Familiarity, Autonomy, and Safety Together (FAST)

a program for adults with dementia and their family caregivers

EDITORIAL

James Bachmann
University of British Columbia

Familiarity, Autonomy, and Safety Together (FAST) is a program idea for adults living with dementia and their family caregivers. FAST has been developed specifically for public libraries, but other types of libraries and organizations can also implement this program[1]. Further, while FAST is aimed at adults with dementia and their family caregivers, others for whom the program is suitable may also attend. This may include people with conditions resulting in temporary or permanent symptoms similar to those of dementia (e.g., certain types of brain injuries or cognitive impairments) and their family caregivers, as well as family members or friends of people with dementia (or similar) who would benefit from the caregiver portion of the program despite not being a (primary) caregiver.

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FAST consists of multiple activity stations, each with a different theme, that people living with dementia are free to move about and participate in (or not) as they choose, while caregivers are given an opportunity to interact with each other while still being readily available to assist their loved ones if needed. As will be expanded upon below, the acronym FAST is based on the following four concepts that are key to supporting people living with dementia:

Familiarity: Familiarity comes in a variety of forms, including through memory items and practicing previously developed cognitive and physical skills, the familiarity of the sense of autonomy, and the familiar presence of family caregivers.

Autonomy: People living with dementia are free to move around multiple activity stations as they wish, deciding whether, when, how, for how long, and at which stations they will participate.

Safety: The presence of family caregivers, the activities, and the physical space allow people living with dementia to move around and participate in a way that is safe.

Together: People living with dementia and their family caregivers are together in the same space, and people living with dementia participate together with staff and fellow program participants at each station.

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1 Other types of organizations that could implement this program include community centres, non-drop-off adult day centres, and support groups seeking to simultaneously provide services for both people with dementia and their caregivers. The portion of the program designed for people with dementia could be implemented without the accompanying caregiver portion at, for example, residential care facilities and drop-off adult day centres.

Target Client Group

Primary: People living with dementia

Almost 50 million people around the world are currently living with dementia, with over half a million living in Canada (Alzheimer Society of Canada 2022a; Government of Canada 2017) and over six million living in the United States (Alzheimer's Association 2022). While dementia is not restricted to the older population, in Canada approximately 7 percent of people aged 65 and older are currently living with dementia (Government of Canada 2017) and in the United States approximately 11 percent of people aged 65 and older are currently living with dementia (Alzheimer's Association 2022). Dementia is an umbrella term for a variety of similar diseases, many of which are progressive and of which Alzheimer's disease is both the most well known and most common (Mayo Clinic 2020a, 2020c). While symptoms of dementia can vary depending on the specific type of dementia and its degree of progression, common symptoms include memory loss; decreased focus and attention; difficulties communicating; difficulties with vision and spatial navigation, coordination, and cognitive tasks such as planning or problem solving; and psychological changes such as changes in personality or onset of depression, anxiety, agitation, hallucinations, and similar (Mayo Clinic 2020a, 2020c). The progression of dementia is typically grouped into seven stages according to the Global Deterioration Scale (Reisberg et al. 1982), and these stages are themselves often grouped into three broader stages of dementia: early, middle, and late (Alzheimer Society of Canada 2022b; Alzheimer's Society 2021). The typical symptoms in each stage vary by the type of dementia and can also vary by individual.

The safety of the person with dementia is often a primary concern, due to the symptoms described above, and the increased control exerted by family members and other caregivers over the person with dementia leads to a loss of autonomy for that person (Berry, Apesoa-Varano, and Gomez 2015; Dworkin 1986; Mayo Clinic 2020b; Moyle et al. 2011). However, involvement in various types of activities can help improve a person with dementia's sense of autonomy, and people with dementia are more likely to participate in activities that include a sense of familiarity (Phinney, Chaudhury, and O'Connor 2007; Smebye, Kirkevold, and Engedal 2016).

These ideas of familiarity, autonomy, and safety underlie dementia villages, a recent development in residential care facilities for people living with dementia. The first of such villages, Hogeweyk, opened in the Netherlands in 2009, and the first in Canada, The Village, opened in 2019 (CBC News 2019; Haeusermann 2018). These villages are set up so that residents are free to move around the village as they please while remaining safe, and include a variety of amenities such as restaurants, theatres, stores, cafes, and parks, as well as opportunities to take part in various activities. Some villages, such as Hogeweyk, include different styles of housing so that residents can live in a housing and cultural environment that most resembles that to which they were previously accustomed. Given the numbers of people living with dementia and their needs, libraries would do well to increase services for these patrons that follow the dementia villages model of focusing on familiarity, autonomy, and safety, as discussed below.

Secondary: Family caregivers

Family caregivers of people with dementia are non-professional, non-paid caregivers who provide care due to a personal connection with the care recipient, such as being a family member or close friend. Family caregivers are often the spouse/partner or adult child of the person with dementia, but may

also be children-in-law, siblings, grandchildren, friends, or other relatives or non-relatives (Bressan, Visintini, and Palese 2020). There are various reasons that someone may provide non-professional, non-paid care for a person with dementia, including love, a sense of fulfillment, a sense of duty, guilt, societal pressures, and cultural norms (Brodaty and Donkin 2009).

While many family caregivers of people with dementia experience positive impacts from caregiving (e.g., enjoying time spent together, personal growth, sense of accomplishment), negative impacts are also common. Family caregivers often suffer from burnout and an assortment of related problems, including depression, anxiety, fear, stress, frustration, resentment, social isolation, problems with physical health, financial difficulties, and concern about the future (Brodaty and Donkin 2009; Lindeza et al. 2020). For example, some studies suggest that rates of depression among family caregivers are as high as 85 percent and rates of anxiety are as high as 45 percent (Brodaty and Donkin 2009).

Family caregivers suffering from negative impacts of caregiving can benefit from support groups that help reduce social isolation, provide support and information, improve coping abilities (with regard to both caring for the person with dementia and improving the balance between caregiving and the caregiver's own needs), and increase sense of hope (e.g., hope that the situation will improve, or at least not get worse, through appreciating a realistic possibility of mitigating these negative impacts) (Alzheimer Society of British Columbia 2023; Bressan, Visintini, and Palese 2020; Duggleby et al. 2009). Libraries can provide such support in connection with supporting people with dementia by developing programs that simultaneously support both people living with dementia and their family caregivers, thus increasing the positive impact of libraries through a single program[2]. Additionally, this combined approach allows family caregivers to receive support even in situations where they might not otherwise be able to due to their caregiving responsibilities and resulting lack of available time.

Overview of Existing Library Programs and Services

Numerous library programs and services currently exist in support of people living with dementia and/or their family caregivers. One of the most well known of these is the program Memory Cafes. Memory Cafes also began in the Netherlands, in 1997, can be held at libraries or elsewhere (e.g., residential living facilities), and offer opportunities for people living with dementia and their caregivers to socialize, participate in activities, and receive dementia-related educational information (Charbonneau and Rathnam 2020; Memory Cafe Directory 2023). While the exact way Memory Cafes run can vary, they involve both people living with dementia and their caregivers participating together in a predetermined activity (Goyer 2022; Memory Cafe Directory 2023).

Other library programs aimed at people with dementia include TimeSlips, in which people with dementia create impromptu stories inspired by stock photographs; Tales and Travels, in which librarians use various supporting materials to take participants on an imaginary trip to a real location; and the use of memory boxes, which are filled with items aimed to trigger memories and at a minimum stimulate interest and curiosity (ACT on Alzheimer's 2018; Witteveen 2017). More common or widespread library programs can also be used specifically for people with dementia, such as story times, crafts, movies,

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2 In developing such programs, libraries should keep in mind that not all caregivers will be interested in the same types of programs and should consider the numerous factors that affect the likelihood of caregivers participating in such programs (Alzheimer Society of British Columbia 2023; Martindale-Adams, et al. 2016).

and games (ACT on Alzheimer's 2018; Witteveen 2017). Library programs can also be aimed specifically at caregivers, such as educational programs on topics related to dementia and caregiver support groups (ACT on Alzheimer's 2018).

Library collections can also support people with dementia and their caregivers. Such collections include educational materials for caregivers and materials specifically for people living with dementia, such as fiction books that are short with easy-to-follow plots, nonfiction books on local history written in an easy-to-follow format, books with lots of colorful images, and music and movies in a variety of formats (ACT on Alzheimer's 2018; Mortensen and Nielsen 2007). Further, training for library staff on how best to communicate with and support people with dementia, and supportive and safe physical environments, are part of the way libraries help better meet the needs of people with dementia and their caregivers (ACT on Alzheimer's 2018; Mortensen and Nielsen 2007; Witteveen 2017).

Overview of FAST Program

The FAST program is based on the needs and interests of adults with dementia and their family caregivers. However, others for whom the program is suitable (e.g., people with certain temporary or permanent cognitive impairments and their family caregivers, people who have a close relationship with someone with dementia but do not have a caregiver role) may also attend. While the program is primarily intended for people with dementia and their family caregivers to attend together, both people with dementia who are able and family caregivers may attend separately. Professional caregivers should also be permitted to attend when accompanying someone with dementia so that the person with dementia may take part in the program, or independently for the purpose of providing education, support, and advice to family caregivers (or receiving such things to the extent useful and relevant).

The program should be held in a room or similar at the library or elsewhere where there is sufficient space to set up multiple stations for people with dementia, a quiet area with comfortable seating for people with dementia to relax and get away from noise and other stimulation, and a section for caregivers. The amount of space needed will vary depending on the number of program participants and stations[3]. The space should be, or should be adjusted to be, suitable for people with dementia. This includes clear signage with strong contrast between the words and background; markings on any glass doors; good lighting that is consistent and avoids particularly bright, dark, or shadowy areas; flooring that is not shiny or slippery; furniture that is plain (e.g., avoid stripes and strong patterns), traditional and easily recognizable (rather than more modern or unique designs), and is of a colour that contrasts with the walls and floors so as to be more easily seen; sufficient space between furniture so that people can easily move around; removal of any tripping hazards (e.g., floor mats, wires); and family or universal washrooms so that caregivers can comfortably assist if needed[4].

Stations should be set up around the space at sufficient distance from each other so that they are clearly separate and distinct from other stations, and each station should have a library staff member or volunteer to run the station and

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3 In determining the quantity and physical layout of stations, it is important to consider cognitive load, levels of stimulation, and other impacts on people with dementia. For a general overview of such issues, see, e.g., Barrett, Sharma, and Zeisel (2019).

4 There are numerous resources available that provide more information on creating dementia-friendly physical environments. See, e.g., ACT on Alzheimer's (2018), Alzheimer's Society (2020), Social Care Institute for Excellence (2020a), and University of Worcester Association for Dementia Studies (2019).

assist patrons. Stations should have different themes, ideas for which can come from other programs for people with dementia as well as program participants themselves. Themes could include memory items of different types, such as technologies from the past or pictures of the way neighborhoods used to look (keep in mind the ages and cultural backgrounds of program participants when choosing such items), arts and crafts, exercise, games, puzzles, and story time, among many others. Attention should be paid to the particular interests and needs of program attendees. For example, if someone used to enjoy carpentry, a station that uses these sorts of skills might be a good choice.

In determining the needs and interests of attendees, keep in mind that people living with dementia may have difficultly remembering and/or communicating their needs and interests, and that their ability to remember and communicate may fluctuate. To the extent possible, learn about these needs and interests from the people with dementia themselves by asking them directly. The best way to communicate with someone living with dementia will depend on the individual and the stage of dementia. For example, as dementia progresses, communication may need to occur in person using short, easier-to-understand questions (for example, What is your favourite hobby? Do you like to paint?)[5] Other ways of learning about these needs and interests can also be employed. For example, ask family caregivers or observe the people living with dementia when they are participating in program activities or other times they may visit the library and make note of what their interests seem to be. If asking family caregivers, be sure to do so in a way that does not belittle, patronize, or overtly exclude the person living with dementia. For example, discuss this topic when the person living with dementia is not present or communicate via email or by using a survey. Also keep in mind that people's interests may change over time and that people who are no longer able to participate in an activity the way they used to may become frustrated (Social Care Institute for Excellence 2020b; University of California San Francisco Weill Institute for Neurosciences Memory and Aging Center 2023).

In addition to suggesting station themes, participants (both people living with dementia and their caregivers) should be allowed to contribute items, either permanently or temporarily, to stations for use during the program (which may be particularly relevant for memory-based stations). Consideration should also be given to how best to support people living with dementia, including consideration of different stages of dementia, when choosing station themes and specific activities.

People with dementia should be allowed to move around the space freely, participating at any station of their choosing (or not participating at all) in the way that they would like and for the duration that they would like, moving on to other stations as they choose. By allowing people with dementia to move about freely in a safe environment, these patrons will both have and appreciate a greater sense of autonomy.

At one end of the room (or in a similarly separate yet present area), a space should be set up for caregivers. This space should allow caregivers to interact with each other while still being readily available to assist their loved one with dementia if needed. Caregivers should be provided with refreshments and offered the opportunity to socialize with each other and/or participate in programming as desired. Programming for caregivers could include support groups, educational speakers or materials, or simply a chance to relax. The exact programming for caregivers should be based on the needs and desires of the attendees. Such needs and desires can be determined in various ways, including

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5 For more information on communicating with people with dementia see, e.g., Alzheimer Society of Canada (2023) and Alzheimer's Association (2023).

through pre- and post-attendance surveys, informal conversations with attendees while attending the program or at other times, and adding a reflection discussion to the end of each program session that allows attendees to share their thoughts on the usefulness of that session and what they would like to do in future sessions. Professionals with experience supporting family caregivers could also be consulted to provide suggestions for useful programming ideas that the caregivers themselves may not have considered.

The FAST program can be held as frequently or intermittently as demand and resources dictate. Additionally, a modified version of the program that includes only the component for people with dementia could be brought to patrons who are unable to make it to the library or other location by setting up stations temporarily in, for example, a residential care facility.

Budget

Costs for this program can vary significantly depending on factors such as the availability of space and resources for the stations and the extent of marketing. Importantly, if budget is a concern, this program can often be held at little or no cost beyond that already included in the library budget. For example, stations can be staffed by librarians and others already employed by the library and/or by volunteers (although ideally people contributing their time should be paid); materials for stations can be obtained for little or no cost through donations (either permanent or temporary) by program participants or other library patrons, by using items the library already has in its collections, and by bargain hunting at vintage or antique stores; and marketing can be limited to low- or no-cost options.

While this program can be held for little or no cost, potential sources of significant expense include renting or modifying existing space; expanding dementia-relevant collections; hiring consultants with relevant expertise to develop the space or stations, train staff, or develop programming for caregivers; hiring additional staff to run each station; and hiring speakers to give educational talks for caregivers.

Conclusion

The FAST program allows public libraries to meet the needs of adults living with dementia and their family caregivers by expanding upon existing programs in a way that best supports both of these patron groups. Through FAST, people with dementia can experience an often-lost sense of autonomy while participating in suitable activities that can even help slow the advancement of their disease, all in a safe and supportive space with their caregivers nearby. Simultaneously, family caregivers can receive support and a sense of community while remaining available to their loved one living with dementia.

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