

# Integrated Community Support for People with Dementia

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## Abstract

**Objectives:** Based on Scotland's eight pillar model of support for people with dementia, this paper proposes a model which leverages on community resources to provide integrated support for people with dementia. This paper explores the applicability of an integrated model of community support for people with dementia in the case of Singapore, a nation facing the double jeopardy of increased number of people with dementia and increased proportion of Singaporeans with limited or no family support.

**Methods:** Data collection for this study was drawn from 20 in-depth interviews, consisting of ten caregivers, six care professionals and four subject-matter experts. In addition, a review of Scotland's eight pillar of community support for people with dementia was conducted and the applicability of the model in the Singapore context was assessed. Comparative analysis was conducted between the information gathered from the care professionals and the Scotland model. Using the information gathered and analysis done, a ground-up model of integrated community support for people with dementia is proposed.

**Results:** The proposed model of integrated community support for people with dementia includes medical care but focuses on non-health aspects - care coordination, public education, assistive technology, caregiver support, funding, building and design and leverages on community support.

**Conclusion:** The proposed model encourages and supports the creation of a dementia inclusive society allows people with dementia to age in place. With integrated community support for people with dementia that is supported by the community, health care cost and caregiver's burden can also be reduced.

**Keywords:** Integrated community support; Dementia; Caregiver

## Introduction

Dementia is a progressive cognitive decline and representing, as its Latin origins suggest, a departure from previous mental functioning [1]. Dementia affects the mental abilities of a person which then leads to failing memory and personality changes. Other intellectual functioning such as communication and language, ability to focus and pay attention, reasoning and judgement, and visual perception can also be affected [2]. The nature of the symptoms means that people with dementia (people with dementia) are more dependent as they have difficulties in coping with activities of daily living in the latter stages [3].

According to Alzheimer's Disease International, there are 50 million people with dementia worldwide in 2018. In Singapore, a study led by the Institute of Mental Health in 2015, had found that one in 10 people aged 60 and above may have dementia, and by 2030, it is projected that one in every five people aged above 60 will suffer from dementia [4].

Singapore faces the challenge of a rapidly ageing population. There are now fewer working-age adults to support each older adult, aged 65 years and above. Singapore's resident old-age support ratio has fallen from 7.6 in 2008 to 4.8 in 2018.

As such, integrated community support for people with dementia in Singapore is important, especially in a nation facing the double jeopardy of an increased number of people with dementia and an increased proportion of Singaporeans with limited or no family support (i.e. singles, childless couples, widows, and those with caregivers who are busy with multiple roles). According to the Department of Statistics Singapore in 2017, the number of household heads aged above 65 years old who live without their children has exceeded those who live with children [5]. Furthermore, the number of household heads aged above 65 years old who live alone has almost doubled, as compared to 2007. A stimulation study showed that there will be more people with dementia

without family support and thereby making it infeasible to live at home [6]. When family support is inadequate, community support becomes even more pertinent in assisting people with dementia to age in place.

## Integrated care

Like most integrated care, integrated community support for people with dementia is underpinned by similar principles of seamless care coordination and continuity across services, joint decision making and on-going monitoring of the people with dementia [7,8]. Integrated care is designed to be responsive to the changing and complex needs of people with dementia [9-11]. In addition to health and medical support, integrated community support for people with dementia requires emotional and practical support for both the people with dementia and the caregivers. Integration can take place at different levels, such as integration of support structures (referring to the working practices of institutions) and support staff (referring to multi-disciplinary teams offering different aspects of care for the people with dementia).

As compared to care services provided in a more fragmented, rigid and task-oriented manner, integrated care enables the most appropriate expertise, resources and skills to be delivered at the right juncture whilst maintaining the dignity of the people with dementia [12-14]. Integrated community support for people with dementia is

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also effective in reducing behavioral issues, and in improving the mood of people with dementia [15,16].

Integrated care is underpinned by the principles of care continuity, co-ordination within and across services and joined-up decision making [17]. The objective is to deliver care in a responsive way, facilitating seamless care provision and allowing for the on-going monitoring of needs into older age [18]. Integrated care has been interpreted in many different contexts-referring to multi-disciplinary teams, cross-institutional service provision and the related health, social service and related systems in which organisations operate in [19].

Singapore implements the Regional Health System (RHS) model across the nation and the CARITAS Integrated community support for people with dementia model in the northern region of Singapore [20]. In fact, the integrated care model for elderly patients is evolving [21]. The latest is the "Integrated general hospital" model, which places the elderly patient under the care of the same team from admission to discharge and under the same hospital, instead of moving the patient from an acute hospital to a community hospital for rehabilitation.

### **Current initiatives-integrated community support for people with dementia**

In Singapore, there is an increased focus in drawing support from the community to build dementia-friendly communities by training businesses and service staff in the community to keep a look out for people with dementia and assist them [22]. For instance, if bank staffs find suspicious money withdrawals, they could be on the alert to detect the possibility for people with dementia being cheated. Trained students and volunteers also patrol the town regularly, identify distressed people with dementia and bring lost people with dementia to designated centers (known as "go-to-points") for their safety and return to their families.

The Mental Health General Practitioner Partnership Programme supports and trains general practitioners to assess and treat mental health conditions in their clinics that are based in various neighbourhoods across Singapore [23]. These general practitioners could then better coordinate the dementia care for the people with dementia and even provide caregiving support for caregivers of people with dementia. Effectively serving as the care coordinator for the people with dementia, the general practitioners could refer their patients with dementia to the hospitals, transitional care service, Agency of Integrated Care (national agency which coordinates care arrangements) and the allied health-led community intervention team when necessary.

Tie-ups between hospitals and polyclinics have helped to reduce cost of an average of SGD 6700 (approximately USD 4900) a year as patients require fewer hospital visits [24]. Caregivers are also less stress as people with dementia are better supported to continue living in the community.

### **Integrated community support for people with dementia vis-à-vis integrated care**

A distinctive feature of the integrated community support for people with dementia model is the inclusion of non-health aspects and the drawing of support from community resources. The aim is to enable the person with dementia to age with dignity in the community as far as possible. The integrated community support for people with dementia model includes hardware support such as building and design of houses and public areas, transport infrastructure and assistive technology. It also includes software support such as services and programs, training, information and resources, community support.

As persons with dementia can live within the community and need not heavily rely on medical and institutional support, it is appropriate for the integrated community support for people with dementia model to be inclusive of non-medical and non-health aspects.

### **Methodology**

With the view of understanding how community can be integrated to effectively provide support, data collection for this study was drawn from 20 in-depth interviews, consisting of ten caregivers, six care professionals and four subject-matter experts (including a medical doctor, an academic and two staff involved in program initiatives, policies and research related to support for people with dementia in Singapore).

In addition, a review of Scotland's eight pillar of community support for people with dementia was conducted and the applicability of the model in the Singapore context was assessed [25]. Comparative analysis was conducted between the information gathered from the care professionals and the Scotland model. Using the information gathered and the analysis done, a ground-up model of integrated community support for people with dementia is proposed.

The Scotland eight pillar model of community support for people with dementia was chosen for comparison because it is one of the most established model of community support for people with dementia [26]. The aims of the eight-pillar model are similar to the aims of the initiatives in Singapore, which are to enable the people with dementia to live independently within the community and reduce caregiver burden. It is therefore an ideal model for the purposes of our study in assessing how Singapore compares to Scotland in providing support for people with dementia and their caregivers, and also adapt good learning points from the model to fill any possible gaps and shortcomings that existing services and programs may have.

For the interviews, thematic analysis was used to interpret the experiences shared, find common themes and distil the narratives to identify the unmet needs and challenges beyond what is expressed [27]. *Priori* codes were listed after the transcribing. Next, open coding was done by going through the transcripts in detail with markings and notes made on the transcripts. The codes were then consolidated into a coding frame to list major codes and associated codes. Following which, a hierarchical coding tree was drawn to sequence the codes based on the flow of the idea, from a major category to associated codes. After the hierarchical coding, relationships between codes were identified and connected in the form of axial coding. Selective coding was then used to identify the core concepts that emerged and these core concepts were further strung and refined into themes.

### **Literature Review**

The Ministry of Health Singapore has drawn several guidelines and service requirements for home-care services and the requirements for community dementia care service [28,29]. There are also other international standards to adopt, such as Alzheimer's association Dementia Care Practice Recommendations 2018, which provides recommendations for quality care practices [30].

In Western countries, case studies and models of integrated community support for people with dementia are well documented [9,17,31-33]. Similar in concept to the Scotland model, these models show how one aspect of dementia care (i.e. diagnosis to treatment and residential care) can be seamlessly coordinated. These models are uniquely designed and adapted to suit specific contexts.

While there are several established models of integrated healthcare in Singapore a national model of integrated community support for people with dementia that is specifically designed for people with dementia is not yet available in Singapore. In fact, the Bupa and ADI joint report on worldwide dementia care reported that over 90% of older adults with dementia in Singapore, live at home [34]. As the majority of people with dementia in Singapore live within a community of other Singaporeans who do not suffer from dementia, the latter can offer assistance to people with dementia. In addition, other non-human resources (i.e. technology, building and design) in the community can also be adapted to support people with dementia' aging in the community.

A successful integrated care system must overcome challenges such as conflicting agendas, different working styles and expectations [20]. The integrated system must be adaptive to emergent issues and unexpected situations. As a starting point, we can learn from the evaluations and reviews of existing integrated health care models in Singapore and in other countries, to improve and adapt them into a model that is specifically for people with dementia.

## Discussion

Living in the community means that needs extend beyond healthcare, people with dementia will also need support in their everyday living, such as transportation, banking and finance. The proposed model of integrated community support for people with dementia includes medical care but focuses on non-health aspects-care coordination, public education, assistive technology, caregiver support, funding, building and design and leverages on community support. The integrated community support for people with dementia model consists of five clusters-medical and health care, community support, assistive technology and design, programs and services, infrastructure (Figure 1).

### Medical and health care

Alzheimer Scotland was commissioned by the Scottish government to provide principles and recommendations for dementia care [35]. In their guideline "Transforming specialist dementia hospital care", they have recommended the need for a multi-disciplinary advance dementia specialist team, especially when those in advance dementia stage may exhibit aggression, self-harm and extreme uninhibited desires. The need for a multi-disciplinary team for evaluation and planning of patient's needs was similarly emphasized in other studies [36-38]. People with dementia benefit from better care services and care professionals can have higher confidence in managing the symptoms of people with dementia.

There should also be greater emphasis on the diagnosis and management of persons with dementia in the curriculum of local medical schools. Ideally, the doctor attending to the person with dementia for the periodic review at public hospitals should be the same doctor. This is because the care management of the person with dementia requires a holistic understanding, which includes their life history, personality, family profile for example.

Doctors attending to persons with dementia should be able to converse in the language of the person with dementia as some caregivers shared in the interviews that the translation by the nurses are not quite accurate. More local nurses who can also converse in mandarin and the dialect of the person with dementia should be stationed at dementia wards to minimize distress associated with communication barriers.

### Community support

To create a more inclusive society, the community development councils, the people's association of Singapore and other community group can organize dementia-friendly events, in collaboration with existing special interest groups such as photography, gardening and nature walks. More public contact staff, such as staff at the information counter of shopping malls, food and beverage service staff in the neighborhood and public transport staff can also be trained to be ambassadors to assist person with dementia.

In view of future demographic changes whereby there will be more singles, childless couples, and people with alternative sexual orientation, a possible care model in the community is to have a care professional stationed at the block or at the same floor level and be a shared resource. The lack of familial caregiving support for these profile groups may lead to higher institutionalization or premature institutionalization if community support is insufficient.

### Public education

Public education helps caregivers understand and cope with the behaviors of a person with dementia. Public education also increases awareness and understanding of dementia for the general public, in order to reduce stigmatization of people with dementia [39,40]. Increased awareness can help in early detection and treatment of dementia, to promote cognitive functioning and independence among older adults [41,42]. Public education of dementia can be effective if dementia is pitched as a prevalent condition through other forms of media, so that the public will not find dementia as a distant condition, but one that can affect their family [43].

The public can be educated on how to relate to, and assist persons with dementia through drama serials, national campaigns and social media. Public education should start from a young age to be effective. Talks can be conducted in school to help children understand and accept behaviors exhibited by people with dementia. The content of these educational talks on dementia can be progressive. For instance, the lower graders can be educated on what dementia is and understand the behaviors of a person with dementia, while the higher graders can be educated on how to assist and relate to people with dementia. As a national incentive, the government can fund associations to produce creative media to be used during these school talks.

### Assistive technology

Various types of gadgets are available to help people with dementia live independently and to ensure their safety. The Alzheimer's Society and alzheimers.net have provided a list of assistive technology for people with dementia [44,45]. While the use of assistive technology is gaining strong traction, concerns on the use of assistive technology are concurrently raised [46]. Assistive technology may be helpful for people with dementia but there are concerns such as restricting the autonomy of people with dementia and intruding into their privacy [47]. To allay ethical concerns, some Alzheimer groups, such as Alzheimer Europe and the Alzheimer's Society had suggested some ethical considerations in the use of technology for people with dementia [48,49].

Regulations should also be drawn to assure the quality of assistive technology. Person with dementia should have access to a range of proven technologies by providing them with informative materials and subsidies. Through government initiatives and funding, Singapore can set up a dedicated team to develop assistive technology for persons with dementia.



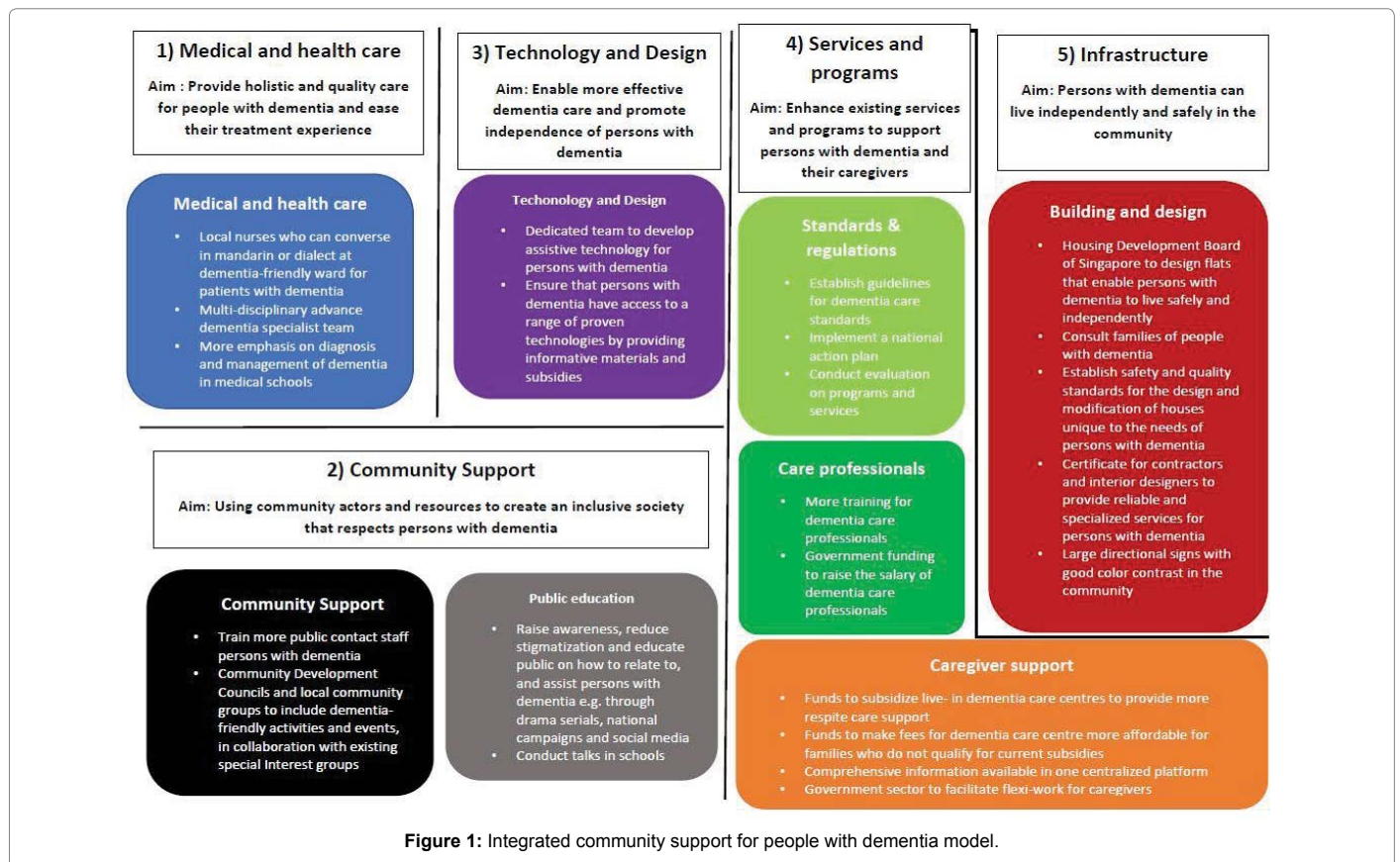


Figure 1: Integrated community support for people with dementia model.

At the moment, different private companies may have vested interests and proprietary rights. Most private technology firms are not yet sharing their application programming interface to allow seamless connection of different company products. With some government regulations and standardization, technological devices which are able to connect across all “internet of things” platforms will make assistive technology available for all. The cost will also be reduced with the critical mass of users.

### Services and programs

**Caregiver support:** The burden of care and stress in caring for people with dementia and the negative psycho-emotional well-being and physical health of caregivers are well-researched [10,50-54]. Of note, is the practical need for financial support in dementia care. In a 2015 presentation on “Dementia Care in Singapore”, we learned that dementia care is costly [55]. Even with government subsidy, the average cost of dementia care is approximately SGD 800 (approximately USD 586) per month. This is a hefty amount, compared to the average monthly household income of SGD 5000 (approximately USD 3670). Dementia care cost is significant and found to be a main stressor of caregivers [56]. The estimated total cost of dementia in 2013 was SGD 532 million (approximately USD390 million) and the estimated annual cost per people with dementia was SGD 10,245 (approximately USD 7500) per year [57].

The Bupa and ADI report recommends that the government budgets funding into three separate baskets for people with dementia, “funding for health care”, “funding for social care” and “funding for other issues”. While government funding focuses on health care and social services, familial caregivers require more financial support if people with dementia are to age in the community. “Funding for

other issues” should thereby include funding for assistive technology, transportation, innovation and research, development into this area and also program evaluation.

As one of the main struggles of caregivers is the juggle between work and caregiving commitments, the Singapore government introduced the Work-Life Grant in 2013 to fund companies to offer flexible work arrangements to staff.

In the interviews, caregivers shared their frustrations on the lack of leave as they often spend all their leave on their loved ones with dementia (e.g. emergencies at home, medical appointments). The government sector can set an example by allowing flexi-work for caregivers of person with dementia and offer more eldercare leave for caregivers. In addition to flexi-work arrangements, ministries, statutory boards and agencies under the government sector should practice “whole of government” effort where caregivers can be transferred to a job (within the same organization or in other government organizations) nearer to where their family members with dementia are residing or where their daycare centre is situated.

On the home front, an easier application process and higher subsidies for families who need to employ foreign male domestic helpers should be considered for males with dementia. Home-dwelling people with dementia should be able to tap on neighbors for support. Resident committees can organize sharing sessions, especially during community events so that families of people with dementia can share their journey with their neighbors and seek support to help and look out for their loved ones with dementia.

Through the interviews, caregivers expressed the need for more information on resources and services to be made available. A caregiver

who was interviewed shared that the current websites and apps provide generic information which she can easily obtain online. Caregivers feedback that a more comprehensive list of applicable services for people with dementia and information on funds, rebates and subsidies can be made available on one centralized platform, such as the Agency of Integrated Care website.

**Dementia care centre:** Based on the information gathered from the interviews, caregivers are most in need of respite care. Apart from day care centres, there is a need to make respite care more affordable and available. Respite care for persons with dementia are often at nursing homes, which is subjected to availability of beds at the time of travel or holiday for the caregivers. Nursing homes reportedly could not project the availability of beds in advanced, hence caregivers could not plan their holidays ahead and often have to rotate overseas travel plans amongst family members, rather than travel together. For those who do not have enough family support for the “rotation”, overseas travel is almost impossible.

Financial support from the government to raise the salary of dementia care staff and subsidize training is needed. Care professionals interviewed shared that the turnover rate at dementia care centres is high due to the low salary and lack of career advancement opportunities. Care professionals had also feedback that they would like to be given more training opportunities to be updated on new and innovative ways of managing and assisting persons with dementia.

Dementia day care centres in Singapore offer a good variety of activities. On top of these activities, people with dementia can be given duties such as setting the table for lunch and tea-breaks. Their participation and contribution will boost their self-esteem. Activities and “toys” at the centres can also use more age-appropriate images. Jigsaw puzzles can use familiar images for reminisce and also offer different levels of difficulties. The use of tablets for brain gym activities is also encouraged.

### Building and design

Lastly, in the field of building and design of communities and facilities for people with dementia, studies in western countries are readily available [58-61]. These studies have proposed evidence-based designs to ensure safety and accessibility for people with dementia in public areas, buildings and residential care. Some of the common suggestions include barrier-free walkways, bright lighting, clear contrasts and well-placed signages. These practical designs are particular useful for people with dementia as their visual judgements and sense of perception may be affected by dementia.

The Bupa and ADI report recommends that any integrated community support for people with dementia model should consult people with dementia, caregivers and care professionals, so that the model is applicable and useful in meeting their needs. In addition, a key national figure should champion the national dementia plan or strategy by endorsing it and by recognizing that community support for dementia is important.

The Building and Construction Authority in Singapore and the Housing Development Board in Singapore should consult families of people with dementia to provide more suitable regulations and designs for housing for people with special needs. Based on the feedback gathered through the interviews, the authorities can establish safety and quality standards for the design and modification of houses unique to the needs of the person with dementia and issue certificates for contractors and interior designers who provide reliable and specialized services for person with dementia.

Building plans should take into account projected figures of people with dementia so as to cater to the rising need, and also take into account the needs at the various life stages of Singaporeans. For instance, the 30-year lease one-room flats should factor the need for a foreign domestic helper if the senior couple is unable to perform a few activities of daily living independently or are too old to support one another in future. In view of such scenarios, providing another smaller room that is sufficient to house the foreign domestic helper will be more suitable than a studio apartment.

Apart from testing smart living houses in new flats for younger couples and families, smart living houses should also be tested and installed for flats of elders and people with dementia. In public places, large directional signs with good color contrast should be placed in the community e.g. at shopping malls, void decks.

### Recommendations

This study has identified some existing gaps and has proposed ways on how integrated community support can fill these gaps and meet the needs of people with dementia. However, the feasibility and effectiveness of the proposed model and suggestions can only be better assessed when applied, and then evaluated by future studies. This study also recommends a deeper understanding on the infrastructural requirements and technological developments needed, by seeking experts in these fields. It is further recommended that inputs from policy makers are included to understand any possible resources and budget constraints at the national level and the sustainability of this model from the health economics and political perspectives.

### Conclusion

Singapore is an ideal country to operationalize the integrated community support for people with dementia model as we are a relatively smaller country with a smaller population size. With community support for people with dementia and by integrating various aspects (environmental design, infrastructure, technology, training, caregiver support, social services and programs), people with dementia are better supported to live in an inclusive community. We build a society that offers help more readily to people with dementia and reduce the reliance on institutionalization. A dementia inclusive society allows people with dementia to age-in-place. Persons with dementia can be safe and secure when moving around the environment. With integrated community support for people with dementia that is supported by the community, health care cost and caregiver’s burden can also be reduced.

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