

# Successful Digitalisation Pathways

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# Carer Matters: Hospital to Home Care for the Caregiver

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Carer Matters offers a caregiver-centric approach to meet the unique and dynamic needs of caregivers of older persons during their adjustment from hospital to home, promoting both their well-being and ability to thrive at home.



## Key Points

- Family caregivers bear the brunt of responsibilities to deliver long-term care for their loved ones, a key factor that facilitates ageing-in-place in the community.
- However, specific support for caregivers' personal needs remains inadequate due to a patient-oriented ecosystem of health and social care.
- To meet Singapore's greying population and concomitant healthcare and social needs, its transformation of population health should embrace approaches that deliver greater support for caregivers, ensuring families can provide sustainable care for their loved ones.
- Carer Matters is a caregiver-centric hospital-to-home programme that holistically screens, identifies, and provides targeted interventions to meet the needs of caregivers of older persons.
- Early feedback and findings of the programme have been positive, demonstrating the value of integrating a caregiver focus into the healthcare systems delivering dyadic support for both the care-recipient and their caregiver.

Singapore's population is rapidly ageing, and this demographic shift has profound implications for the nation's health and social care needs. It is anticipated that in 2030, one in four Singaporeans will be aged 65 or older, with over 900,000 seniors, a rapid increase from its 2015 estimates of 440,000 (Chan 2021). With the increasing prevalence of chronic diseases and limitations on their ability to perform activities of daily living independently, many of these seniors will rely on their family members to provide care to enable ageing-in-place in the community.

Family caregivers form the backbone of the healthcare

system, often shouldering the bulk of long-term care. However, caregivers often assume the demanding role with little formal training or preparation while simultaneously straddling other responsibilities in their personal lives. There is an increasing amount of time spent on caregiving that risks a knock-on effect on the economy, with more time spent on caregiving than on waged labour. Recent estimates suggest that the average time spent caregiving per week is expected to increase drastically by 41%, from 29 to 41 hours by 2030 (Chan 2021). This will disproportionately impact families caring for loved ones with multiple functional limitations,



necessitating intensive around-the-clock care.

Furthermore, caregivers' needs extend beyond understanding their loved one's health condition and the skills to deliver direct care. Their needs are often highly complex and varied across multiple domains: physical, emotional, social, psychological, and financial (Chan et al. 2019b; Ong et al. 2022). Without any assistance or relief, these stressors can manifest as grief, distress, and anxiety, epitomised in the term "caregiver burden" which reflects caregiving's negative emotional, physical, practical, and social impacts. Unresolved caregiver burden is a recipe for future stress on the healthcare ecosystem. One in three caregivers of hospitalised older adults is at risk of depression, anxiety, and a poorer quality of life (Chan et al. 2018; Chan et al. 2019a). Unresolved stress can directly strain the hospital system, with caregiver distress contributing to emergency room admissions of older persons and their increased length of stay (Lau et al. 2021).

While effort has been made to smoothen care transitions through discharge planning, some caregivers still find the flow from hospital to home a frustrating experience. This points towards unaddressed gaps between current services and the assistance caregivers require to navigate the care transition effectively. For instance, caregivers often run into unanticipated problems during the transition home as they readjust their routines and take on new responsibilities to meet their loved ones' post-discharge needs. Realising that the skills taught by ward nurses during discharge may not always be transferable or applicable in the home context, caregivers can feel lost and distressed, unsure of who or where to turn to when these questions arise. This highlights an existing care gap for immediate post-discharge support for caregivers, especially if their loved ones do not possess complex care needs that require close follow-up by community health teams. Instead, such patients and their caregivers often 'fall through the cracks', assumed to be able to self-manage and cope until their outpatient follow-up.

With caregivers playing an indispensable role in supporting older persons, it is vital to ensure that their well-being is protected to allow the delivery of optimal, effective, and

sustainable care. This reinforced the need for caregiver-specific interventions and targeted support beyond basic nursing skills. To help both the caregiver and the older person thrive at home, healthcare systems can provide additional holistic support to address caregivers' psychosocial stress and needs.

### Smoothing the Transition from Hospital to Home

Hospitals provide an important touchpoint where caregivers experience higher stress levels due to the acute deterioration of a patient's condition and may need to acquire new skills to continue caring for patients, post-discharge. Recognising that hospitalisation serves as an opportune time to support caregivers, we established Carer Matters. This is a caregiver-centric hospital-to-home programme to holistically screen, identify and provide targeted interventions for caregivers of older persons hospitalised at TTSH. Carer Matters' suite of interventions are delivered by a team of caregiver support nurses, registered nurses specially trained in the management of older persons and addressing caregiving stress.

Since its establishment three years ago, Carer Matters has supported over 600 caregivers, helping them to navigate the care journey back home. Carer Matters' framework and structure can be described in four key components reflected in Figure 1. More details on the individual interventions provided for caregivers and the mechanisms are discussed in our earlier paper (Chan and Glass 2022). We have also included below some of the findings from a feasibility study we conducted on Carer Matters below. The study elicited feedback from caregivers and relevant stakeholders and revealed programme evaluation findings, using data collected over the programme's pilot from 2019 to 2022. Two case studies of caregivers supported through Carer Matters can be found in Table 3.

#### 1. Identifying and Assessing Caregivers' Needs and Stressors

The identification of caregivers begins when they visit their loved ones in TTSH inpatient wards. Caregivers are approached by the inpatient ward team, such as nurses and ward clerical staff, to communicate the objectives of Carer Matters and its services, directing them to complete an online needs assessment form upon affirming their interest.

Risk stratification methods are essential to identify caregivers at the highest risk of poor physical and mental health outcomes, enabling better triaging into appropriate services and tailoring care. To identify caregivers at risk of distress and burden, Carer Matters uses a locally validated brief screening tool to screen and stratify family caregivers



Figure 1: Carer Networks Framework and Structure

at risk of negative health outcomes (Chan et al. 2019a). The tool is shown in Table 1. Caregivers at risk of stress are then flagged for priority telesupport, detailed below.

Domains	Questions
General information	I am: <input type="checkbox"/> A new caregiver <input type="checkbox"/> A caregiver for some time <input type="checkbox"/> Caring for my care recipient with advanced medical conditions My care recipient has: <input type="checkbox"/> Dementia <input type="checkbox"/> Stroke <input type="checkbox"/> Others: (please specify)
Caregiving burden	1. Do you feel that because of the time you spend with your care recipient you don't have enough time for yourself? 2. Do you feel stressed between caring for your care recipient and trying to meet other responsibilities for your family or work? 3. Do you feel strained when you are around your care recipient? 4. Do you feel uncertain about what to do about your care recipient?
Mastery	1. I have little control over the things that happen to me. 2. There is really no way I can solve some of the problems I have. 3. I can do just about anything I really set my mind to do. 4. Often I feel helpless in dealing with the problems of life. 5. Sometimes I feel like I am being pushed around in life. 6. What happens to me in the future mostly depends on me. 7. There is little I can do to change many of the important things in my life.
Community resources requested	I need information on the following community resources: <input type="checkbox"/> Services to help with the care of my care recipient (transport and escort services, home medical care, home nursing care, home personal care, daycare) <input type="checkbox"/> Financial assistance <input type="checkbox"/> Counselling services <input type="checkbox"/> Respite care services (temporary care services that you can use to take a break from caregiving) <input type="checkbox"/> Support groups (platform to meet other caregivers and learn useful resources and caregiving tips)

Table 1: Caregiver screening tool (Adapted from Chan et al., 2019a)

## 2. Educating and Empowering Caregivers

The entry into caregiving can be abrupt and unexpected. Caregivers are increasingly called upon to deliver complex care, monitor and manage their loved ones' health symptoms, but often possess unmet needs as they lack the information, support, and confidence to perform these tasks adequately. Additionally, caregivers may not be aware of the range of support services for them and their loved ones, posing a barrier to accessing formal support services.



Figure 2: Caregivers Guide

### Personalised resources sent to caregivers

To increase the accessibility to information and education

resources, Carer Matters provides personalised resources to caregivers via email or text messages. Based on their identified needs, caregivers receive a caregivers' guide containing relevant resources such as information on their loved one's condition, community-based services, and financial aid. Some extracts from the guide are in Figure 2. All caregivers referred to Carer Matters have received resources personalised according to their needs, which were automatically despatched upon completing the needs assessment form. Individuals new to the caregiving role were especially appreciative of the list of collated emergency contacts and links to respite care, counselling, and support groups.

### Caregiver training courses

The caregivers' guide also offers recommendations for in-house and community training courses to assist them with caregiving, strengthening their ability to care for themselves and their loved ones. One example is an adaptation of Mount Sinai Hospital's CARERS Programme, which equips caregivers with practical skills and knowledge of their loved one's health condition and management. Such courses enhance caregivers' competence and readiness to handle current and future care needs. A list of these courses is shown in Table 2.

Underpinned by adult learning pedagogies, Carer Matters delivers a range of in-house training courses that adopt a combination of experiential learning and social learning approaches. For instance, caregivers of persons with dementia can learn practical skills to improve communication and better manage difficult behavioural and psychological symptoms of dementia, such as agitation and aggression. During the course, caregivers are also encouraged to share their caregiving experiences, personal tips, or advice with other participants. The recognition of their shared experiences helped to build a sense of interconnectedness and reduce feelings of loneliness and isolation inherent in caregiving.

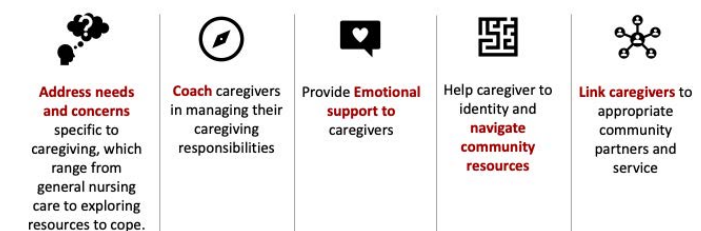


Figure 3: Telesupport

## 3. Supporting the Well-being of Caregivers

It is essential to provide emotional and psychological support to caregivers, which can take the form of telesupport or routine text-based wellness check-ins to assess their current coping capabilities. We do so through our telesupport, as shown in Figure 3.



Training Courses	Courses Description
CARERS (Coaching, Advocacy, Respite, Education, Relationship, Simulation) Programme (Chiu et al., 2013)	A therapeutic group intervention that features a unique hands-on simulation exercise in the presence of a simulated patient to practice the application of problem-solving techniques. The course is co-led by two facilitators and held weekly over eight weeks in small groups of four to six participants.
TEACH Programme	An interactive group course aims to build caregiving skills and provide emotional support for family caregivers. Sessions are tailored to central themes of caregiving (changing relationship, community resource navigation, future planning, self-care).
Understanding Dementia	This course helps caregivers understand dementia, the nature of Behavioural and Psychological Symptoms of Dementia (BPSD) and general approaches to challenging behaviours.
Problem-solving techniques	This course introduces a five-step problem-solving technique adapted from the CARERS programme. This is a group session tailored to help caregivers address practical problems faced (Chiu et al., 2013).
Self-care techniques	This course will help caregivers recognise the importance of self-care and learn practical self-care tips.
Caregiving Essentials	This group course will help caregivers understand more about caregiving and provide practical caregiving tips.
Public forums/Seminars	Seminars are designed to provide generic sought-after information for caregivers, such as financial support availability and home safety.

Table 2: List of caregiver training courses delivered by Carer Matters (Accessible at <http://www.ttsh.com.sg/Patients-and-Visitors/for-caregivers/Pages/Programs.aspx>)

Through the needs assessment, caregivers identified to be at risk of stress will be prioritised for immediate telesupport and proactively contacted and engaged. The caregiver support nurse first obtains a better understanding of their caregiving context, needs, and available resources and subsequently adopts a collaborative approach with the caregiver to problem-solve and explore various care options.

The help rendered includes directing caregivers towards medical or social support services and advising them on the process of navigating community resources, arranging clinic appointments and coordinating with other clinical teams to facilitate access to care services. Caregivers were greatly appreciative of the telesupport and information provided, sharing that it gave them a sense of relief knowing that they were not alone on their caregiving journey and that the nurses were just a phone call away.

#### 4. Strengthening Collaboration and Coordination among Stakeholders

Carer Matters aims to bridge service linkages between healthcare and community care services. Establishing tighter referral processes with other service providers allows

caregiver support nurses to quickly connect caregivers to relevant services or programmes in the community. The caregiver support nurses then assess the caregivers' needs and caregiving context and hand the case to the community partners for long-term follow-up and monitoring.

Carer Matters have also worked closely with TTSH's Central Health's community partnership team to establish eight partnerships with community providers in our region.

#### Impact of Carer Matters

The preliminary successes of Carer Matters have been promising, extending its outreach to caregivers in need beyond the hospital setting. To date, 664 caregivers have been identified and referred to Carer Matters upon completing the needs assessment form. 275 caregivers were identified as at risk of caregiver stress and were contacted by the caregiver support nurses, 74 of whom required longer-term follow-up support by the nurses. Additionally, a total of 27 caregiver training courses have been conducted, benefitting 240 caregivers. 97% of surveyed caregivers reported that the training improved their knowledge of their care recipients' disease, and 99% said the programme addressed their



needs. This shows the value of caregiver-centric training and equipping, strengthening their knowledge and skills for care. Carer Matters has linked several caregivers to community partners' services and connected many caregivers in need with peer support groups.

### Building Towards Family-Oriented Patient Care

The transition from hospital to home can be a stressful and challenging experience for both patients and caregivers. To create a society where seniors can age-in-place and lead empowering and enriching lives, the invisible contributions of

caregivers should not be ignored. Implementing a hospital-to-home service for caregivers like Carer Matters provides an opportunity to transform the caregiving experience and improve patient outcomes, such as reduced readmissions and institutionalisation. Moving forward, Carer Matters can be a building block for establishing dyadic care from the hospital-to-home, designed to benefit both the patient and their caregiver.

### Conflict of Interest

None. ■

#### Caregiver at low risk of stress and burden

Ms H is a caregiver looking after her father with early-stage dementia while juggling her full-time work commitments. While Ms H was initially not found to be at high risk of caregiving stress, she subsequently contacted Carer Matters. She was uncertain how to cope in the future, concerned with the possibility of her father developing wandering behaviour.

The caregiver support nurses provided her with a comprehensive caregiver's guide developed by local community partners on supporting persons with dementia who wander. Ms H was also encouraged to download the Dementia Friends mobile application to access relevant dementia and caregiving resources. Ms H found the resources very helpful.

Through the caregiver support nurse, Ms H found out about various in-house Carer Matters programmes. She attended most of them as she felt the need to equip herself with more caregiving knowledge and prepare herself for her father's future care needs. Gradually, she was empowered to be more resourceful and felt more confident in caring for her father.

She found great value in the group sharing sessions, where she could connect with other caregivers to share her personal caregiving journey and caregiving tips. She also began to advocate for self-care through the programmes, encouraging other caregivers to care for their personal well-being. As an activated caregiver, she did not require any regular telesupport from the nurses but was appreciative that she could always reach out to the nurses if she had further queries or needed support.

Ms H now actively encourages other family members to attend caregiver programmes, building a team of family members who are equipped and able to support her in caregiving.

#### Caregiver at high risk of stress and burden

Mr K is a full-time caregiver caring for his 93-year-old mother, who has limited mobility and experiences constant pain due to her fractured back and pelvis. Mr K is widowed and does not possess any source of income or social support from his extended family. During his mother's first hospital admission, he completed the needs assessment form and was found to be at high risk of caregiving stress.

The caregiver support nurse quickly followed up with him through telesupport to understand his caregiving situation and specific needs. Mr K was then informed of the different financial aid grants and community services available, of which he was previously unaware. Realising that Mr K struggles with technology and encounters difficulty applying for grants, the caregiver support nurse applied for a home modification grant on Mr K's behalf. Grab bars were installed at his house, enabling his mother to move around the house safely.

During a recent readmission, Mr K felt helpless and lost as he was unsure how to manage his mother's knee pain and sleep problems. He sought advice from the caregiver support nurse, who advised him to adhere closely to the pain medication regimen prescribed by the doctor, and provided a list of tips for better sleep (e.g., reducing naps during the day, limiting caffeine consumption during the evening). Additionally, the caregiver support nurse suggested that he could explore seeking help from a physiotherapist to identify treatment goals and better plan on reducing his mother's pain. Being a caregiver who wishes to provide his best for his mother, Mr K placed a high level of expectation on himself, which caused him to feel anxious. The caregiver support nurse offered emotional support to allay his caregiving concerns and reaffirmed his commitment to caregiving while reinforcing the importance of self-care and taking time to recharge.

Through the support of Carer Matters, Mr K is able to return to work full-time while caring for his mother.

Table 3: Stories of caregivers who were supported through Carer Matters

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