted* <http://sharethecare.org/>

### > Mediation

- Respite and Relief program, Champlain CCAC, Ontario: Uses elder mediation techniques to help caregivers to create a circle of care by uniting the caregiver's support network into a common position. Mediation techniques including acting as a neutral third party, fostering links with health system providers, and using collaborative communication to help resolve potential conflicts before they occur.
- Responsive behavior interventions
  - Functional analysis: A therapist explores the meaning or purpose of the person with dementia's challenging behavior (e.g., agitation, aggression). They use this understanding to develop individual strategies that are uniquely tailored to the person with dementia or caregiver. (Moniz Cook et al., 2012)
- Adult day programs:
  - Person with dementia can receive services that address ADLs, nursing, and other medical needs, psychosocial care, meals. The caregiver gets a break from their caregiving role during the day. (Fields, Anderson, & Dabelko-Schoeny, 2014)

### Gaps, Limitations and Opportunities

- > Caregivers have diverse needs, e.g., also managing complex chronic conditions, in addition to dealing with issues directly related to dementia.
- > Helping the range of individuals who may all be considered care partners (e.g., spouses, children, grandchildren, friends, neighbours).

- > Dealing with conflicts among multiple care partners: Pre-existing, long simmering family conflicts often come to the surface when making decisions around dementia care.

### Stakeholders

- > People with dementia
- > Caregivers
- > Local community centres
- > Local government
- > Schools
- > Libraries
- > Volunteers





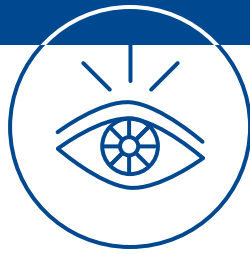
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## CHALLENGING STIGMA

There is substantial stigma around dementia: Fear over the terms “dementia” and “Alzheimer’s” leads people to avoid seeking a diagnosis and make doctors reticent to give a dementia diagnosis. 40% of people with dementia report being excluded from daily life, and up to 60% report that friends and family began to avoid them after a diagnosis (Batsch & Mittelman, 2012). Caregivers also experience stigma: 28% reported that people avoided or treated them differently.

### Current Practices

#### > Dementia Cafes

- Alzheimer Cafés in the Netherlands: Attended by people with dementia and their families and friends, as well as anyone else who is interested in dementia, such as students, politicians, and the media. The event often includes discussions or presentations followed by a less structured period for people to share their experiences with others. Started in the Netherlands in 1997, but others have started around the world.

<https://www.alz.co.uk/dementia-friendly-communities/alzheimer-cafe>

#### > Dementia-friendly communities

- Orange Patrol, Matsudo, Japan: City provides dementia awareness classes to city workers so that they can identify people with dementia and more effectively interact with them.

<http://www.npr.org/sections/health-shots/2016/08/23/489629931/japan-offers-dementia-awareness-courses-to-city-workers>

- Blue Umbrella, Alzheimer Society Peterborough, Kawartha Lakes, Northumberland & Haliburton: Businesses and organizations receive education about dementia and learn strategies to provide good customer service to people living with dementia. They are then designated as a dementia-friendly location and display the blue umbrella to potential customers. People with dementia may wear a blue umbrella pin to identify themselves. This project is now being implemented in other Alzheimer Societies in Ontario.

<https://uwaterloo.ca/murray-alzheimer-research-and-education-program/dementia-friendly-communities-blue-umbrella-project-update>

- Care and Connect Dementia Friendly Places app from the University of Newcastle upon Tyne, UK: allows people with dementia and their caregivers to rate and discover indoor and outdoor places on staff interaction, physical layout, clarity of wayfinding, and atmosphere.

<https://medicalxpress.com/news/2015-03-mobile-app-dementia-friendly.html>

- Dementia Friendly Neighbourhood in Sheffield, the UK: Dementia awareness events and training sessions are held with community members who interact with people with dementia (e.g., police support officers, housing managers). People working for businesses may get involved, for example, a local gym runs sessions specifically for people with dementia.

[http://www.innovationsindementia.org.uk/projects\\_communities.htm#communities](http://www.innovationsindementia.org.uk/projects_communities.htm#communities)

<http://dementiawithoutwalls.org.uk/dementia-friendly-communities/>

- (Also see “Dementia-friendly communities in Environment and Housing and Social Connectedness topics)

### > Awareness campaigns

- Dementia Friends Canada: Based on similar international initiatives, this is a national campaign to increase awareness of signs of dementia and to understand what it's like to live with dementia. Anyone can sign up to become a "Dementia Friend" on their website.

<http://www.dementiafriends.ca/>

- ReThink Dementia, Alzheimer Societies Ottawa & Renfrew County and Cornwall & District: Website with information on dementia for people in the community, people with dementia, caregivers, and health professionals. Includes videos showing how people can interact with people with dementia and make their communities more dementia-friendly
- FreeDem Films: Freely available education and awareness films from Trinity College, Dublin, designed to increase awareness and challenge stigma around dementia.

<http://freedemliving.com/>

### > Dementia experiences (Batsch & Mittelman, 2012)

- Memory Footprints, Alzheimer Society of Montreal: Workshop for health care workers to gain insight and empathy for people with dementia through hands on exercises.
- Sort Me Out, Alzheimer's Disease Association Singapore: A viral ad campaign had people install an app that was designed to re-create the experience of memory loss by gradually erasing their Facebook friends, pictures, and videos.
- Alzheimer Experience, Ecuador: Campaign on World Alzheimer's Day 2011. Staff in supermarkets rearranged items on the stores' shelves so that people could not find what they were looking for, to help provoke empathy with how people with dementia might feel at a supermarket.

### Promoting earlier diagnosis and access to information

- Uji city, Japan: An early diagnosis checklist sent to all citizens age 65+. Medical and welfare specialists in "Early-stage Dementia Intensive Support Teams" go out to people who are thought to have dementia in the community to prevent delay in access to care.

<http://www.city.uji.kyoto.jp/cmsfiles/contents/0000014/14401/sasshienglish.pdf>

<https://www.alz.co.uk/dementia-friendly-communities/uji>

- Know the 10 Signs: Early Detection Matters' campaign, Alzheimer's Society U.S.: Media campaign to increase knowledge of dementia signs and importance of early detection. The Alzheimer's Early Detection Alliance allowed companies to sign up and educate their employees about the warning signs of dementia.

<http://www.alz.org/10-signs-symptoms-alzheimers-dementia.asp>

- First Link program, Alzheimer Society of Canada: Links people with dementia and their caregivers to support services early following diagnosis. Health care professionals can directly refer recently diagnosed people to this program. (McAiney, Hillier, Stolee, Harvey, & Michael, 2012)

<http://www.alzheimer.ca/en/We-can-help/Resources/For-health-care-professionals/first-link>

### > **The Best Friends™ Dementia Bill of Rights**

(Bell & Troxel, 1997): Can be posted and signed by all people who work with individuals with dementia.

“Every person diagnosed with Alzheimer’s disease or other dementia deserves:

- To be informed of one’s diagnosis.
- To have appropriate, ongoing medical care.
- To be treated as an adult, listened to, and afforded respect for one’s feelings and point of view.
- To be with individuals who know one’s life story, including cultural and spiritual traditions.
- To experience meaningful engagement throughout the day.
- To live in a safe and stimulating environment.
- To be outdoors on a regular basis.
- To be free from psychotropic medications whenever possible.
- To have welcomed physical contact, including hugging, caressing, and hand holding.
- To be an advocate for oneself and others.
- To be part of a local, global, or online community.
- To have care partners well trained in dementia care.”

<http://bestfriendsapproach.com/about/the-best-friends-bill-of-rights/>

### Gaps, Limitations and Opportunities

- > Gaining broad public awareness, including people who may have less contact with those with dementia (e.g., young people)
- > Ensuring that people with dementia have a voice in policy decisions
- > Maintaining a balance between being positive about the richness of the lives of people with dementia, but also not sugar-coating the illness. Different people have different approaches to this: They may feel positive or negative, and all reactions of people with dementia and their caregivers are valid. Positive approaches may be very off-putting to people who feel negative about their diagnosis, and especially may be hard to swallow for caregivers dealing with major burdens.

### Stakeholders

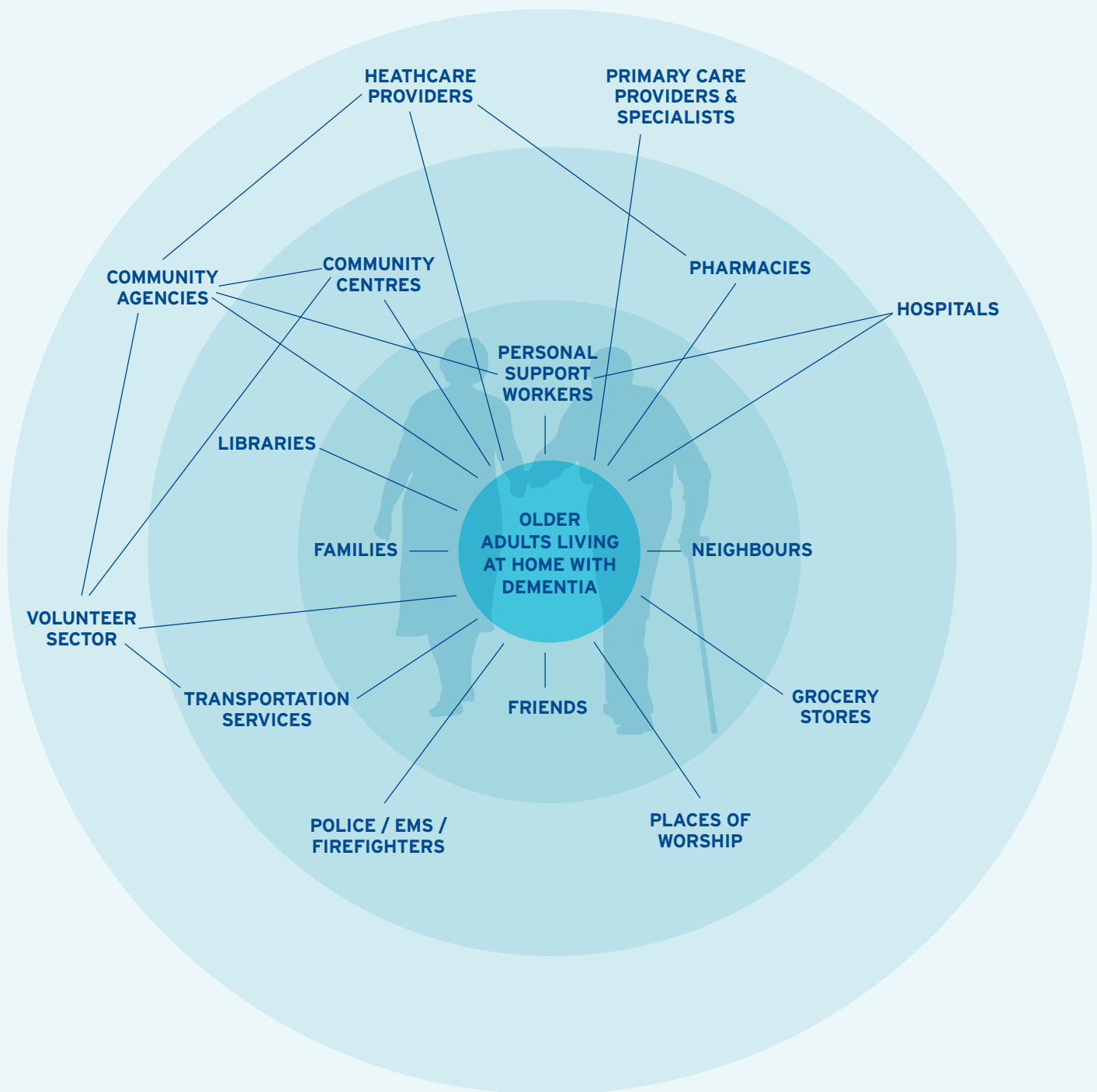
- > People with dementia
- > Caregivers
- > Professionals who directly serve people with dementia
- > Everyone



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# COMMUNITY STAKEHOLDERS



How might we disrupt the current care and service landscape by delivering an unexpected solution for older adults aging at home with dementia?



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