



W H O

C A R E S

?



Transforming the caregiving
experience in Singapore



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?

Transforming the caregiving
experience in Singapore

This book is dedicated to all Caregivers
no matter how complex their loved ones' needs are.

*Dear Caregivers,
We know you.
We've talked to you,
We've listened to you,
We've followed you.
Thank you for giving your care.
You care for someone else.
Do remember to care for yourself too.*

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National Council of Social Service & fuelfor

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Caregiver **'kɜːgɪvə/**

A Caregiver—sometimes called an informal Caregiver - is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbour) involved in assisting others with activities of daily living and/or medical tasks.

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Foreword

Anita Fam

Board Member, National Council of Social Service

Caregiving can be a very lonely and challenging journey. But it can also be a very personally fulfilling one. It has been said that in one's life, one is either a caregiver, was a caregiver or will be a caregiver. As I write this foreword, I have just realised that I am no longer a caregiver after having been one for eight years - six years for my father and more recently two years for my mother. My mother passed away in the wee hours of this very morning. It has not even been 24 hours and already I feel a void in my life. This shows how consuming caregiving can be. Yet most times caregiving is overlooked and undervalued.

This book presents deep insights gained into the lives of caregivers and the trials and tribulations faced, their joys and possibilities for growth as individuals and together as a family. However, each of our lives, as sons, daughters, parents, siblings, spouses, in-laws - as caregivers and potential caregivers - can be enriched by support from the community. We need not exist as individuals in isolation. Policies and individual mindsets can also be changed to facilitate a more fruitful supported caregiving journey.

This book also presents thought-provoking concepts and ideas plus a prototype toolkit for us to use - so that we can take charge, step forward, contribute in our professional capacity or as part of our community - to recognise and support our caregivers of today and tomorrow.

I wish you a very thoughtful and reflective read.

1st July 2016

Introduction

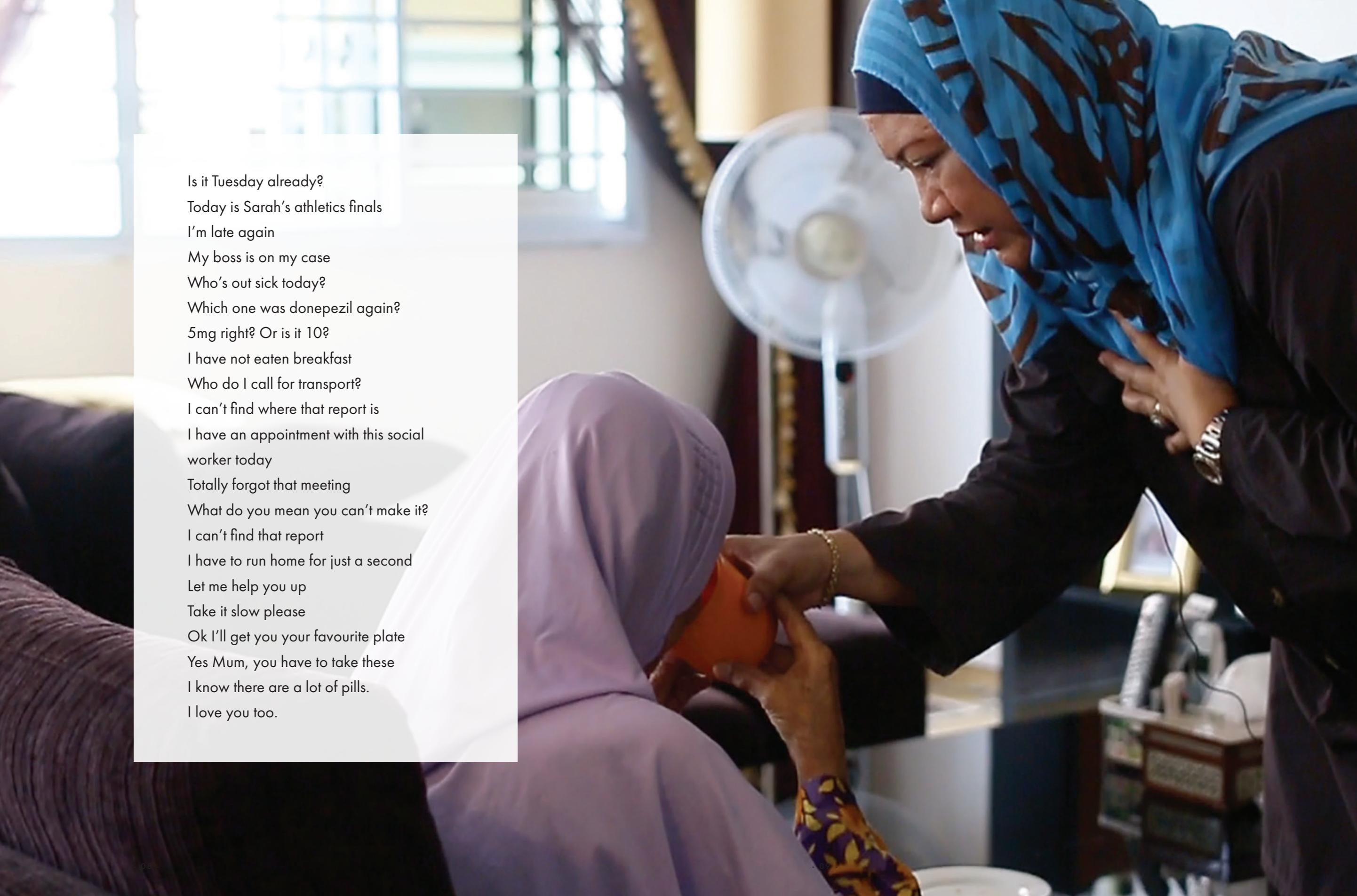
Sim Gim Guan

Chief Executive Officer,
National Council of Social Service

Meeting the needs of the community is at the heart of what we do. When the idea of a design ethnographic study into the lives of caregivers was proposed, I was supportive, as caregivers and their needs and struggles have often remained relatively 'invisible' despite their contributions. It is timely and necessary that we look into how we can better support caregivers and their families as they look after their loved ones, even as healthcare and social service systems are evolving to cope with the demands of an ageing population.

Design ethnography is an empathic approach that we have used which dives into the journey of our caregivers. It uses a series of research tools and design processes to shed light onto the difficulties faced by caregivers navigating today's care system. From our research findings, we have found that there is more that needs to be done to transform the caregiving experience in Singapore. The current caregiving landscape needs creative solutions to help caregivers meet changing needs for the future. For those of us in service planning, I hope that the concept ideas laid out in the book will help drive the beginning of more caregiver-centric support and initiatives. For those of us who are in the community, I hope that the insights from this book will move us to lend a shoulder and help meet the needs of others who need our support, so that collectively we can take caregiving beyond where it is today.

We would like to thank all who have contributed to this research - to fuel for, our co-creators from the community, service providers and colleagues from our ministry and agency partners. Our thanks go especially to the caregivers who have so openly and valiantly shared of their lives and stories. Because of their courage to share, we now know more, and can do more for this group of people. I look forward to the day when caregivers will no longer have to navigate or make sense of the caregiving landscape alone; when because of the structures and programmes put in place, their needs as individuals are considered and met; and when education transforms mind sets, to catalyse a more compassionate and understanding community.



Is it Tuesday already?
Today is Sarah's athletics finals
I'm late again
My boss is on my case
Who's out sick today?
Which one was donepezil again?
5mg right? Or is it 10?
I have not eaten breakfast
Who do I call for transport?
I can't find where that report is
I have an appointment with this social
worker today
Totally forgot that meeting
What do you mean you can't make it?
I can't find that report
I have to run home for just a second
Let me help you up
Take it slow please
Ok I'll get you your favourite plate
Yes Mum, you have to take these
I know there are a lot of pills.
I love you too.



Who cares for those with complex needs among us?

A mother feeling alone and scared upon finding out that her child was born with a condition called distal arthrogyriposis ¹, delaying his mental and physical growth; a daughter at the cusp of adulthood being given the sudden heavy responsibility to take care of her mother diagnosed with early onset dementia; a bachelor who got into an accident leaving him paralysed waist down, with estranged family members who do not want to take care of him.

These are the experiences of Caregivers in the most complex care situations, doing an unpaid but necessary job - that of a Caregiver to their family members, or for themselves.

Who cares for those with complex needs among us?

Who cares for the Caregiver?

Who cares for the future of caregiving?

1. Distal arthrogyriposis is a rare disorder occurring in 1 out of every 3,000 live births that are characterised by multiple joint contractures (stiffness) and involves muscle weakness found throughout the body at birth.

Why Caregivers need care?

Caregivers are almost always thrust into a new world of intricate responsibilities without warning. The challenges are difficult. They have to navigate their way around a complex maze of assistance and aid. Oftentimes, they worry more about the people they are caring for than for themselves. The journey is overwhelming, stressful and lonely, made worse by society's lack of understanding.

Despite the extraordinary care they provide, Caregivers are often invisible. They are an informal network of people, who step up as the first line of support to take care of their family members who would need extra attention, such as those with chronic illnesses and those with disabilities.

Singapore will be in a situation needing and relying more and more on fewer Caregivers. An estimated 210,000 people aged 18 to 69 provide regular care to family and friends, and this number is expected to rise ². However, today's care systems do not work for the families depending on care, or for the workers who provide it. Our healthcare is strained, and the population is ageing. At the same time, today's families are becoming smaller and living further apart, making the caregiving job more burdensome and increasingly difficult to manage, and more reliant on fewer people. Caregiving has a major presence in the human condition—it requires so much time and effort, plays such a large role in people's lives, and has such a major impact on the wellbeing and productivity of society as a whole.

How might we then, design a better future for caregiving?

2. Basu, R. (2013, September 27). Singapore's caregiver crunch. Straits Times. Retrieved from <http://www.straitstimes.com/singapore/singapores-caregiver-crunch>

Is this book for you?



You are someone who is interested in a better future of caregiving.



You may be a professional in the social service, healthcare, or education sector. You might be a policymaker, a civil servant, a volunteer, a designer, a social entrepreneur, a maker, a software programmer.

You might be facing Caregivers daily as your clients, you might know someone who is a Caregiver.



You might be a Caregiver yourself.

This book is for you if you think that the care landscape of Singapore needs to change to better support Caregivers, and if you are looking for ways to innovate and improve it.

Keep an eye out for these icons, they act as signposts to parts of this Book that might be most relevant for you. However, they are just a guide, so feel free to explore...



About this project

The National Council of Social Service (NCSS) commissioned a strategic design project to design a better caregiving future for Singapore. Applying the principles of design to the systemic challenge of the social care sector would help define how problems are approached, and identify opportunities for targeted action to deliver more holistic solutions.

This project takes an ethnographic research approach to unearth deeper insights with regards to the experiences faced by Caregivers in the complex needs space. By designing a better social care experience for these Caregivers, all Caregivers can potentially benefit from enhanced support from society. Guided by the principles of human-centred design and universal design, new products, services, tools, spaces, policies, programmes and campaigns could be created to drive revolutionary systemic changes. The project was given to fuel for, an award-winning design consultancy specialised in innovation for health and care.

With a human-centric design approach, and informed by current socio-cultural trends that will shape the caregiving landscape in the next five to ten years, fuel for set out on a design ethnography process to understand the needs, values, hopes and fears of Caregivers. They interviewed and video-shadowed ten Caregivers caring for the most complex cases; meaning taking care of either a care recipient with a mental illness, or more than one care recipient, or a care recipient with multiple issues, or caring for someone while they themselves

need care. Participants were between the ages of 21 to 78, across income classes, number of years of caregiving, belief systems, education levels, number of care recipients, and the complexity of the care recipients' condition.

The outcome of this project seeks to present the nine key insights from the research and how they translate towards a future vision of caregiving. This vision is articulated as an actionable design strategy, visualised through seven concepts maps that can inform innovation and drive implementation of near, mid and long term solutions.

The output of the project includes this publication, seven movies to communicate the fundamental emotions of complex caregiving, a prototype of a new toolkit to help social care professionals care for caregivers, and several targeted launch events and sharing workshops. With this new knowledge and set of tools, all of us can facilitate in the transformation of the social care sector.

The first half of this publication details the daily experiences of our ten chosen Caregivers caring for people with complex needs, as captured through video ethnography, with interviews and shadowing. This work gave the team insights into the reality of the caregiving experience today. In the second half, an ecosystem of possible solutions and concepts are proposed to design a better caregiving experience for tomorrow.

This is what
caregiving looks like
today.



Context of Caregiving Today

“When applied to living spaces, public services, and government policies, design can improve our quality of life. It will catalyse our use of technology and data in our path to becoming a Smart Nation, and encourage the same sense of experimentation and creation as in the Smart Nation Programme. It will be the source of healthcare and lifestyle solutions that will enable Active Ageing and build a more inclusive society, toward a Singapore which is both liveable and loveable.”

— Minister for Communications and Information, Dr Yaacob Ibrahim ³.

Based on a review of current major trends, the following will be key drivers of change in the landscape of caregiving in Singapore.

Economic

Caregivers are a big help to strained healthcare infrastructure.

Family Caregivers represent the backbone of health and social care delivery in countries throughout the world. It has been shown that Caregivers help delay or prevent the use of nursing home care. In Singapore, existing day-care centres have a nationwide occupancy rate of 84 per cent, but the

waiting time for a place in some locations can be up to 50 days ².

Caregiving cuts into traditional hours of work.

Increase in chronic illnesses in Singapore will lead to more Caregivers having to make work accommodations for caregiving. The more intense the caregiving the more adjustments Caregivers would have to make, from cutting back on work hours, to stopping work entirely. Employer support for family Caregivers, while important, is also currently “weak, grudgingly granted or quite absent” ⁴.

Social

Families are getting smaller and living further apart.

While the dominant household structure is still the nuclear family, which is the typical two-generation family with a married couple living with their children or their parents, the proportion of these families has fallen over the years. There is a significant increase in the proportion of one-person households and households headed by a married couple who are childless or are not living with their children. Smaller, more dispersed families lead to less people naturally stepping in as Caregivers.

2. Basu, R. (2013, September 27). Singapore’s caregiver crunch. The Straits Times. Retrieved from <http://www.straitstimes.com/singapore/singapores-caregiver-crunch>

3. Ministry of Communication and Information. (2016). Design 2025, Singapore by Design. Retrieved from https://www.designsingapore.org/Libraries/Docs/Design2025Masterplan_v2.sflb.ashx

We will continue to have an ageing society.

Although Singaporeans are living longer, they are running the risk of spending the last decade of their lives in poor health and disability, according to a Global Burden of Disease Study 2010 ⁴.

Demographic trends in the next several decades are likely to reduce the supply of informal Caregivers and increase the demands on a smaller number of Caregivers per elderly person with a disability.

Roles of women are changing, with increased participation in the workforce.

Women traditionally take on the role of caregiving compared to men ⁵. As women’s workforce participation increases, caregiving could pose even greater financial challenges for many women workers, due mostly to lost wages from reduced work hours, time out of the workforce, family leave or early retirement to care for their loved ones fully, especially as women usually live longer than men. As it is, working mothers face mounting stress, even more so those working mothers who are caring for complex needs.

Technological

Younger Caregivers are becoming solution-builders for their loved ones.

In many families, Caregivers, especially the younger ones, also double as tech support. Their digital understanding, coupled with an appreciation for quality of life, will help families use technology in a dignified way for their care receivers. As tech savvy consumers, they will demand better products and services for their loved ones because they know what is available in other such markets, and they want the same for their family. Many young

entrepreneurs are taking this a step further, and are rolling up their sleeves by building the services that they want to see for their loved ones.

Political

Infocomm technology (ICT) in the social service sector is enabling information flow between key stakeholders.

Since 2012, the Ministry of Social and Family Development (MSF) has been working with the Infocomm Development Authority of Singapore (IDA) to improve the ICT capability of social service providers and equip social service personnel with more ICT tools like Social Service Net (SSNet). IDA also promotes adoption and innovation in the healthcare sector, through building a common information network and data standards that enable integration and patient-centric coordination of care, combined with easy-to-access patient health information. Such systems help the government anticipate emerging needs, and build the necessary innovations and capabilities to meet them.

Designing a Loveable Singapore by 2025.

Innovation to enhance caregiving has the potential to provide the biggest immediate impact on reducing healthcare spending and enhancing individual quality of life. The vision of Design 2025 is for Singapore to be a thriving innovation-driven economy and a loveable city by design. Residents in and visitors to Singapore will enjoy services as well as user and customer experiences that are people-centred. The community will also embrace the use of design and actively participate in co-creating their living environment, which will in turn, cultivate a stronger sense of belonging and develop an endearing home for all.

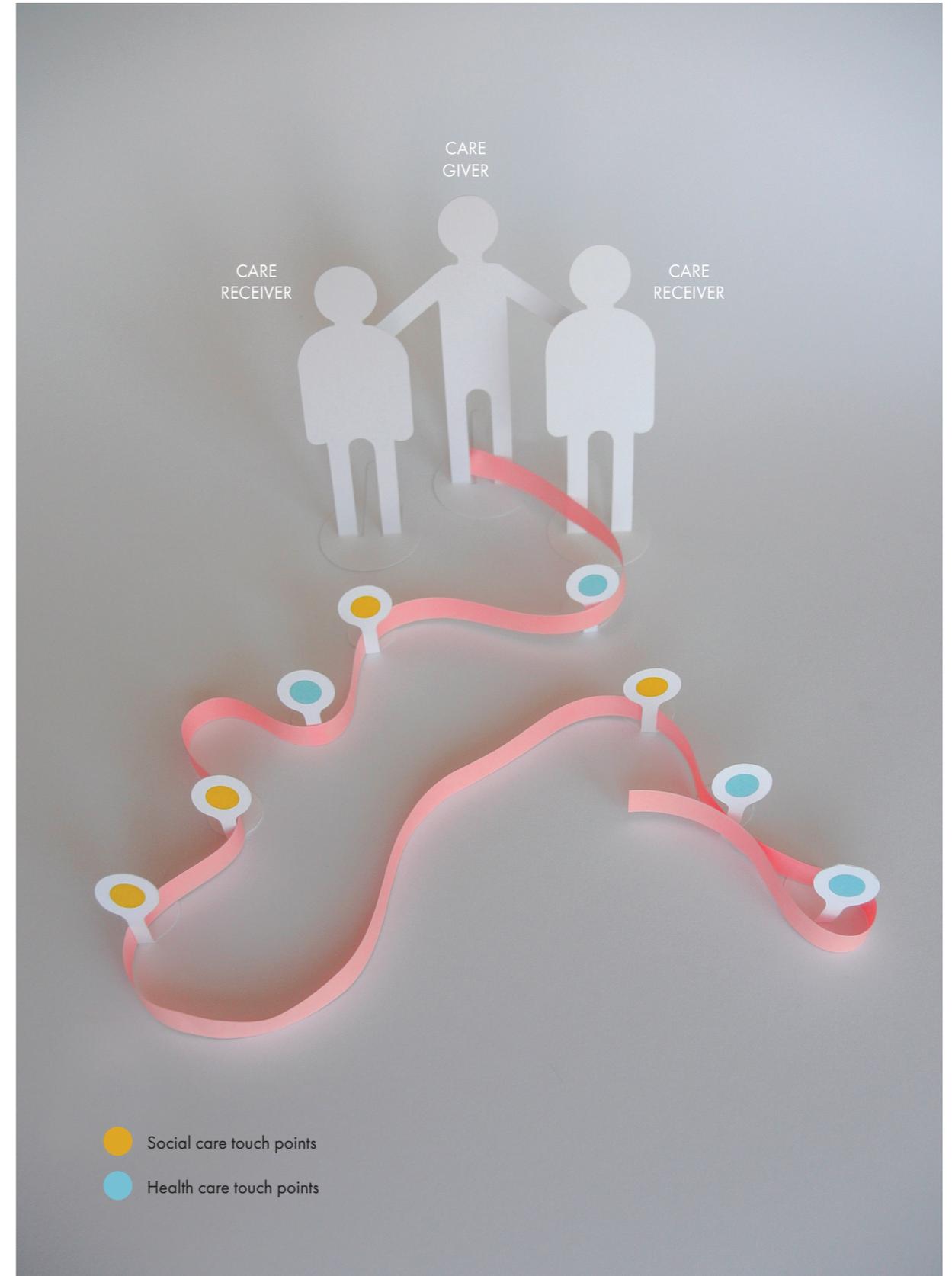
4. Cheong, T. (2015). Why Are Singaporeans Living Longer? (2015) Health Xchange. Retrieved from <http://www.healthxchange.com.sg/healthyliving/seniorhealth/Pages/Why-Are-Singaporeans-Living-Longer.aspx>

5. Zheng, Z. (September, 2011). Caregiving in Singapore. In Statistics Singapore Newsletter. Retrieved from https://www.singstat.gov.sg/docs/default-source/default-document-library/publications/publications_and_papers/health/ssnsep11-pg12-14.pdf

Caregivers are the Red Thread

across the Social and Health Care Landscape...

Aid and attention are usually given to the patients in healthcare, or to the clients in social service agencies. However, when we step back to look at the journey of patients or clients, we begin to see the Caregivers who are always alongside them, accompanying their loved ones who are needing attention throughout these care journeys. Family Caregivers are the main care coordinators, acting as a red thread, trying to tie together the fragmented pieces of their family member's care across several different touch points: clinicians, hospital stays, polyclinic visits, dealing with social service agencies and other community services. They link the key transitions between care touch points and home or everyday life.



Who did we talk to?



10 caregivers

Between the ages of 21 to 78.

Across income classes, years of caregiving, belief systems, education levels, number of care recipients, and the complexity of the care recipients' condition.

Complexity in this project was defined as Caregivers who are:

- Taking care of a care receiver with a mental illness
- Taking care of more than one care receiver
- Taking care of someone with multiple issues
- They are care receivers themselves and need care

Participants were recruited in close collaboration with these Voluntary Welfare Organisations:

1. AWWA Ltd.
2. Alzheimer's Disease Association (ADA)
3. Caregivers Alliance Limited (CAL)
4. SPD



Insights on Caregiving

Caregivers today experience a mix of emotions along the caregiving journey; not all are felt, or even experienced in a given sequence, but they reflect the fundamental highs and lows of this unique role and responsibility.

In this section, we present nine key insights into today's experience of caregiving, through the palette of emotions that Caregivers feel.

Look out for QR codes in this section to watch an Insight Movie and get a deeper understanding of a Caregiver's experience.



Emotions of Caregiving

Caregiving today is made up of a mixed palette of emotions that Caregivers feel as they carry out their responsibility.

FEAR



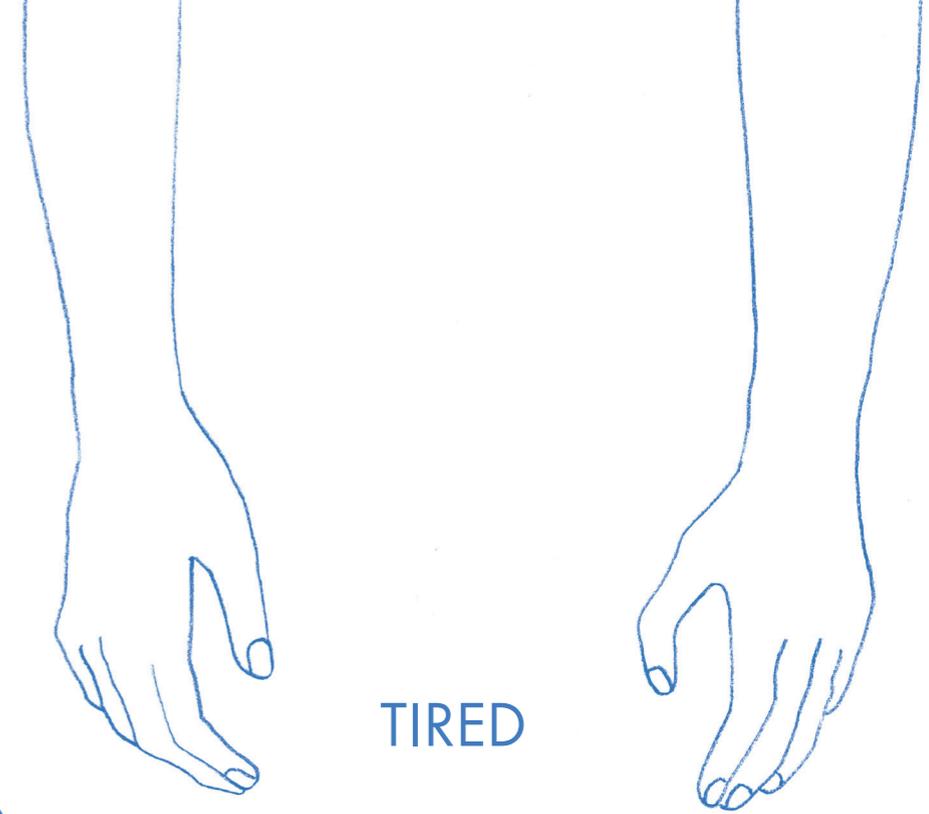
HOPE



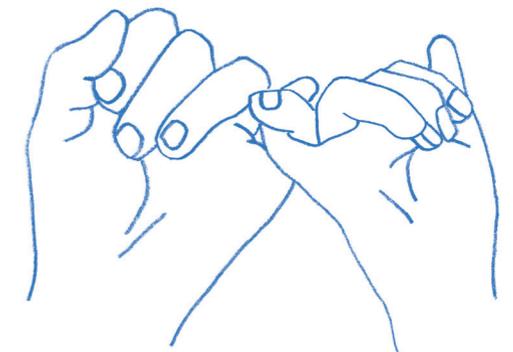
COMPASSION



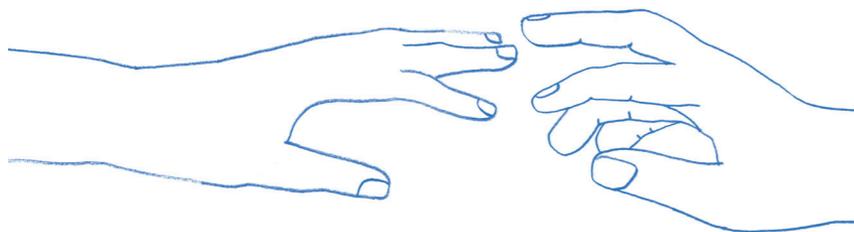
TIRED



TRUST



LOST



ISOLATED





fear

Caregivers get frightened or worried by something dangerous, painful, or bad that is happening or that might happen. Becoming aware of the need to be a Caregiver, and even starting the process of caregiving can be daunting and scary.

“Taking care of dementia patients can only be described as ‘thinking on your feet’. No other choice, I need to think of solutions on my own. (My husband) can act out any time, it’s scary to even think about it. The first thing I do when I wake up is to gear myself first, prepare the things I need, pack a bag, like running away. No choice. It is really very scary. His medicine, important documents, pack them well. We must prepare. Once something is not right, I try to coax him to get out of the house.”

- Caregiver Wife whose husband has frontotemporal dementia ⁶

“When doing caregiving you are so stressed that you cannot think out-of-the-box. You can only think, “Oh dear, there will be no help, there will be no solution for this, what am I going to do? When I was eight, (my mother) was feeling out of breath at home and there was no one I could approach for help. I brought her down to take a cab to the hospital. I didn’t have money to pay the cab fare, I told the uncle, “I’m so sorry I don’t have enough money.” The uncle was very nice, “Oh it’s ok, just bring your mum to the hospital.”

- Caregiver Daughter, an only daughter with a mother who has asthma and other chronic illnesses.

6. Frontotemporal dementia (FTD) is a progressive, degenerative brain disease that gradually destroys the ability to behave appropriately, empathise with others, learn, reason, make judgments, communicate and carry out daily activities

from emotion



Watch the "Fear - Living in survival mode" Movie

to insights

Caregivers are in a constant survival mode, watching out for, or responding to crisis situations. They do not have the capability, capacity or time to think of how best to improve their situation.

Caregivers often find themselves in chaotic and confusing situations. When crisis occurs on a regular basis, the Caregiver's only option is to operate in survival mode and live on a day-to-day basis, reacting to any situations that crop up as and when. This requires a lot of physical stamina and mental energy from the Caregiver, who is often overwhelmed and unable to make actionable plans and strategies for future care. It is difficult for them to think systematically about what kind of help or support they need. They fear any situation when there is no strategy to fall back on, as they might end up in violent or dangerous circumstances for themselves and their care receivers.

Caring for someone with mental health issues is especially challenging. It requires flexibility from the Caregiver because the nature of the illness, as well as the trial-and-error approach in treating patients with medicine, makes patients behave unpredictably and out-of-character. Caregivers need to keep changing tactics to constantly evolve with the care receiver's progression in the illness.

to opportunity

How might we create strategies to help Caregivers better cope with crisis situations, and build resilience for future crises?



isolated

Not meeting or talking with anyone else in a similar situation can make Caregivers feel alone and unhappy. They might feel they are the only ones in the world going through the experience, and that no one else can understand or help. If they are lucky, they meet the right person or service that can keep them connected to society.

"The hospital just said 'there's no rehabilitation centre here'. If they really want to help me, they will refer me to another hospital...I tried my best. I will ask for help, but I will not insist on being helped. If someone really wants to help you, even if you don't ask, they will help you."

- Self-Caregiver

"The first time I stepped into that school, I cried. I thought 'It's okay to have those children'. I see for the first time children with other disabilities, and I see how they (the teacher) handles (them) and they were so supportive. I had friends, finally I had friends with children just like my son."

- Caregiver Mother of son who has distal arthrogyposis.

"I contacted my Community Development Council (CDC) and Residential Committee (RC) but since the accident and until now, no one from the RC visited me. I heard on the radio how RC looks after the elderly, giving them gifts, but I had nothing. I know I stay in a 4-room flat. They only care about those living in the 3-room flat or below."

- Self-Caregiver

from emotion



Watch the "Isolated -
Lonely and isolated" Movie

to insights

The quality and level of assistance that Caregivers receive depends on the knowledge and experiences of the providers they meet. It also depends on their financial health and tends to overlook family dynamics. Some Caregivers with poor assistance then become isolated, and do not get the help they really need.

Caregiving is a relatively common experience, though many Caregivers may feel they toil alone. This perception deprives them of emotional support from those who can help, and also means people do not share and learn from each others' experiences. Few Caregivers are able to find others who share similar challenges; this makes it challenging for them and their loved ones to find ways to participate in society.

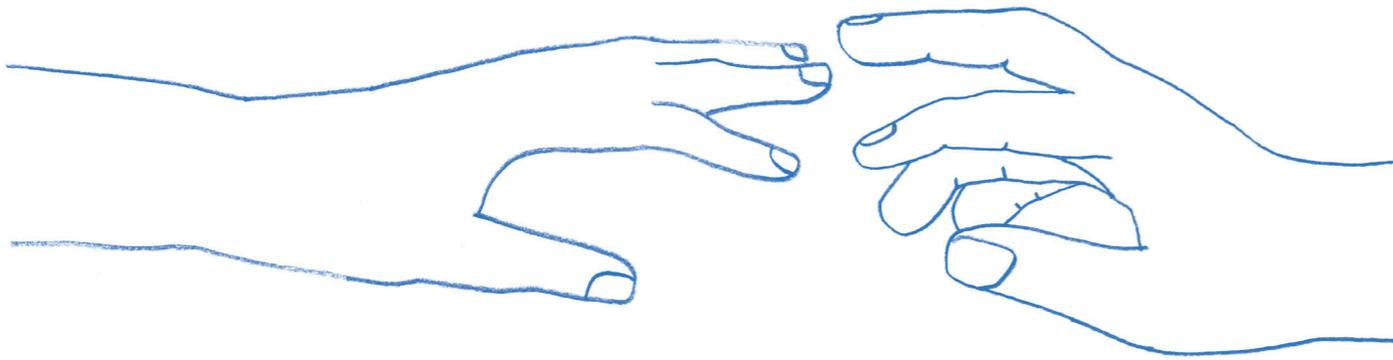
Caregivers' engagement with services largely depends on who they meet and what that person knows. Referrals to other VWOs, especially when cutting across healthcare and social service, are often based on the care provider's personal connections. This ad-hoc system can either expand or limit Caregivers' options, changing the course of the caregiving experience. The fragmented, blurry landscape of social support makes it tough to see if, where, how, and when help is available.

The current system of needs assessments in the social service sector is mainly focused on delivering the quickest help to those in need, by evaluating the amount of help needed against income level and the presence of family. However, having a family does not necessarily mean there is support given by them. In complex cases, emotional support is vital for Caregivers.

Financial situations are not easy for social services to grasp; a family with a decent level of income is assumed to have adequate finances and Caregivers with time and resources to care. The pressure and high priority for Caregivers to provide financially for the family can sometimes be overlooked.

to opportunity

How might we use the collective intelligence of care providers, so that all Caregivers can access useful and helpful information that is tailored to their needs?



lost

When Caregivers want to look for help, they often do not know where to go first. They stumble around feeling confused, looking for help across systems which were not originally designed to work together.

"From Monday to Friday, he can still go to the activity centre. The problem arises when he acts out more on weekends. It's difficult to find people for help on Saturdays and Sundays, because they usually work till Friday. Even the doctor is hard to get."

- Caregiver Wife whose husband has frontotemporal dementia

"I am very grateful for the Caregivers programme, they didn't have it 10 years ago. We didn't even know which department to approach for help."

- Caregiver Husband of wife who has depression

"The transport service is very hard to get because a lot of elderly need the services and the hospital appointment is also very hard to get. It's hard for me to coordinate which are the days where transport and doctor appointment are both available.

I approach a lot of organisations for help, but it seems they can only provide counselling. There is no hands-on help for Caregivers. Just counselling, befriending, attending courses. They say 'We don't have this kind of (transport) service'. It's not going to solve my problem! It seemed like no one is able to help. It is very tiring...but I tell myself, even though I am being rejected, I still need help. It's okay that the person or organisation cannot help me, I can always approach another organisation for help. Eventually I'll get it."

- Caregiver Daughter to parents with multiple chronic illnesses

from emotion



Watch the “Lost - Services in silos are tough to navigate” Movie

to insights

Caregivers lack clarity in terms of how social services work when they ask for help. This is due to a lack of coordination among stakeholders and confusion on schemes available. So Caregivers try to navigate this landscape and fill in the gaps themselves.

The Singapore Government has adopted the Many Helping Hands (MHH) approach; a community-based framework to provide social assistance to the socially vulnerable and disadvantaged. Self-help initiatives put forth by community organisations would make up for areas in which the government would be less effective providers. Responsibility is shared by various segments of society, rather than by civil servants.⁹ Centre for Social Development Asia (CSDA) found that this approach posed challenges in Singapore’s social service sector due to lack of coordination among the many stakeholders, and confusion over multiple schemes available which affects efficiency in giving help.¹⁰ Our project also found that since the sector caters mainly to needy clients, such models posed limitations to fully meeting Caregivers’ needs.

Caregivers struggle to ensure continuous and holistic care whilst accompanying their loved ones

through different life stages, each with varying physical, psychological and emotional needs. During the journey they have to make sense of and connect different people in the medical, social and legal sectors who do not communicate amongst themselves. Caregivers piece together information and help from multiple support services that were not designed to work together. As a result, solutions do not address their multi-faceted problems, leaving gaps in support.

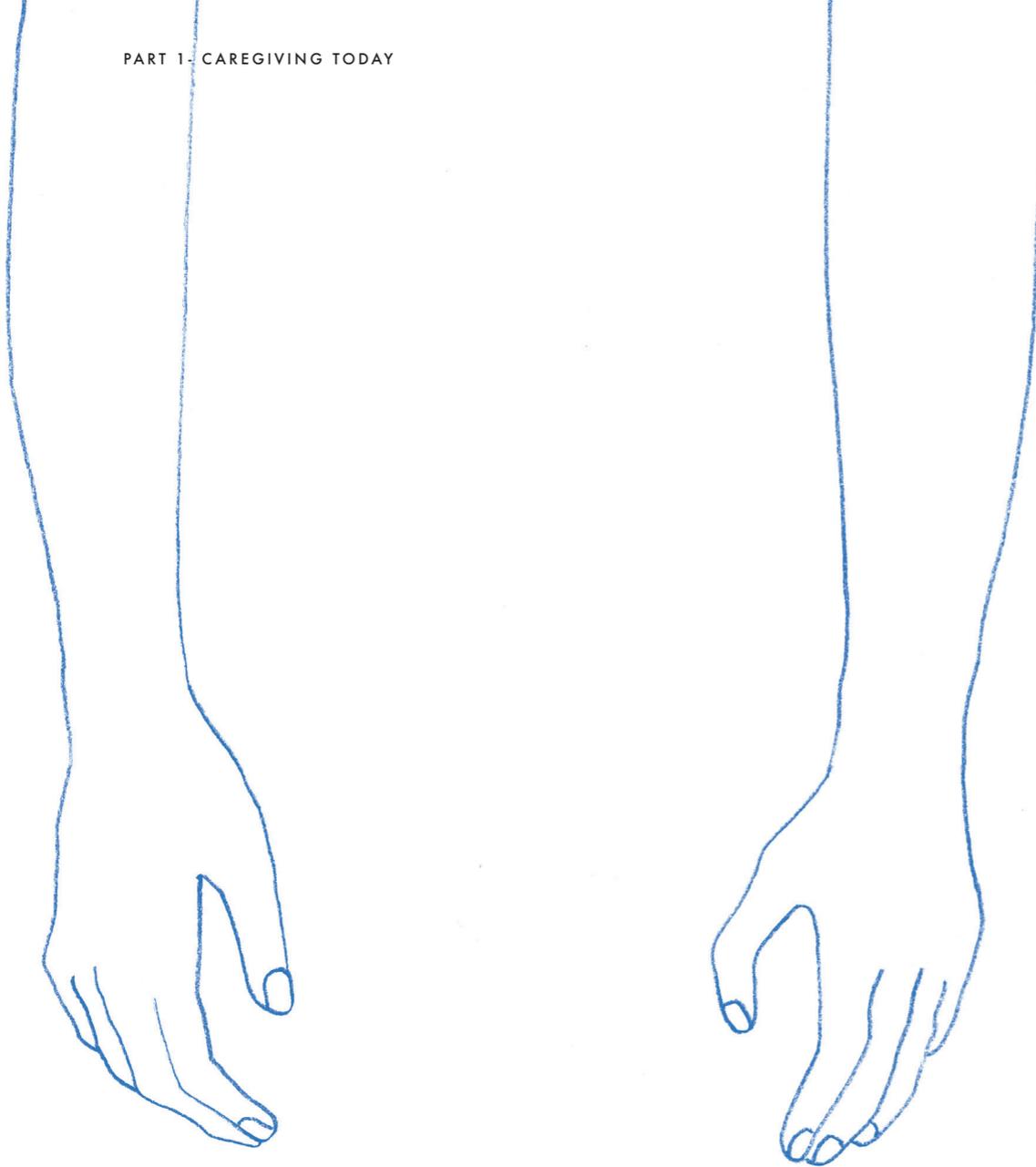
Additionally Caregivers, who are the primary interface with the healthcare system, receive less support from health professionals, as healthcare services are traditionally aimed at patients. Caregivers can then often be left out in planning for patients’ home care, even when health professionals require family cooperation to achieve a successful (clinical) outcome.

to opportunity

How might we design integrated health and social care systems that make continuous support for Caregivers available, accessible, and viable?

9. Mehta, K. K. (2006). A Critical Review of Singapore’s Policies Aimed at Supporting Families Caring for Older Members. *Journal of Aging & Social Policy*, 18(3-4), 43-57

10. Sim, I., Ghogh, C., Loh, A. Chiu, M. (2015) The Social Service Sector in Singapore: An Exploratory Study on the Financial Characteristics of Institutions of a Public Character (IPCs) in the Social Service Sector.



tired

While taking care of their loved one, Caregivers can get drained of strength and fatigued to the point of exhaustion. They either do not realise the importance of taking care of themselves, or find it hard to do so as caregiving takes up their entire time, so they go on caring selflessly.

"I do think I miss out on life events of friends, like my social life."

- Caregiver daughter, aged 21

"She doesn't encourage me to go cycling, she says it's dangerous. She says I need to rest more. I usually go to Punggol to cycle during the weekend for two to three hours. She worries. I tell her that I know how to take care of myself."

- Caregiver Husband with wife suffering from fits

"I was there (at the hospital) just for one day, not four or five days. Cannot stay for so long...I was worried about my family. If I operate on my foot I will be there for six weeks. Who will check on my wife?"

- Caregiver Husband who injured his foot when he fainted while drying clothes, with a wife suffering from heart and kidney problems

from emotion



Watch the "Tired - Caregivers need self-care too" Movie

to insights

Caregivers want to take a break from the daily psychological and physical stress of caring for their loved one, but they are unable to find suitable avenues. They may also be unaware that they have to take care of themselves, or feel guilty when they try to do so. Hence, Caregivers will always try to put their loved ones' needs first.

Singapore's system of social security is based on enabling self-reliance, supported by strong family and social networks. However, self-reliance can become a double-edged sword. As Caregivers micro-manage their care receiver's needs and expend their energy, they are ashamed of asking for outside help due to the expectation that they should be taking care of everything themselves.

The often daunting challenges of caregiving may include balancing career and family responsibilities, finding personal time to relax and care for oneself, and managing the emotional and physical burdens of caregiving. Caregivers roles can be that of a nurse, personal assistant, and someone in charge of finances. Caregivers feel the pressure to perform and often have to live up to their own, their family's and society's expectations of selflessness, strength and steadfastness.

On the other hand, there is little attention paid to the risk of Caregivers neglecting their own wellbeing or isolating themselves and their loved ones. They might even feel guilty for taking a pause, which encourages self-neglect. Attending to their own needs is essential in enabling Caregivers to sustain their health and their role as a long-term family Caregiver. Informal Caregivers are at significant risk of depression and other morbidity, especially when they care for individuals with Alzheimer's disease.¹¹ In particular, young Caregivers risk missing out on opportunities for self-development and growth.

to opportunity

How might we encourage and make it intuitive for Caregivers to take care of themselves?

11. Alzheimer's Association. (2011). Alzheimer's facts and figures. Retrieved from http://www.alz.org/alzheimers_disease_facts_and_figures.asp



trust

Caregivers want to believe that they can trust another with their loved one, to share the responsibility and experience of caregiving.

They also want to put their trust in plans that they can rely on. However, it's not easy when a loved one's condition keeps changing.

"We (me and my sisters) went through a lot of heartache, anger with each other because of this (sharing caregiving of our mother with dementia). You go through the worst and then you get better. When it's co-sharing it becomes much more pleasant and bearable, to the point where you can really enjoy that person."

- Caregiver Mother of son who has distal arthrogryposis and mother who has dementia

"I have never asked any help from my relatives. Later they will scold me. They will say that you have your own children, why not ask them. My husband cannot be relied on. My two children cannot be relied on. It makes me very angry."

- Ageing Caregiver Mother of a son who has cerebral palsy

"I do talk to my sister-in-law, she tells me not to worry we'll figure something out, but if we don't do that now, how are we going to figure out then? I would like to start the process of sharing what I know with another family member to take over caring of my mother right now, rather than right before I leave overseas to study."

- Caregiver Daughter who took one year break from undergraduate studies to care for her mother with early onset dementia

from emotion

to insights

The caregiving experience redefines family relationships, forcing families to continuously adapt and share roles and responsibilities. They struggle to talk openly and safely with each other about caregiving issues. Caregivers also do not know how to plan for transitions in life stages, and are unable to trust in any plans they might make, as they know their situation is unpredictable.

Becoming a Caregiver redefines relationships within families. Unaware of the challenges they face, they may see their duties as a natural extension of their familiar relationship as a wife or son, etc. The appointment of a main Caregiver can be influenced by cultural values. Due to filial duty, the role is often assumed to be taken up by the person who is most available. As time goes on, the person's assumed role may not be reviewed as the family takes their role for granted. The roles and relationships may continue to change over time when the illness progresses, and sustained resilience is needed to accept this constant change. Ageing Caregivers of children with disabilities, and Caregivers not empowered in terms of education, literacy, or residential status are in an especially vulnerable position, as they depend on their care receivers.

Within families, communication about these new roles and responsibilities is often lacking because of avoidance, stigma, or shame, as well as knowledge gaps between family members. The resulting lack of clearly redefined values, roles and responsibilities adds to Caregiver stress and uncertainty. Missing communication channels between Caregiver and care receiver can lead to needs being overlooked, misunderstood or even unknowingly sabotaged.

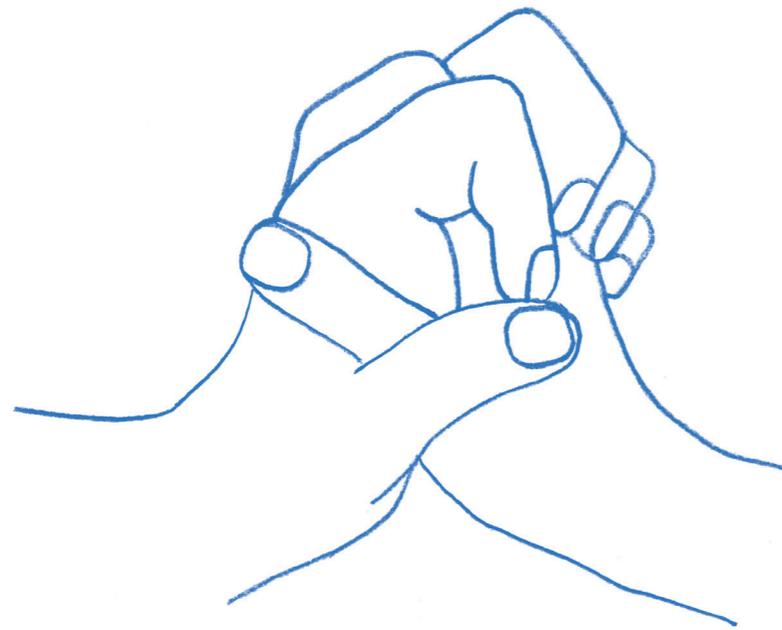
Experiences of the same situation vary among family members, and even between Caregiver and care receiver, making it more difficult for the family or social service personnel to understand the situation. Different Caregivers have different tolerance levels and will experience caregiving in different ways; this makes it difficult for shared caregiving to take place.

to opportunity

**How might we normalise conversations about new roles and responsibilities of caregiving within families?
How might we assist them in planning for a future they can believe in?**



Watch the "Trust - Caregiving is a family affair" Movie



hope

Caregivers wish for something good to happen. A comforting message from within, or from faith, family or friends can make them feel hopeful and lead them through uncertainty. However, hope may be elusive when Caregivers are at an utter loss of how to care. Despair, then, sets in.

"I always knew I would be a Caregiver to my parents but not in this way... because I am their child right? So I should be taking care of them. I think that was the only preparation I had in mind. When I started I didn't know what to do or how to do it. I did not expect myself to be doing so many things immediately."

- Caregiver Daughter of mother with early onset dementia

"How much one eats or (what one) wears is all pre-destined... maybe I had walked too much before the accident, so the heavens stopped letting me walk."

- Self-caregiver who became paralysed waist down after an accident

"I was shocked at the time when I realised his development was affected. We take it day by day because if you become a coward; what's gonna happen to your child? From then on, I was researching, reading a lot of books, about what is wrong with my son. They did not tell me the diagnosis.

They put it as a mentally retarded, that's it. So now we know he has Attention Deficit Hyperactivity Disorder (ADHD). I didn't give up, I left it up to God and I keep on praying."

- Caregiver Mother of son who has epilepsy and intellectual disability

from emotion



Watch the "Hope - Uncovering the value of caregiving" Movie

to insights

Caregivers often lack the awareness, skills and resources needed along their caregiving journey that would help them to be confident in themselves, and assist them to be a better long-term Caregiver.

It is difficult for Caregivers to look at the caregiving journey as a positive and manageable experience, amidst the countless negative experiences.

Many Caregivers lack adequate finances, social resources, information, and the emotional support needed to manage the health and social care needs of their family members. Their level of education also affects their care-seeking capability. Caregivers are often faced with a knowledge asymmetry as compared to care providers; they may not command the necessary level of English literacy or vocabulary to be well understood by care professionals, struggling to articulate their thoughts well enough to get the help they need.

Care-seeking is a scary and potentially embarrassing experience, as Caregivers have to keep asking for help. Where mental health issues are concerned, it is challenging to communicate the difficulties of caregiving to care professionals. Caregivers feel inadequately understood and helpless. These effects may help explain why those

with mental health issues in Singapore are not receiving adequate treatment, as they fail to identify the illness, face stigma, and access appropriate help.

Caregivers try to make sense of their caregiving situation in order to keep caregiving. Some seek answers in religion or the notion of retribution. Others are motivated by the positive change they see in their lives, such as new friendships and personal growth. But focusing on the positive side of caregiving is difficult when faced with such negative experiences. However, even minor changes can bring the greatest joy, such as a child with disabilities learning to say 'papa'.

How a Caregiver explains their caregiving experience reflects their attitude towards caregiving, towards the future and how hopeful they are.

to opportunity

How may we assist Caregivers to make sense of their situation, in order to cope and remain hopeful?



compassion

Caregivers know that others feel sympathy and sadness for their suffering or bad luck, and wish to help them alleviate their situation. However, the compassion of others is not always welcome. Caregivers can find themselves in a bad situation and still not ask for help, because they maintain a level of pride that they wish to hold on to.

'What will I be hiring a helper for? Housework? I do that very quickly. It's a small thing, I don't think it's necessary. So, for what? When he wants to go out, I bring him out. So I think it's just another burden. Not necessary for now as he is still mobile. If it gets serious, then send him to the hospital for a few days, no need a helper. [...] When he gets violent, I will even need to care for one more person.'

- Caregiver Wife whose husband has frontotemporal dementia

"Even if the government sends volunteers they can't solve problems for me, they can't follow me around all day. It would be harder on me. Whenever I have a problem, I'd try my best to solve it. If I can't solve it, there's no choice. I feel bad receiving so much help. I can't repay the favour. And it lengthens my time here. Because you can only leave after returning everything."

- Self-caregiver whose body is paralysed waist down

from emotion



Watch the "Compassion - Building caring communities" Movie

to insights

Caregivers prefer to shoulder their burdens alone. For them, this seems to get things done faster and easier.

Caregivers are reluctant to share caregiving responsibilities because they feel they should be able to take care of their own care receiver, and that they are the only ones who know best. With many tasks at hand, sharing the responsibilities may feel like an additional task to their long list of tasks. It seems easier to do everything themselves, rather than to have to stop and share or delegate the responsibility. Handing over to others is perceived as more time-consuming, difficult and cumbersome, because it is often emotionally and logistically tougher.

However, by taking on all caregiving tasks themselves, Caregivers are likely to become the weakest link; a bottleneck for the quality of care

towards their care receivers, and a potential burnout candidate themselves. When they fall ill, the complete caregiving structure breaks down. When the situation gets out of control the Caregiver is faced with two extremes; taking on everything themselves or giving up everything to professional Caregivers - the impersonal system to whom they are not indebted.

Some Caregivers have no choice. When there is a lack of support on both family and individual levels, the full burden of caregiving falls on the shoulders of the individual Caregiver. Society's expectations to take care of your own problems and be self-reliant also plays a part in Caregivers shouldering their burdens alone.

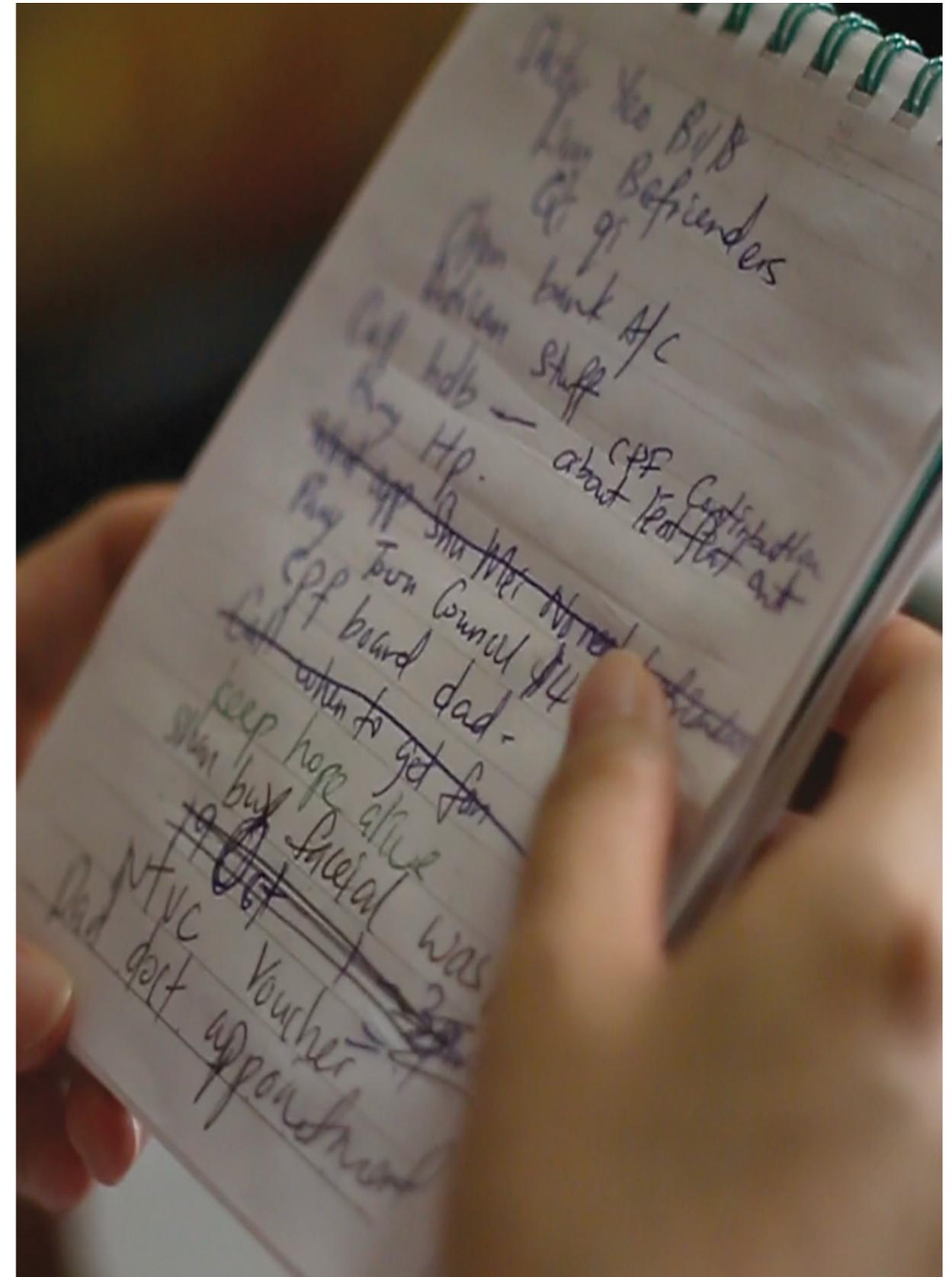
to opportunity

How might we facilitate Caregivers to build the capability and trust they need to be able to share or delegate their caregiving responsibilities?

What did we learn?

After conducting design ethnography, interviewing and video-shadowing our ten participants, the following are the nine key insights from this project.

1. Caregivers are in a **constant survival mode**, watching out for, or responding to crisis situations. They do not have the capability, capacity or time to think of how best to improve their situation.
2. The quality and level of assistance which Caregivers receive depends on the knowledge and experiences of the providers they meet. It also depends on their financial health and tends to overlook family dynamics. Some Caregivers with poor assistance then **become isolated**, and do not get the help they really need.
3. Caregivers lack clarity in terms of how social services work when they ask for help. This is due to a **lack of coordination** among stakeholders and confusion on schemes available. So Caregivers try to navigate this landscape and fill in the gaps themselves.
4. Caregivers want to take a break from the daily psychological and physical stress of caring for their loved one, but they are unable to find suitable avenues. They may also be **unaware that they have to take care of themselves**, or feel guilty when they try to do so. Hence, they end up putting their loved ones' needs first.
5. The caregiving experience **redefines family relationships**, forcing families to continuously adapt and share their roles and responsibilities. They struggle to talk openly and safely with each other about caregiving issues.
6. Caregivers do not know how to plan for transitions in life stages, and are **unable to trust in any plans** they might make, as they know their situation is unpredictable.
7. Caregivers often **lack the awareness, skills and resources** needed along their caregiving journey that would help them to be confident in themselves, and assist them to be a better long-term Caregiver.
8. It is difficult for Caregivers to look at the caregiving journey as a positive and manageable experience, amidst the **countless negative experiences**.
9. Caregivers prefer to **shoulder their burdens alone**. For them, this seems to get things done faster and easier.





What should
caregiving look like
tomorrow?

Designing Tomorrow's Caregiving Landscape

Who cares for those with complex needs among us?

Who cares for the Caregiver?

Who cares for the future of caregiving?

We do.

If you're reading this far, you do.

So let's dream, design, and build for tomorrow.

The nine deep ethnographic insights guided the ideation process of designing what tomorrow's caregiving experience would look like, centred around the Caregivers' experience. We wanted to transform negative feelings of fear, being isolated, feeling lost and tired to be more positively experienced, and install or enhance the positive feelings of trust, hope and compassion where they exist.

We understood that Caregivers take care of a diverse variety of conditions and have different capabilities, so we intended our designs to be as inclusive as possible. To be usable by as many people as reasonably possible, without the need for specialised adaptation for each type of capability or condition.

Here we present recommendations towards an inspiring vision for Caregivers, articulated as an actionable design strategy, and visualised through product-service-system concept maps that can inform and inspire innovation and implementation.

The concepts have been fine-tuned based on feedback with different stakeholders - Caregivers, Voluntary Welfare Organisations (VWOs), and healthcare and social care professionals themselves. We came up with solutions that would be most efficient in impacting and improving support for Caregivers. The concepts you see here are grounded in reality and deliberately provocative; they seek to provoke the critical and creative thinking required to reframe and rethink solutions for the challenges of caregiving. As such, each idea is ripe for further development, for piloting and fine-tuning. We are definitely excited about co-creating tomorrow's caregiving landscape for Caregivers, with those who care.

After each concept you will find some questions to think about and space to pen your thoughts. We encourage you to read, reflect and record your response to each idea.

How would you make these ideas a reality?

Concept Overview

Tomorrow's landscape is made up of seven different concepts that fit together to create an eco-system of new products, services, tools, spaces, policies, programmes and campaigns. Each concept impacts a variety of levels from policy to persons, reshaping behaviours, experiences and practices. We designed new entry points to the social care landscape, new roles to assist in navigation, and new tools for people to

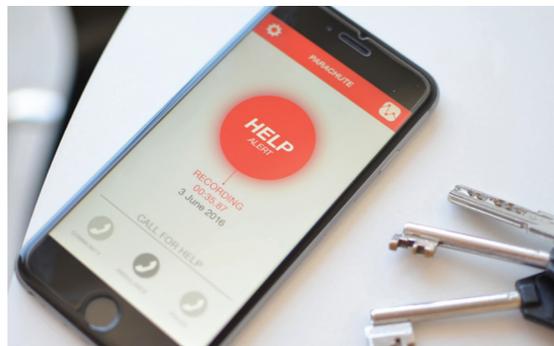
use to achieve a better caregiving experience.

The concepts exist in a Caregiving Ecosystem facilitated by a virtual **Care Cloud** run by the **Care Hub**. The Care Hub is a building in the community that has been designed with Caregivers in mind, where Caregivers would be able to visit and make time for their own **Caregiver Wellbeing**. When Caregivers need help in moments of crisis, they can activate the **From Crises to Prizes** service,

which would support them with on-demand help, and prepare them for future crises by increasing their resilience through skills training. **Smooth Care Touch Points** would facilitate transitions between health care and social care services. With **The WayForward Programme**, Caregivers receive proactive guidance in navigating health and social care services. The **Care Concierge** would assist in helping families to talk to each other, share tasks

and plan for next steps. Moving upstream with intervention, **Empathic Education** is introduced in schools to prepare a support system for Caregivers by educating caring citizenship from an early age. With the **Compassionate Community** concept, a network of compassion would be activated in the local community to support Caregivers in their own neighbourhood.

From Crises to Prizes



Smooth Care Touch Points



Care Concierge



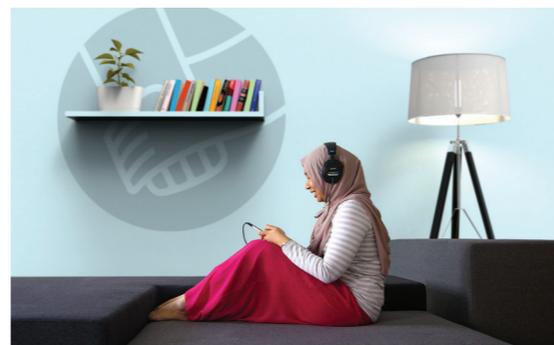
Compassionate Community



The WayForward Programme



Caregiver Wellbeing



Empathic Education



The Caregiving Ecosystem

Care Hub

The Care Hub is a physical space built with Caregivers in mind, delivering services and programmes that will bring a wide range of benefits to Caregivers. It is a natural next step that Singapore might head towards in the future, basing off the increase in Caregiver support service centres, and respite centres run by different organisations across Singapore over the past years. The Care Hub will function as a meeting point upon detecting families in need. The Care Hub will also be a centre assessing support when needed.

Care Cloud

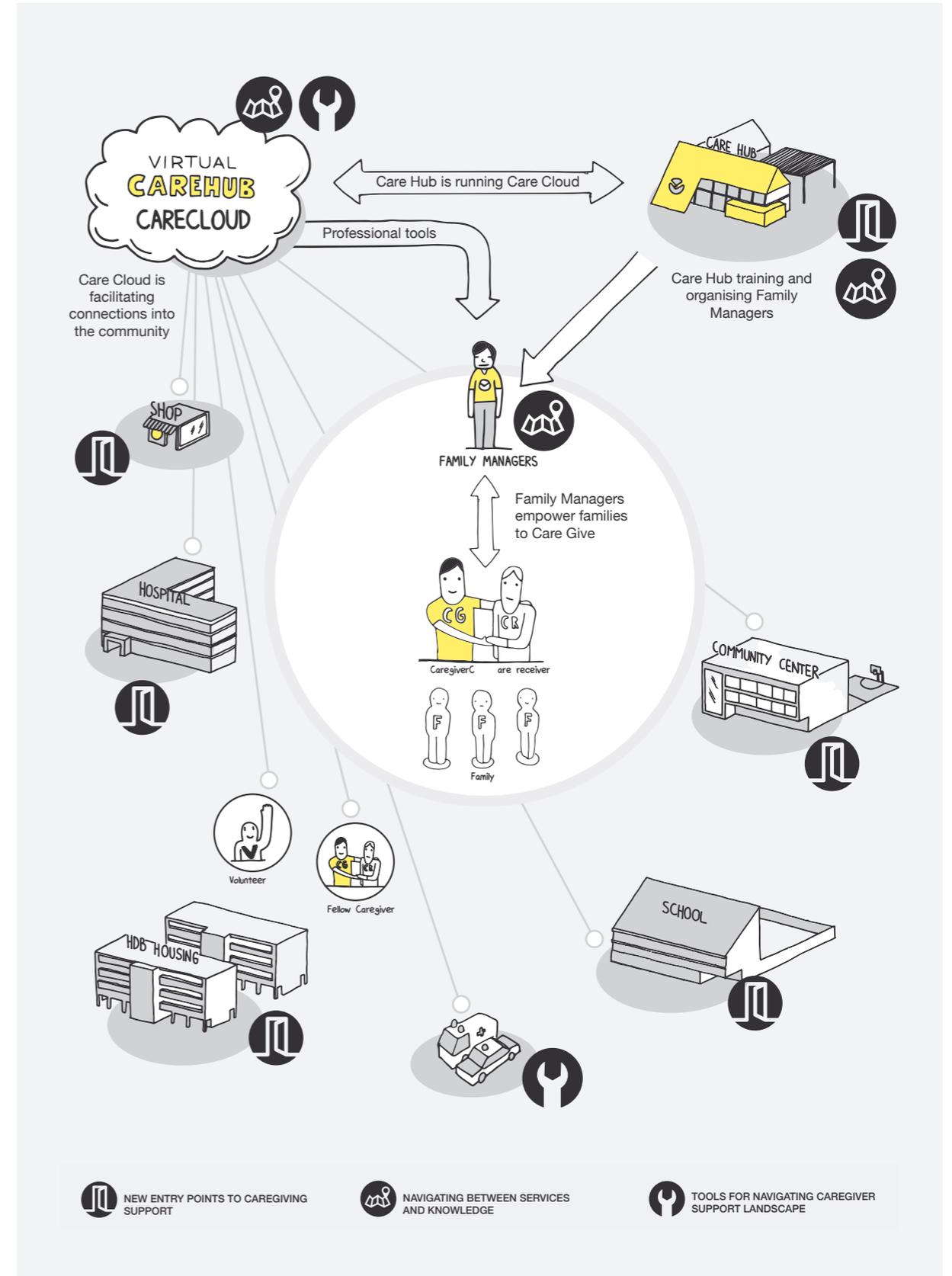
We propose that this Care Hub runs a Virtual Care Cloud connecting the physical Care Hub to key touchpoints in the community, through which a Caregiver can receive and share knowledge, download support tools, access services, and communicate with relevant stakeholders.

Care Cloud is an efficient, intuitive digital mesh layered on top of existing infrastructure networks to make support simple, efficient and convenient for everyone involved, including Caregivers, and relevant personnel in hospitals, schools, law enforcement and in the community setting such as community centres, grassroots organisations, self-help groups, Family Service Centres (FSCs) and the Care Hub. The Care Cloud would enable

them to access the right knowledge, and facilitate direct and simple exchange of information. With data presented simply, they can take quick action, streamlining existing care patterns and best practice behaviours.

Family Manager

Currently, families who need help in their caregiving journey come into contact with many social workers and healthcare workers. However, these workers are limited in their assistance as they do not always know the family context of their clients. The individual professionals who are supporting the very same families do not systematically talk to each other to share their knowledge. The Family Manager is a role to unify current existing multiple persons who are already fulfilling different roles. Feedback from sector decision-makers and service managers reveal that this is a needed role, but one that requires careful co-development with stakeholders to ensure it simplifies and does not add complexity to the landscape.



From Crises to Prizes

Support Caregivers in moments of fear with on-demand help.

This concept is about tools and training to help Caregivers capture, review and analyse their crisis situations in order to learn from them. Based on their personal crisis history and profile, they can attend tailored training programmes at the Care Hub, with the goal of building resilience and capabilities in dealing with crises. As Caregivers develop their crisis management skills, they can eventually grow to become coaches of other Caregivers facing similar situations.

The Parachute app supports Caregivers in moments of fear. This is an app that Caregivers can download upon recommendation from their Family Manager, and use when they are confronted with threatening or difficult behaviour from their care receiver. Two types of specialised training programs will be offered with the app by the Family Manager, to target both Caregivers as well as first responders:

- 1. Team ReACT** For the Care Hub to train a specialised force within the Emergency Services of police and ambulance services.
- 2. ACT Now** Personalised training for Caregivers to equip them to deal with a crisis - how to react, respond and who to call based on their personal situation and history.

Characteristics of the app include:

1. Personalised journey mapping

The app visualises the Caregiver's journey through past crises to the present, so that they can keep an overall perspective on their experience, and learn from their crises patterns with the help of the Family Manager.

2. Direct contact to public emergency services

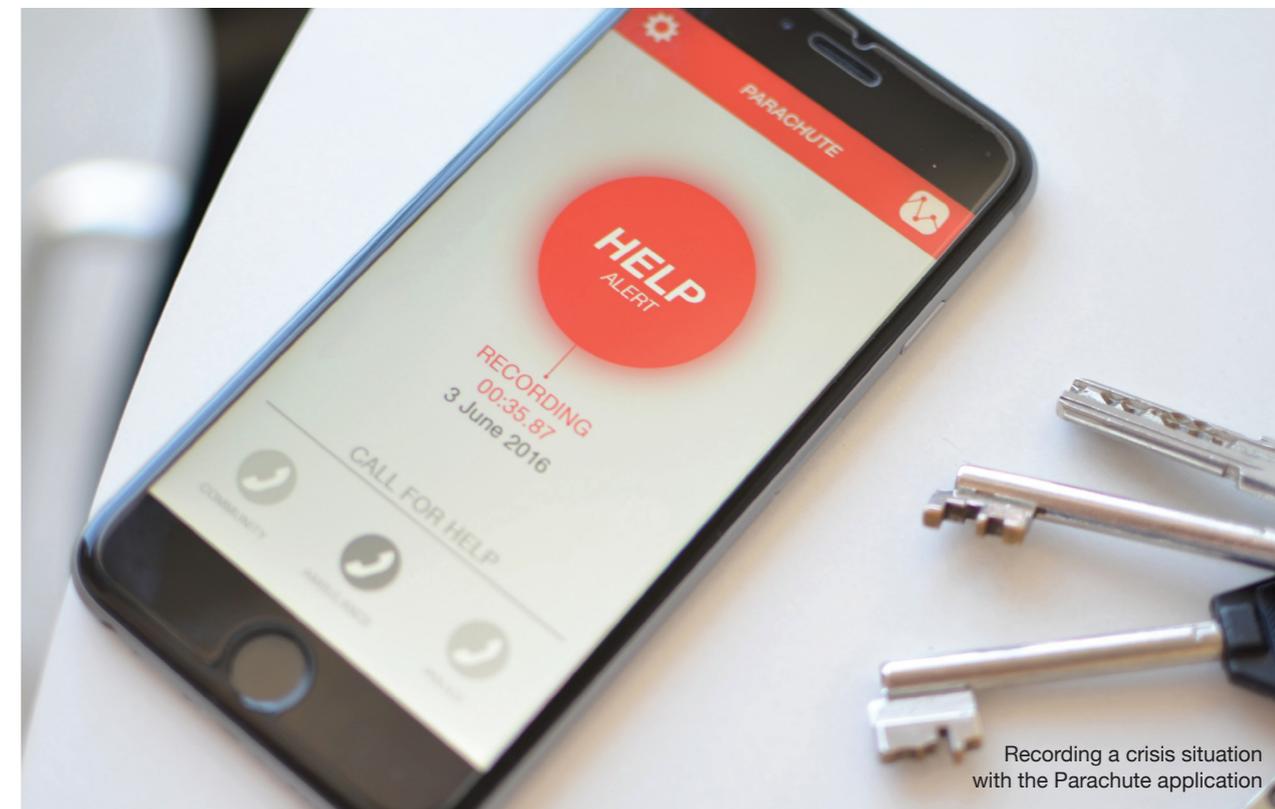
Caregivers can also access more personalised support, for example to set up favoured response strategies together with the Family Manager. The app can connect with the special forces teams in emergency services who are now trained to deal with such situations, quickly and sensitively.

3. Record crisis situations

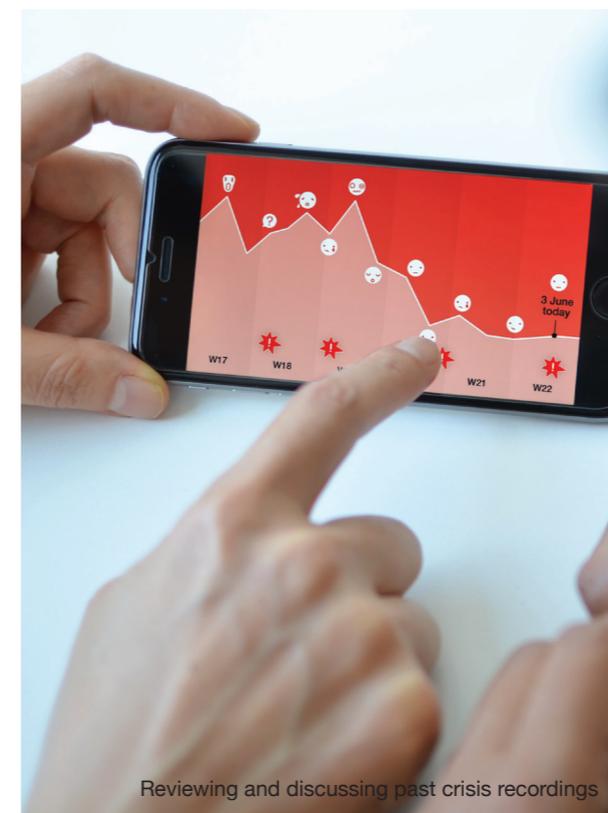
The app can be used to capture crisis situations and make it possible to share them when necessary and with the relevant stakeholders, such as social and healthcare professionals, or other family members.

4. Keep track of Trophies

Caregivers can work towards reACT training milestones, feel a sense of achievement as they win Trophies as symbolic rewards, and learn to better deal with their crises situations.



Recording a crisis situation with the Parachute application



Reviewing and discussing past crisis recordings



Overview of achievements in the reACT crisis training

Another unpredictable day starts for Madam Wong. Her husband's illness causes her lots of anxiety...

I AM SCARED, HE CAN ACT OUT ANYTIME

I AM READY TO ESCAPE!!!

Her Family Manager suggests she use the Parachute App to facilitate help during crisis situations...

DOWNLOAD PARACHUTE APP



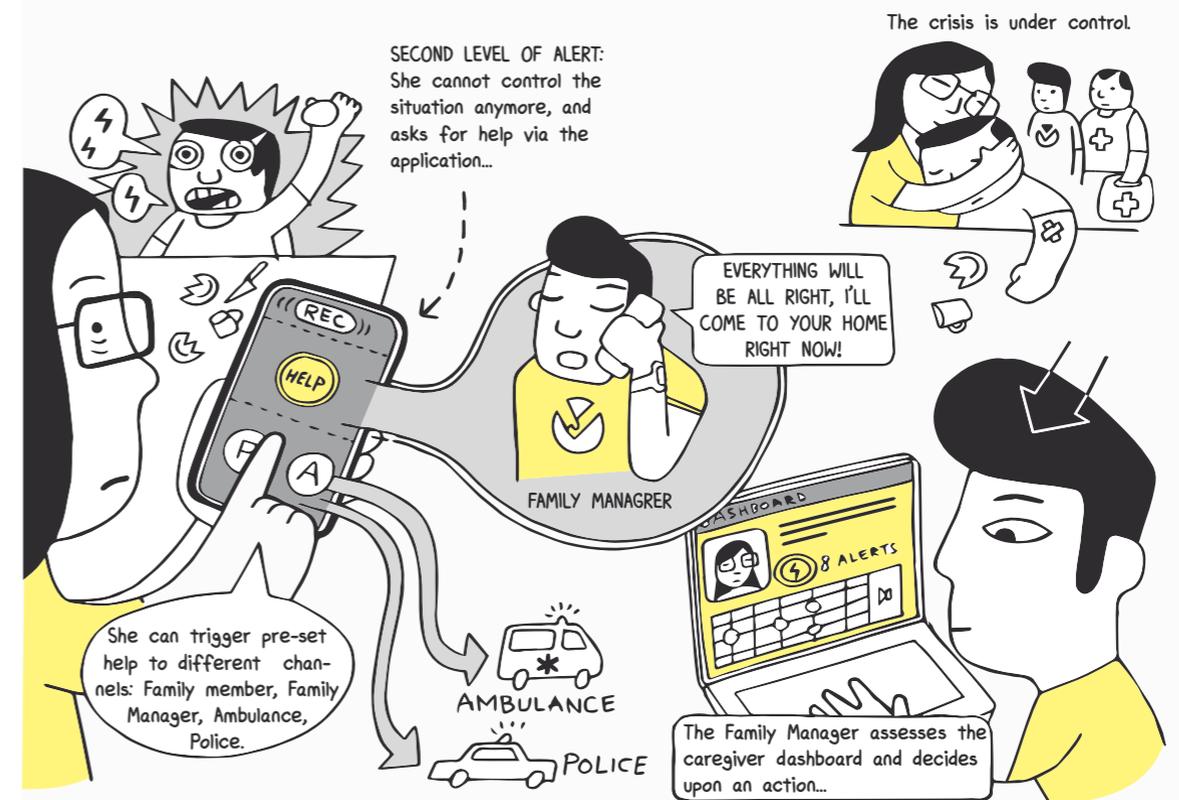
The Family Manager receives a message so he becomes aware of the situation.

When a crisis situation is about to happen...



FIRST LEVEL OF ALERT: When activated, the app functions like a black box recorder.

Meanwhile she attempts to calm her husband down.



SECOND LEVEL OF ALERT: She cannot control the situation anymore, and asks for help via the application...

The crisis is under control.

EVERYTHING WILL BE ALL RIGHT, I'LL COME TO YOUR HOME RIGHT NOW!

FAMILY MANAGER

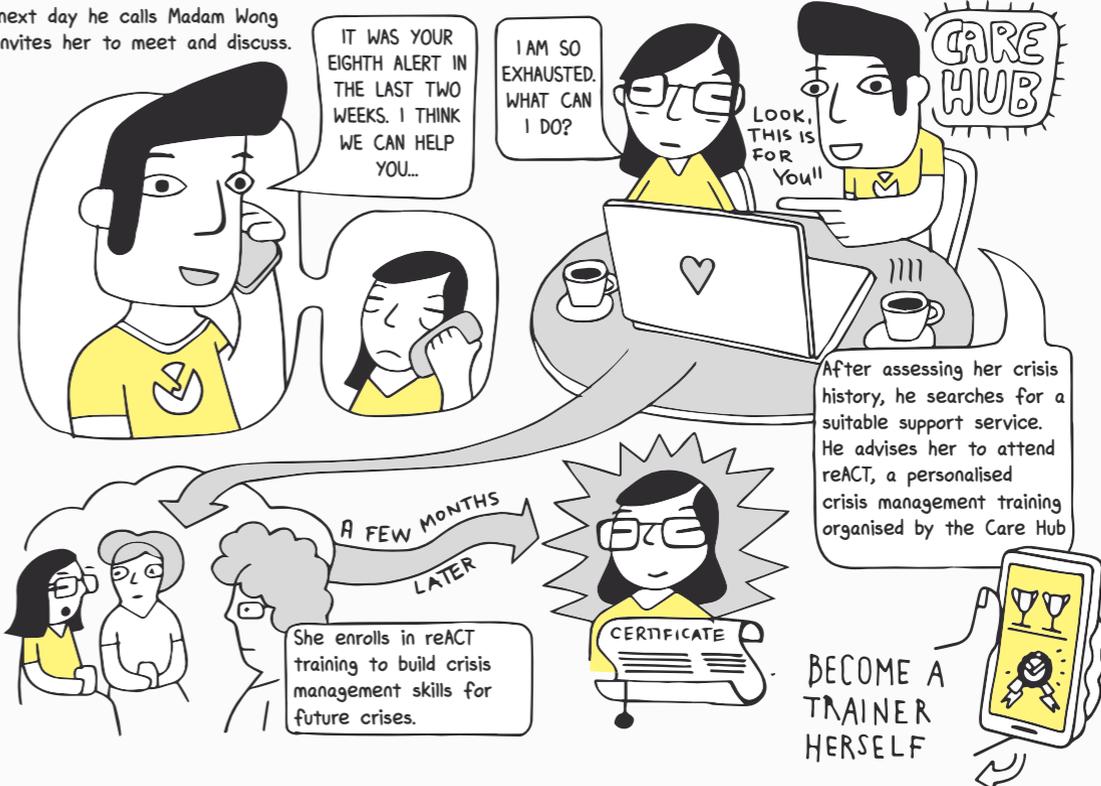
She can trigger pre-set help to different channels: Family member, Family Manager, Ambulance, Police.

AMBULANCE

POLICE

The Family Manager assesses the caregiver dashboard and decides upon an action...

The next day he calls Madam Wong and invites her to meet and discuss.



IT WAS YOUR EIGHTH ALERT IN THE LAST TWO WEEKS. I THINK WE CAN HELP YOU...

I AM SO EXHAUSTED. WHAT CAN I DO?

LOOK, THIS IS FOR YOU!!

CARE HUB

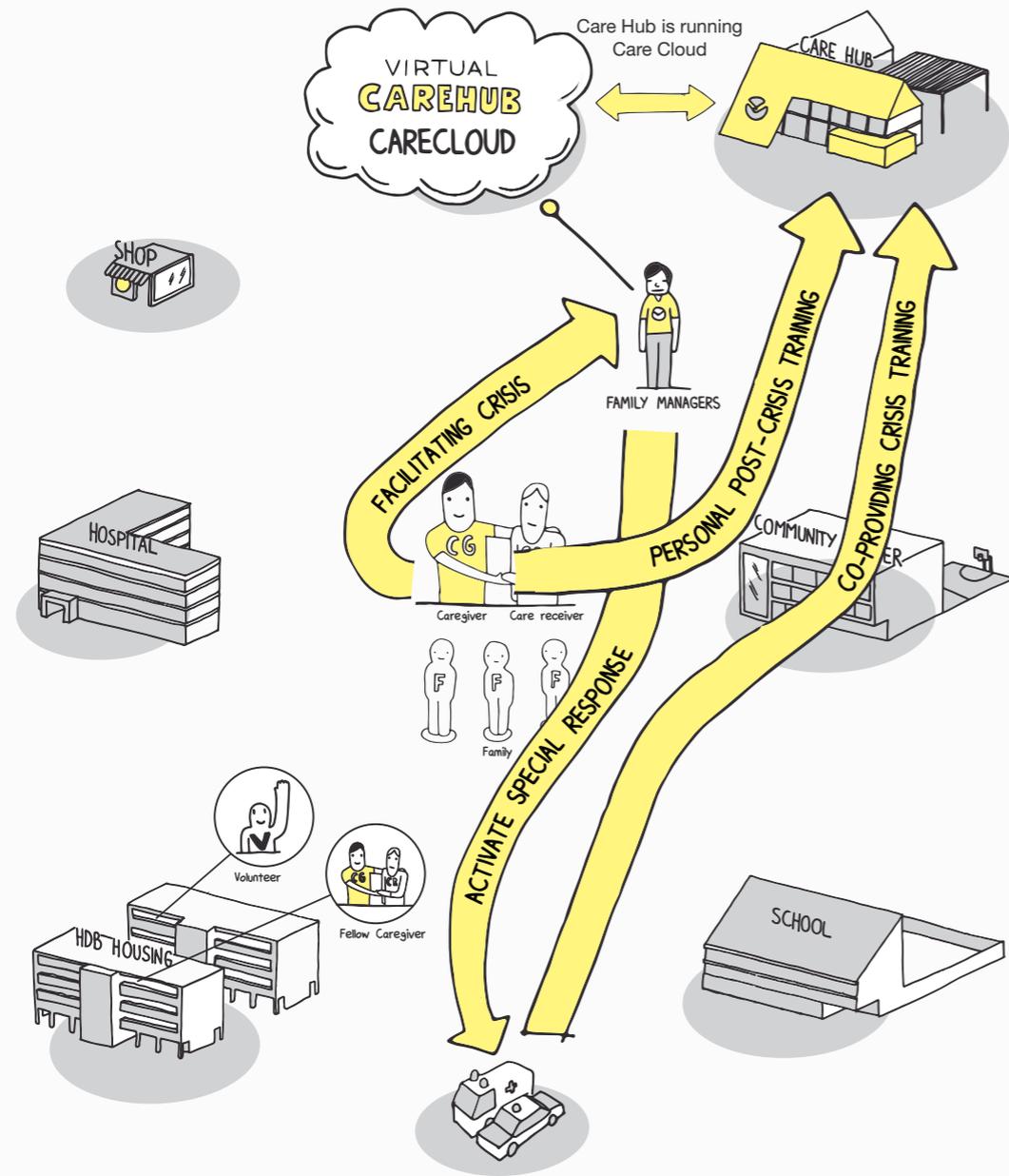
After assessing her crisis history, he searches for a suitable support service. He advises her to attend reACT, a personalised crisis management training organised by the Care Hub

A FEW MONTHS LATER

She enrolls in reACT training to build crisis management skills for future crises.

CERTIFICATE

BECOME A TRAINER HERSELF



Your Call to Action



CAREGIVERS :

Imagine you find yourself in a scary or challenging situation confronting the person you care for. Is there something you would like to record or capture in the moment? How could you use this to share your experience with others? Or to reflect and learn from it yourself?



PROFESSIONALS :

As you get to know your clients and patients, you probably see patterns in their crisis behaviour and issues over time. How would you share this understanding with them directly and together formulate personalised strategies to help?



POLICY MAKERS and DECISION MAKERS:

Emergency services are called in to help Caregivers in crisis situations, but their presence can add to the fear and stigma of the situation. How would you set up a special forces team that could sensitively support Caregivers in crisis?

Smooth Care Touch Points

Facilitating transitions between health care and social care services.

Caregivers currently tread across healthcare and social service systems which are in silos - both equally complex, each a fixed ecosystem on its own. Furthermore, healthcare as experienced by Caregivers today can be crisis-oriented, episodic, and impersonal, as healthcare resources are overstretched. The opportunity then lies in releasing support to community-based touch points, such as the polyclinic or Community Clubs (CCs), that can locally serve and support Caregivers by connecting health and social service personnel together and improving communication between them. In designing the transitions from healthcare to social care in such a continuous and personalised manner, Smooth Care Touch Points aims to improve Caregivers' satisfaction with care as well as professionals' service outcomes, control emergency-related healthcare costs, and keep patients in their homes longer.

Blue Flag Protocol

During a healthcare appointment, medical professionals in the community, such as General Practitioners who are embedded in neighbourhoods, are able to follow a new protocol that marks out a family that is facing a complex

care challenge. They can then refer the family and Caregiver to social care professionals, such as a Family Manager based at the Care Hub. These in turn can reach out and proactively support the Caregiver and their social care needs - personal, emotional and practical.

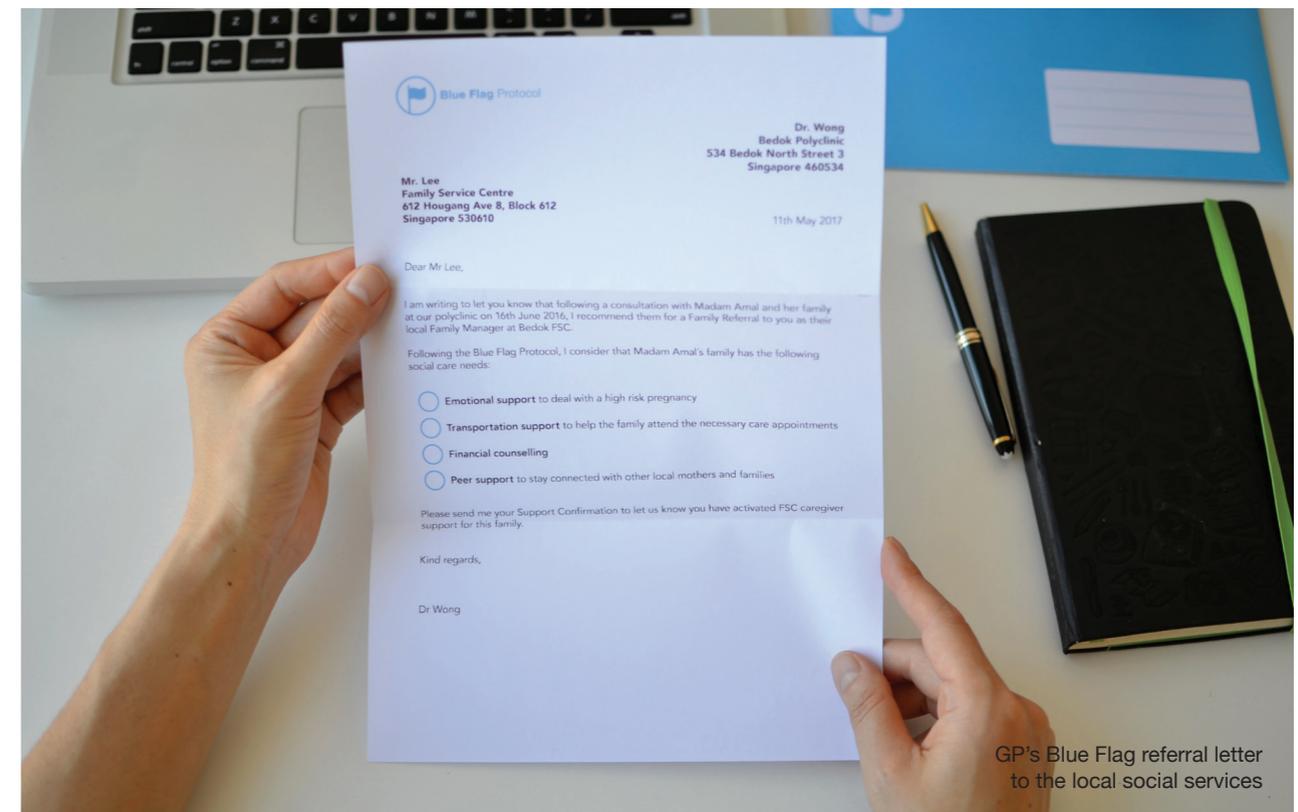
Sharing Cove

Here, the Medical Social Worker and the Family Manager collaborate to establish continuity in support between healthcare and social care services for the Caregiver. The Medical Social Worker refers for support to a local Family Manager, through the Care Cloud, using the back-end IT platform and tools.

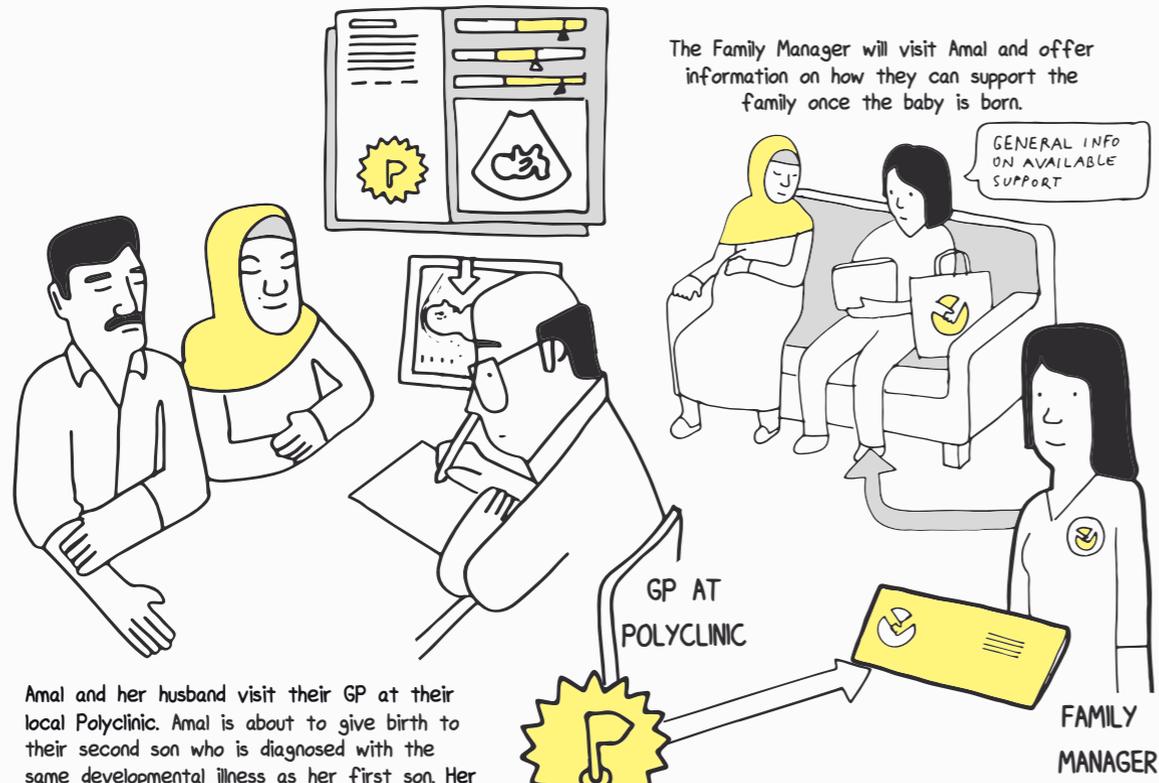
The Family Manager will help to coordinate localised, personalised support after and between healthcare visits. The Medical Social Worker and Family Manager can hold online virtual case management conferences to deal with specific issues, or to check in on the progress of a particular Caregiver and the family. The content shared can be exchanged to keep the multidisciplinary care team informed and up to date.



A Blue Flag information letter sent to the family



GP's Blue Flag referral letter to the local social services



The Family Manager will visit Amal and offer information on how they can support the family once the baby is born.

GENERAL INFO ON AVAILABLE SUPPORT

GP AT POLYCLINIC

FAMILY MANAGER

BLUE FLAG PROTOCOL

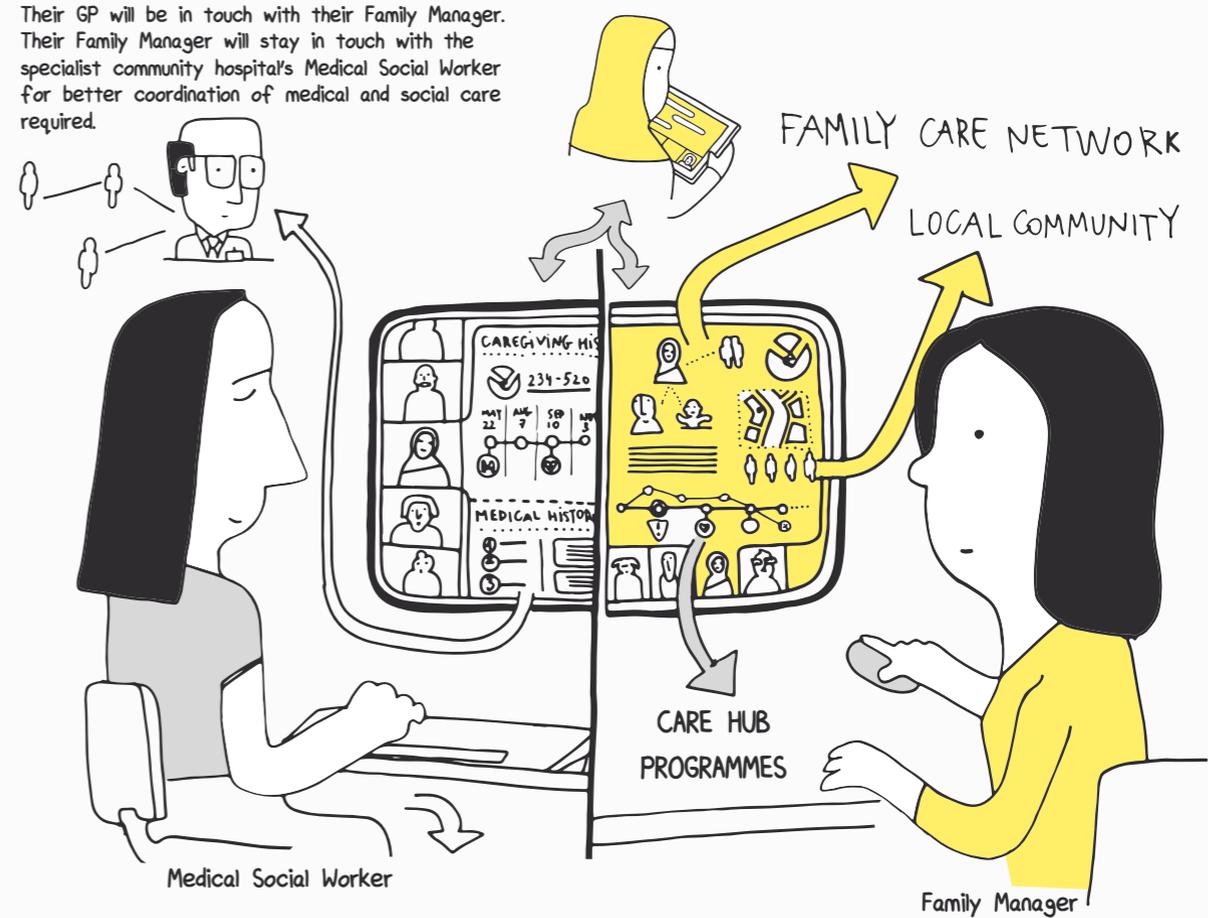
Amal and her husband visit their GP at their local Polyclinic. Amal is about to give birth to their second son who is diagnosed with the same developmental illness as her first son. Her GP is looking through the diagnosis from the specialist clinic. Knowing how hard it is for Amal and family to manage with their first son already, he expects they might need social care support. He triggers the Blue Flag Protocol, that flags Amal's family to the local Family Manager, at the local Care Hub.



After the baby is born, the new Family Manager will setup a personalised plan with Amal and family. This plan includes a structural support program called The Family Care Plan, and the Caregiver Toolkit that allows them to keep in touch, manage activities, medication, and to be connected to other families facing similar challenges.

FAMILY CARE PLAN

CARE GIVER CHECK-UP



Their GP will be in touch with their Family Manager. Their Family Manager will stay in touch with the specialist community hospital's Medical Social Worker for better coordination of medical and social care required.

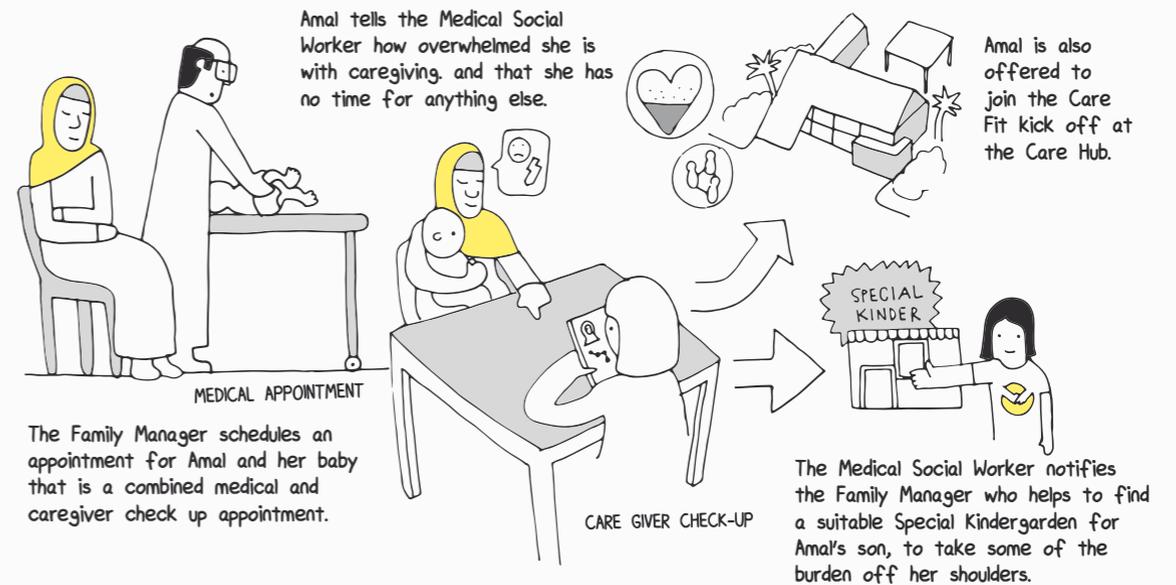
Medical Social Worker

Family Manager

CARE HUB PROGRAMMES

FAMILY CARE NETWORK
LOCAL COMMUNITY

During the early years of the new born, both Medical Social Worker and Family Manager keep in touch and support the family's needs as a team; coordinating regular healthcare checkups, monitoring the family situation, signposting available services and trainings.



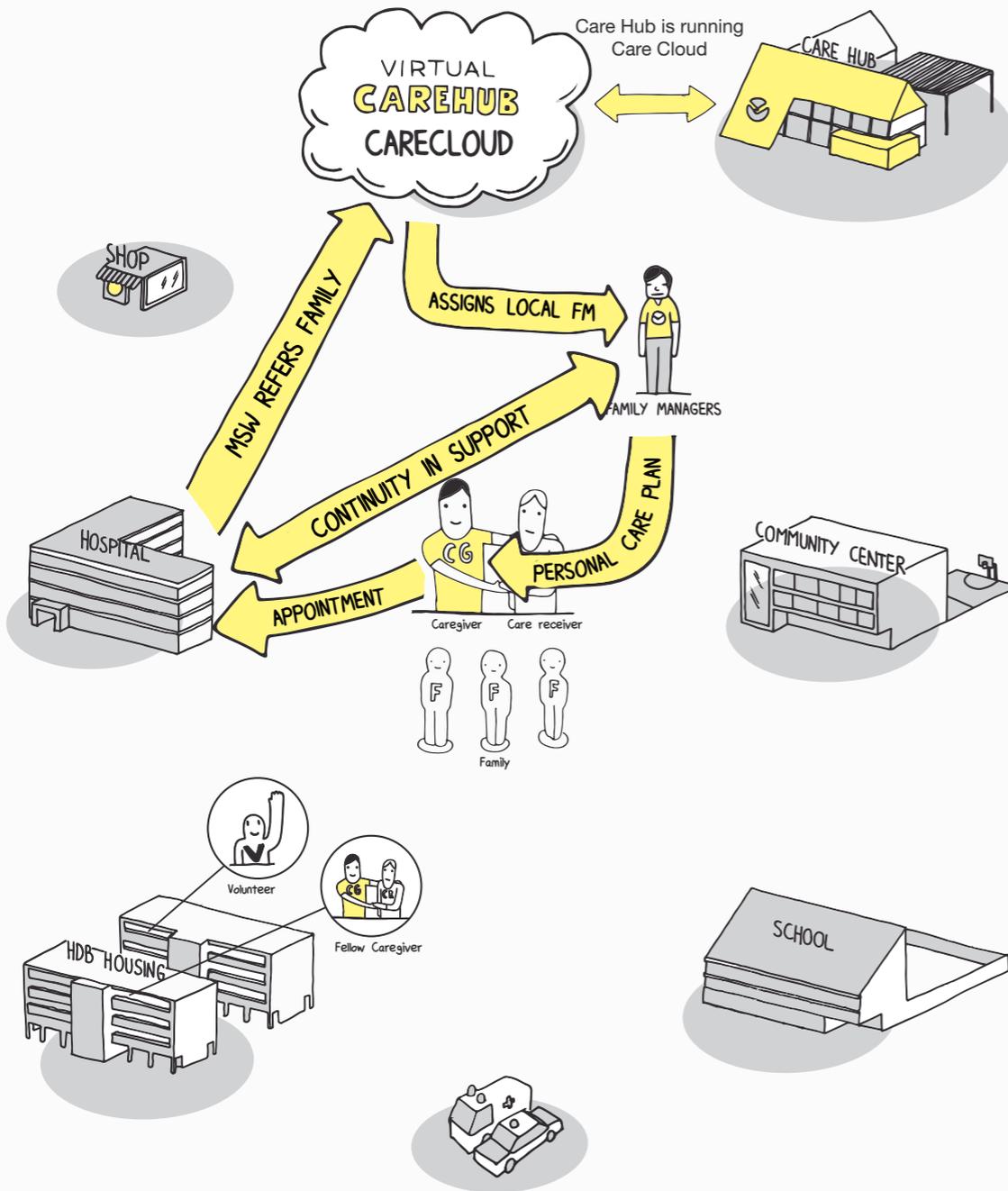
Amal tells the Medical Social Worker how overwhelmed she is with caregiving, and that she has no time for anything else.

Amal is also offered to join the Care Fit kick off at the Care Hub.

The Family Manager schedules an appointment for Amal and her baby that is a combined medical and caregiver check up appointment.

The Medical Social Worker notifies the Family Manager who helps to find a suitable Special Kindergarden for Amal's son, to take some of the burden off her shoulders.

Your Call to Action



PROFESSIONALS :

New healthcare and social care personnel might have limited experience in identifying and dealing with complex cases. What if there was a shared database to refer to where collective knowledge is made accessible?



POLICY MAKERS and DECISION MAKERS :

Current levels of assistance are based mainly on the financial health and presence of family Caregivers. What if there was a more efficient way to see who really needs help?

The WayForward Programme

Proactive guidance in navigating services so Caregivers don't feel lost.

The **WayForward Programme** introduces a much needed role into the social care system, that of a navigator for Caregivers; someone who firstly understands the family context, and secondly, supports the Caregiver's needs, helping them find the best pathway of support through the system using a variety of proactive management tools.

The **WayForward Toolkit** comprises:

- A **ProCare Journal** that provides social workers or Family Managers with a resource guide and set of tools designed to facilitate their conversations with Caregivers, and help them reflect and develop best practice for personalised support. (Download the ProCare Journal at <http://ncss.gov.sg/caregiving>).

- The **ProCare App** allows social workers and Family Managers to have a direct line of communication with Caregivers, enabling them to follow and support the Caregiver in their day-to-day caregiving. This includes being able to see an emotional journey of a Caregiver, to spot the highs and lows and offer appropriate support when needed.

Part of this concept involves the creation of a new social care role called the **Family Manager**; this could be a professional or a trained volunteer, an existing social worker trained for this purpose, or even a former Caregiver trained to step up into this role. The Family Manager is a concept that is

expected to be further co-created with relevant stakeholders, in order to be effective and efficient. For now we see the Family Manager functioning as:

- A coach and facilitator for Caregivers in crisis. He would be multi-disciplinary and highly trained in cases of abuse, disability, child protection, mental health, with sufficient expertise in administering medicine. He would either have knowledge of these or have quick access to team members who would have this knowledge.

- A navigator for Caregivers who feel lost. Family Managers need to be knowledgeable about available services and technologies, and can take the time to understand each family's unique situation, and make it possible for Caregivers to get the full benefits of technological solutions. They could also teach skills for managing multiple, competing responsibilities.

- Community builders, locating, mobilising suitable neighbours and empowering them to reach out to the families in need.

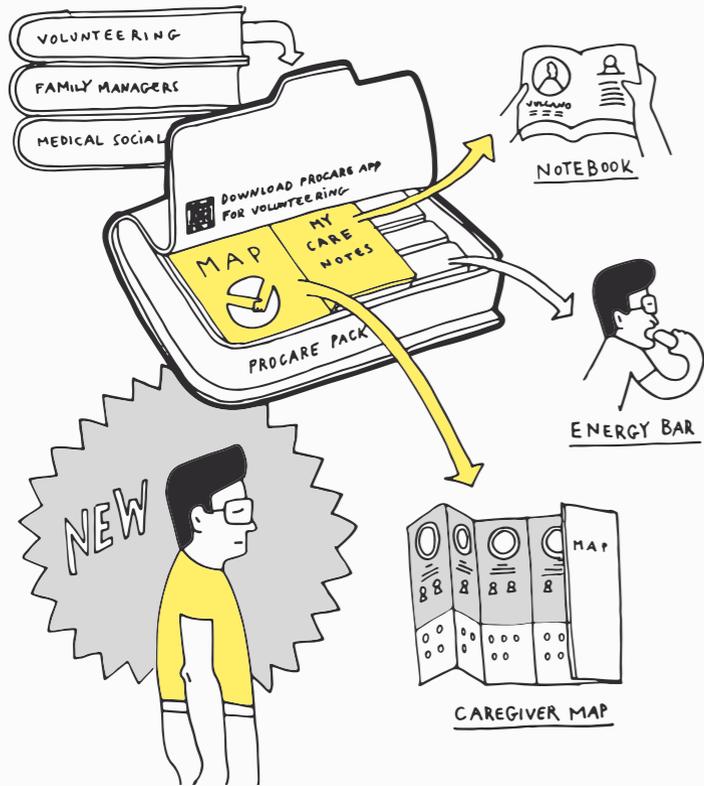
The Care Hub plays two key roles in this concept; from being the training centre for Family Managers, to offering an enabling platform with the Care Cloud hosting knowledge, content and tools for the Family Manager to use. If Family Managers are a mobile workforce to stay close to Caregivers in the community, the Care Hub acts as their headquarters and base.



The ProCare dashboard interface to follow caregivers at-a-glance



The ProCare Caregivers overview interface shows alerts, emotional history, messages and planned appointments



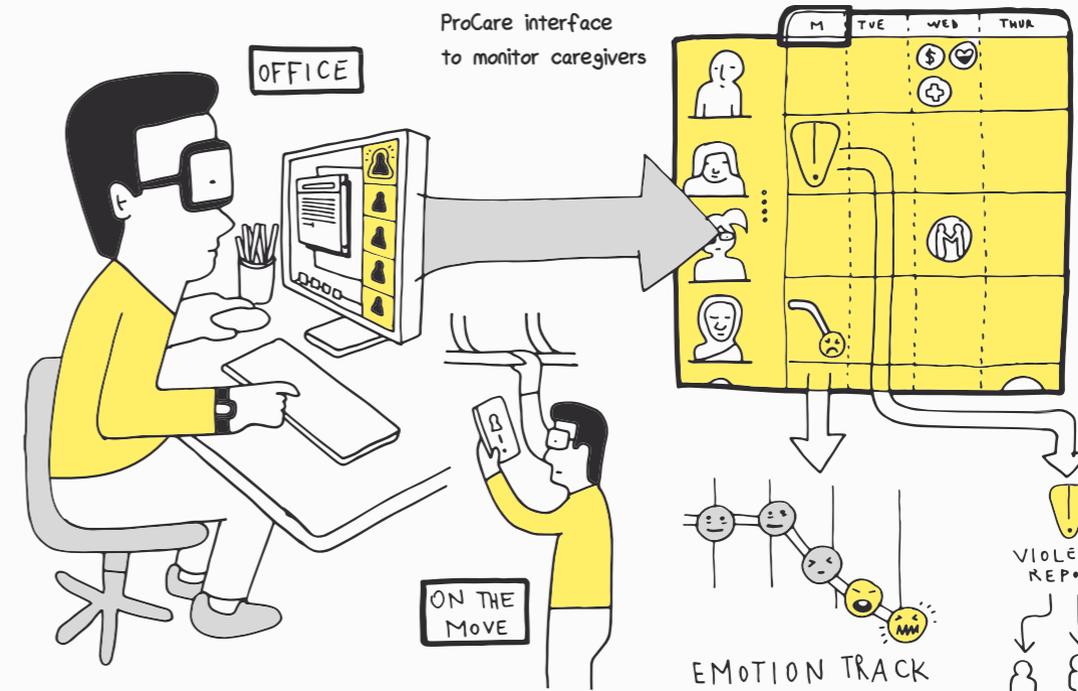
When a new volunteer, social worker or Family Manager joins the social services, he or she will get a Procare Pack that helps to transfer knowledge and ways of working.



Jonas is using the Care Notes, and the ProCare App to get up to speed on how best to provide care for caregivers. He can also shadow three of his Training Buddies during their monitoring of caregivers and family visits.



Jonas uses his ProCare App or Care Journal while visiting one of his new family clients as their Family Manager. He is facilitating the family conversation about how they plan to care for their care receiver, as well as helping them to navigate amongst the available care services. He sets up the CareCard for the main caregiver and gives the Caregiver Starter Pack to download the Care Cope App.



While Jonas is performing administrative work at his desk or on-the-move, he has a real-time overview of the caregivers he is managing. He can pick up warnings, and status, as well as follow up with timely actions.

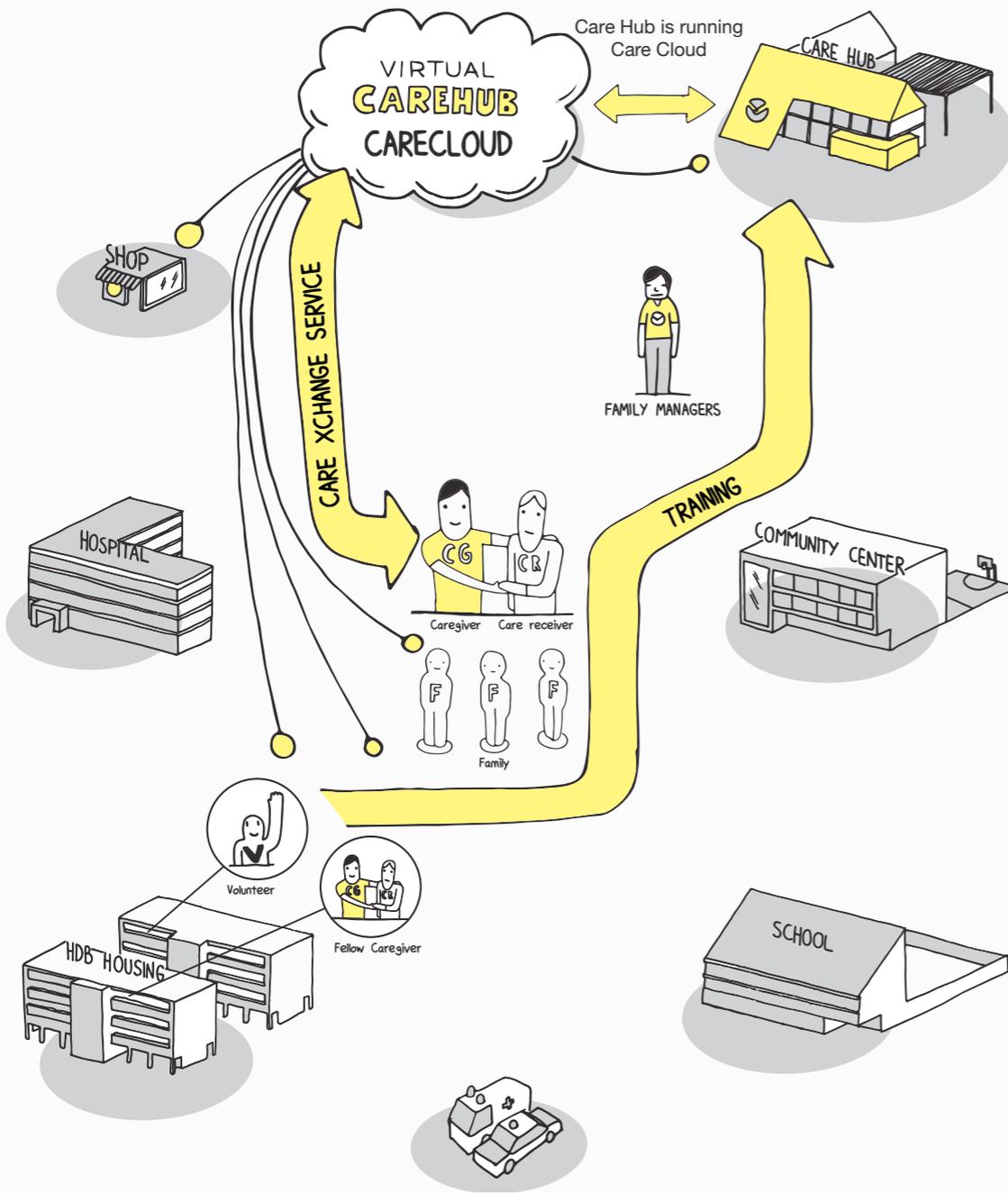
Warning of an emotional decline in one of his caregiver client over the past few weeks. Crisis Alert pops up when a caregiver initiates a crisis situation with their Parachute App.



Following up on Mirza's emotional alert, Jonas calls her to understand the situation and find out what's happening. Based on this, he will plan in a Flash Visit to visit her the next morning, and help her find suitable support services.

He also will put out a request to the community of social workers, volunteers and community members in Mirza's neighbourhood to check on her. A volunteer answers, and provides fast relief for Mirza.

Your Call to Action



PROFESSIONALS :

There are multiple social service providers providing the same help in this landscape, focusing only on the client. What would help healthcare and social service providers understand the family context beyond a client, navigate and communicate across social care and health care, and provide personalised support and best resources for the family?



POLICY MAKERS and DECISION MAKERS :

There is lack of coordination among the many stakeholders, and confusion over multiple schemes available which affects efficiency in providing help in a timely and efficient way. Is there a way to expand the scope of social services so that the family can have social support in a more organised way, and across different needs and various services? What policies, tools and training would be needed to offer structural support for Caregivers?

Caregiver Wellbeing

Kick start self-care at the Care Hub, continue being fit-to-care in everyday life.

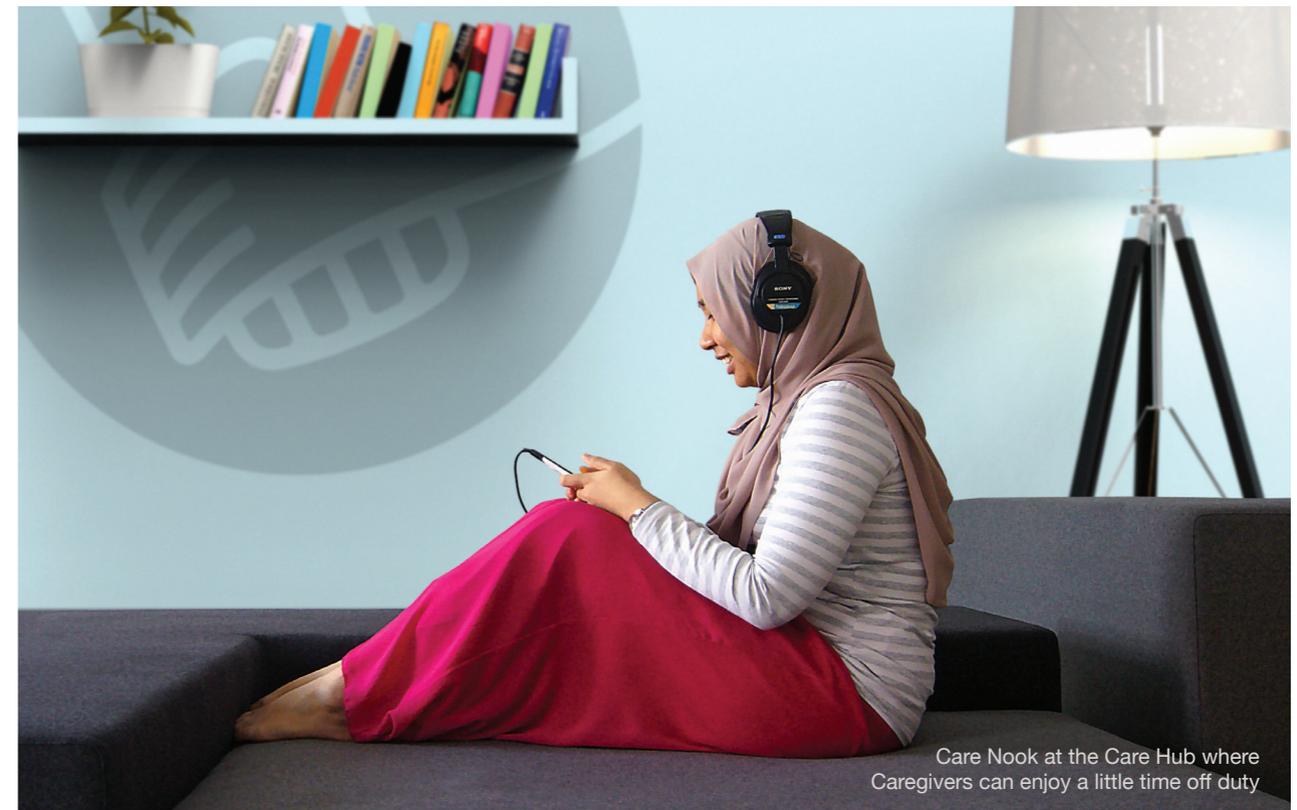
As Singapore relies increasingly on informal family Caregivers, it is imperative that Caregivers realise the need to take care of themselves, in order for them to keep up the stamina and continue to be long-term Caregivers. With that in mind, this concept focuses on helping Caregivers realise the importance of their personal wellbeing. The **CareFit** programme identifies, activates and supports Caregivers in their need to care for themselves mentally, emotionally, and physically. Caregivers can go to the Care Hub to kickstart their CareFit programme. The Care Hub offers them a safe, physical space to vent, rejuvenate, learn, and share their issues, knowledge and strategies with others. A **CareFit Coach** can be on hand to guide the Caregiver.

Using the **Care Cloud**, Caregivers can continue this care fitness in their everyday life wherever they are, by accessing their personalised online programme. The personal plan brings the ‘me time’ to everyday moments by offering programmes, support and community links that can motivate the caregiver to stick to their CareFit programme.

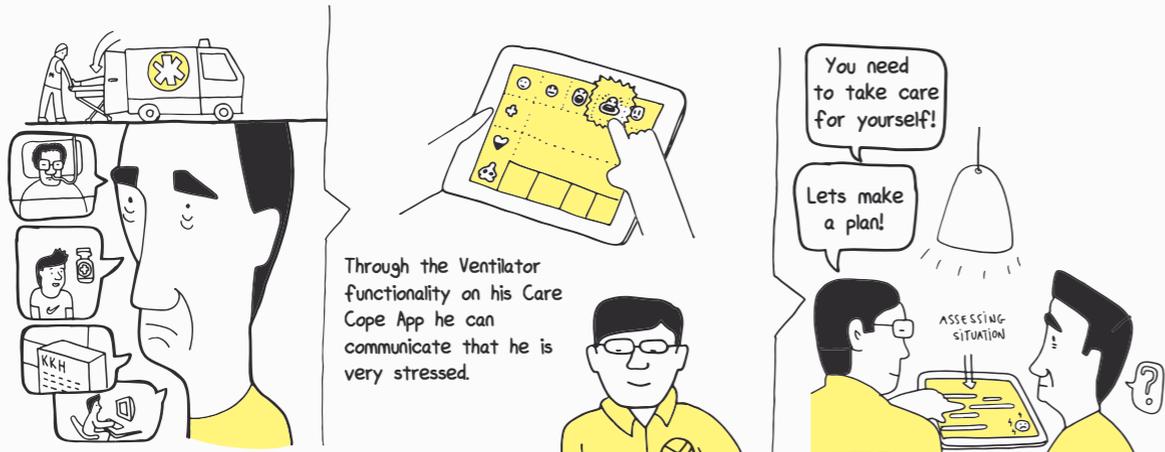
The **Care Nook** at the Care Hub also acts as a sanctuary that offers 24/7 access for Caregivers to quickly find space for themselves. It is also a place where communities of Caregivers can come together to be nurtured and strengthened collectively.



The CareFit app with an overview of planned and suggested activities and programming for Caregivers



Care Nook at the Care Hub where Caregivers can enjoy a little time off duty



Through the Ventilator functionality on his Care Cope App he can communicate that he is very stressed.

Mr. Lim's wife is taken to the hospital with a heart attack, he is suddenly overwhelmed and finds it extremely hard to manage all caregiving responsibilities on his own.

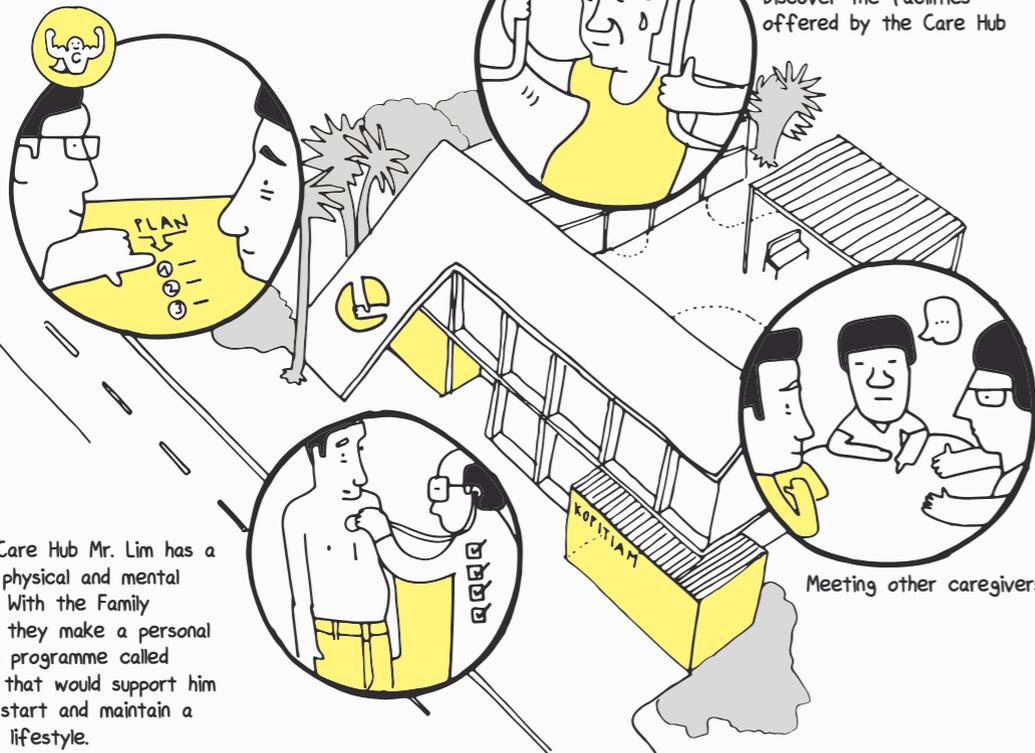


The Family Manager receives an alert through his ProCare interface about Mr. Lim's wife being in hospital, as well as Mr Lim being stressed out.



Together with the Family Manager, Mr. Lim makes a plan that will allow him to focus on his mental, social and physical wellbeing. Mr Lim's personal wellbeing programme starts at the Care Hub.

CAREFIT



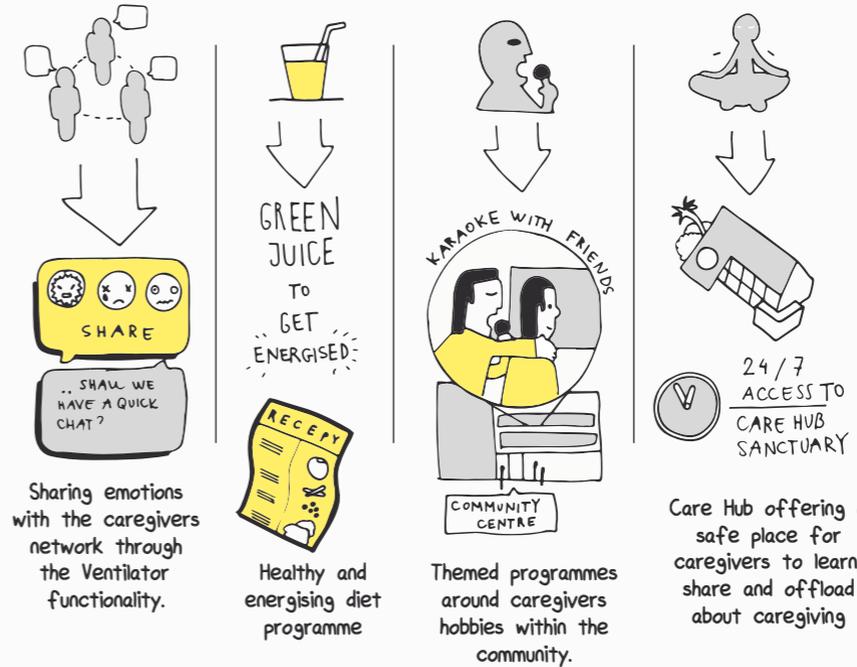
At the Care Hub Mr. Lim has a medical, physical and mental checkup. With the Family Manager they make a personal wellbeing programme called CareFit, that would support him to kick start and maintain a healthier lifestyle.

Discover the facilities offered by the Care Hub

Meeting other caregivers

CAREFIT

The CareFit Personal programme is facilitated through the CareCope App, and it offers caregivers ways to take a step back from the everyday caregiving duties and start considering themselves.

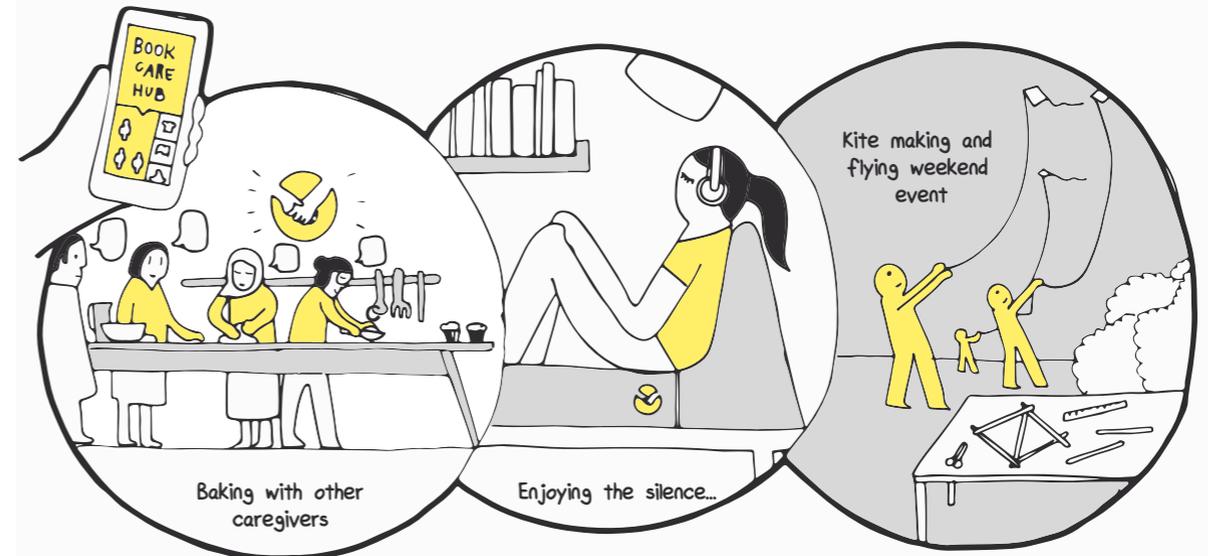


Sharing emotions with the caregivers network through the Ventilator functionality.

Healthy and energising diet programme

Themed programmes around caregivers hobbies within the community.

Care Hub offering a safe place for caregivers to learn, share and offload about caregiving



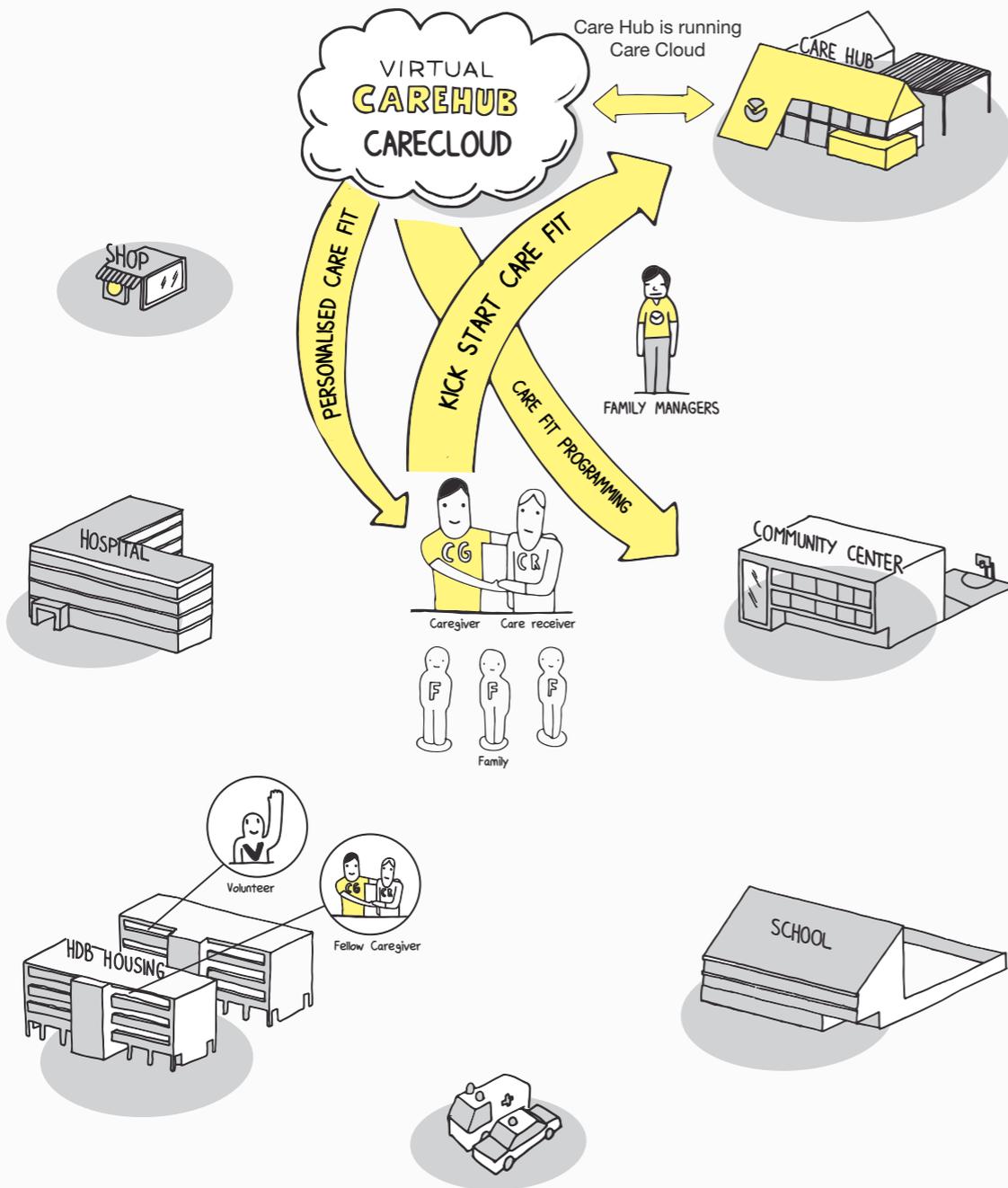
Baking with other caregivers

Enjoying the silence...

Kite making and flying weekend event

At the local Care Hub caregivers can find and book activities, spaces, resources that will allow them to have an hour or two to swich off the daily grind, meet and share with other caregivers, and occasionally participate in caregiver's team building activities.

Your Call to Action



CAREGIVERS :

Do you think you have sufficient rest and time for yourself? What stops you from making time for yourself? How would you design a Caregiver care fitness program that could work for you in your everyday life?



PROFESSIONALS :

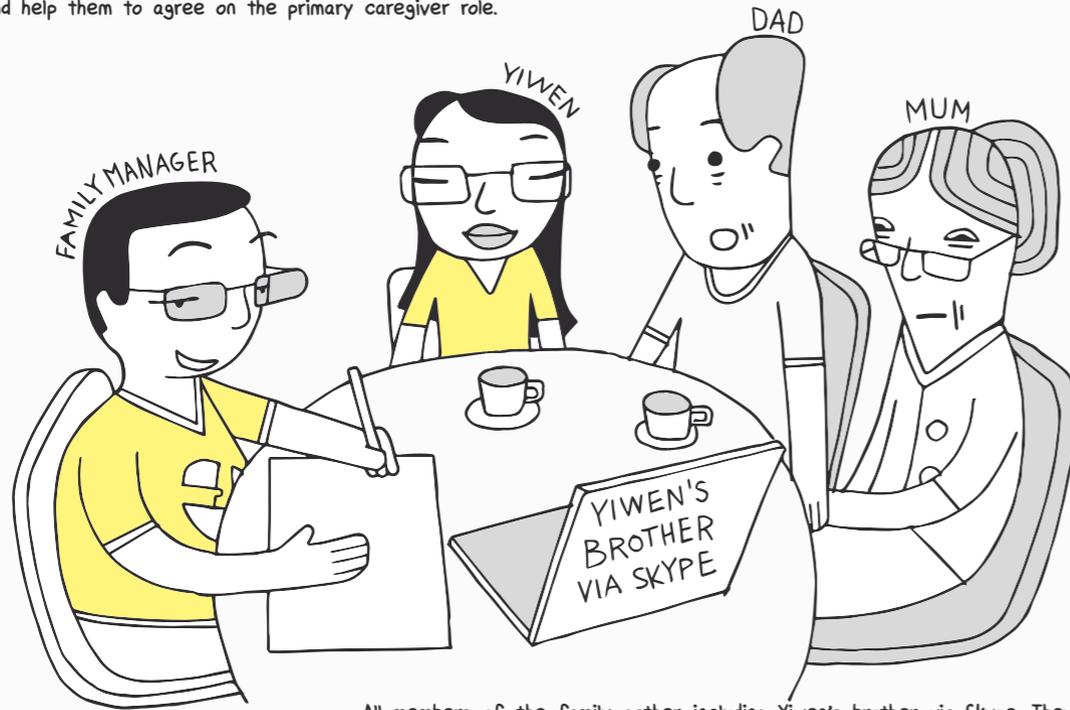
Different Caregivers face different challenges in getting their critical time to care for themselves. How would you try to enable your Caregivers to take some time off for themselves, in order to rest and recharge to stay strong?



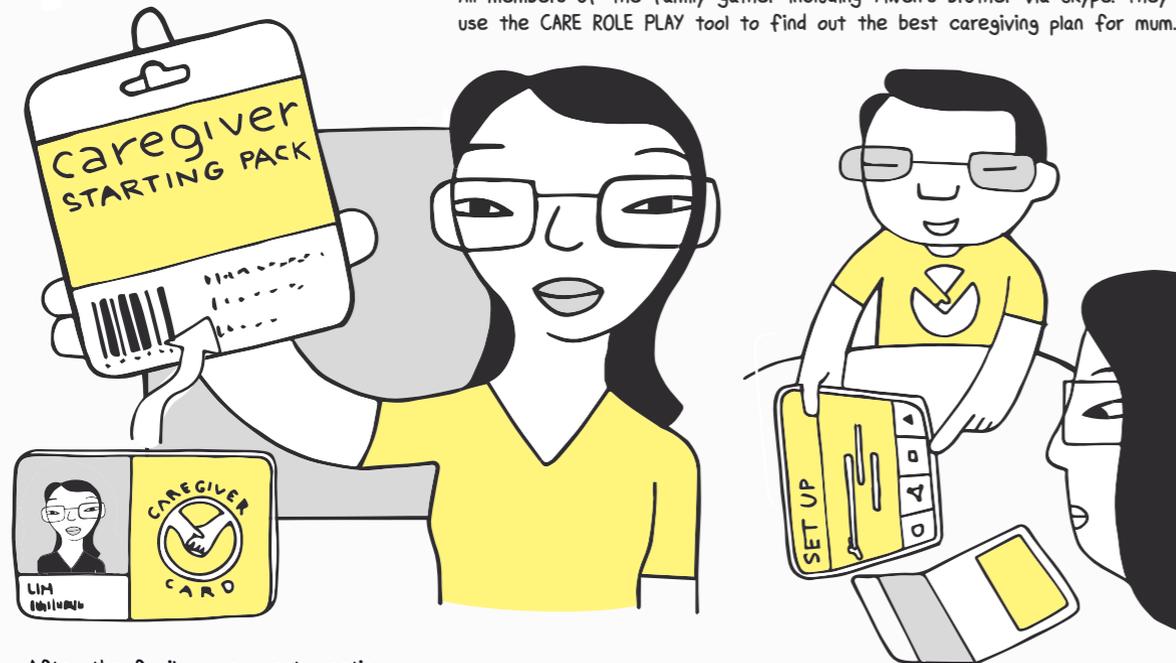
POLICY MAKERS and DECISION MAKERS:

Many Caregivers struggle to balance their own lifestyle with the demands of caregiving. As a policy maker or decision maker can you consider ways that policy can facilitate protocols to offer more flexibility in working arrangements or education, such that a Caregiver need not give up their existing life?

After the diagnosis of her mum, the hospital put Yiwen in contact with a Family Manager. Their assigned Family Manager visits them to assess their care needs and help them to agree on the primary caregiver role.



All members of the family gather including Yiwen's brother via Skype. They use the CARE ROLE PLAY tool to find out the best caregiving plan for mum.



After the family assessment meeting it became clear that Yiwen is the only one who can take the primary caregiver role.

She receives a Starter Pack and a Caregiver Card from the Family Manager...

...and he introduces her to the Care Cope platform which she can use for coordinating family communications, appointments, accessing self-care services etc.



The Care Cope digital platform facilitates Yiwen to plan tasks, overview appointments, connect to the care community, share and save important moments and care about her own wellbeing.



After one year of caring for her mom, Yiwen is about to leave abroad to continue her studies. She needs to pass the caregiving role to her younger brother. This is made easy with the share and transfer caregiving functionality of the Care Cope app.

Empathic Education

Preparing Caregiver support upstream, by educating caring citizens from an early age.

As Caregivers and potential Caregivers generally feel at a loss of what to do when they suddenly become Caregivers, raising awareness about the need to care through education would soften the impact and equip citizens to find assistance to help themselves, or to help others. Becoming a Caregiver should be a natural life stage we can all feel confident and ready to embrace.

One idea to increase the awareness of caring for others is for the **Care Hub** to offer training services to schools under the programme name **Care Class**. This is an experiential curriculum organised by life stage that helps students explore the value of caring, and how they can be caring citizens to their friends, family, schoolmates, community in a participatory and hands-on way. They could explore how caring happens across Singapore,

from the past till the present, and learn about other student groups who are contributing to caring for their nation.

Care Class is also a way to activate the **Blue Flag Protocol** mentioned in the Smooth Care Touch Points concept; to identify families in need of support who may otherwise fall through the cracks. Families in need of support can also be identified by creating greater awareness and sensitivity in a school setting among staff and children. The Care Hub may follow-up to 'diagnose' the needs and direct options for Caregiver support.

Care Class could be a programme co-developed by the Care Hub and other caregiver-centric organisations. It could also be taught by appointed Voluntary Welfare Organisations.



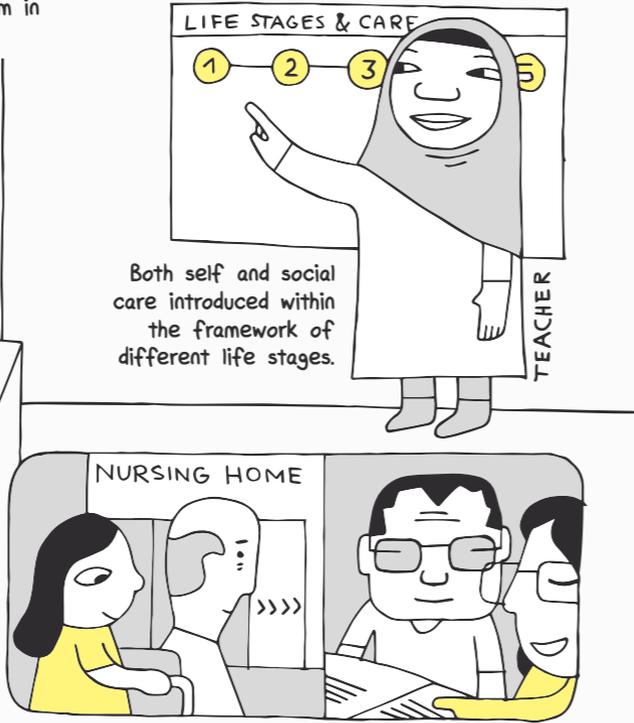
The Care Class curriculum toolkit

Care Class is part of the school curriculum in order to better prepare Singaporeans for the challenges of caring in life.



Pupils can experience various kinds of care services and institutions and build an understanding of care in the society.

Little Huiwen just visited a nursing home in her neighbourhood and now she is doing Care Class homework with her dad.



Both self and social care introduced within the framework of different life stages.

A few months later Huiwen's mum is diagnosed with an illness that suddenly gives her a caregiver role.



Her classmate friend recognises her bad mood and wants to help her.



In the Care Class I remember we were told to pay attention to each other.

The best is to talk to our teacher!

My mom is sick and my dad works hard. I need to do all the work around our home.



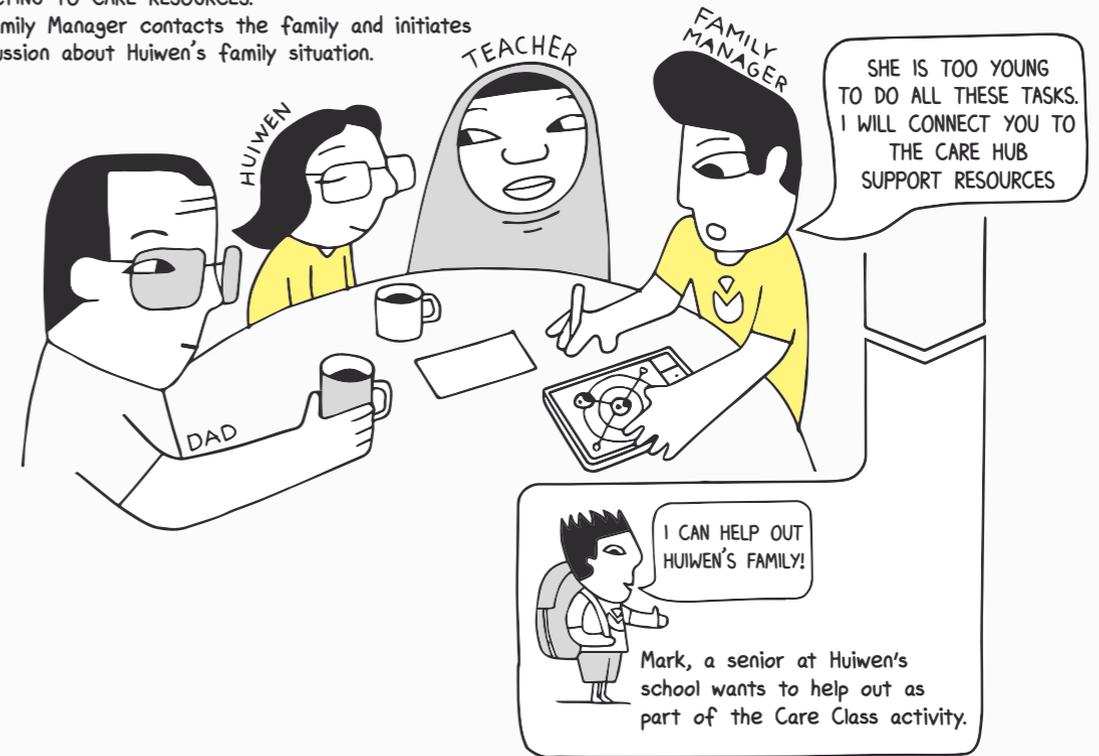
CARE SERVICES ACTIVATED

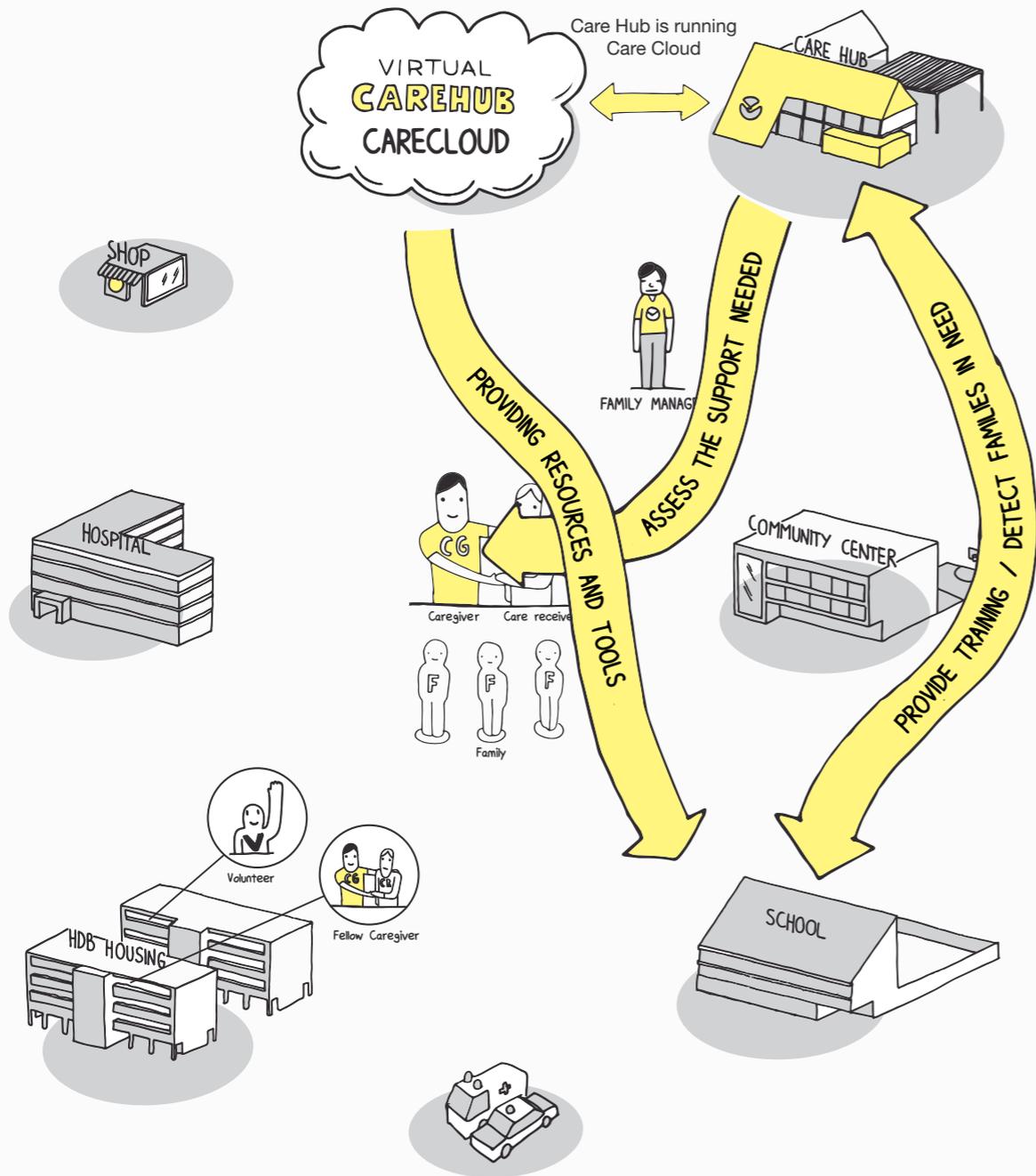
Huiwen's classmate activated a process through the teacher, to connect Huiwen and her family to the Family Manager to seek help for their problems.



REDEFINING FAMILY ROLES AROUND CAREGIVING, CONNECTING TO CARE RESOURCES.

The Family Manager contacts the family and initiates a discussion about Huiwen's family situation.





Your Call to Action



YOUNGER CITIZENS :

Singapore has no shortage of people to care for. How could you better educate yourself and look out for persons or communities which need care? What would make this responsibility exciting for you?



PROFESSIONALS :

Social care professionals have a lot of experience dealing with care situations. What if the experience and care stories were developed into educational packages tailored to students at different ages to cultivate caring citizens? What kind of tools and facilities would you need to teach this subject in an engaging way?



POLICY MAKERS and DECISION MAKERS:

The future of caregiving in Singapore is in the eyes, hands and hearts of the young. Could we encourage schools to provide a carefully tailored curriculum to care for others? Who should develop this curriculum? Who should be the partners in delivering the course? How would you measure success?

Compassionate
Community

Activate a network of compassion in the community to support Caregivers.

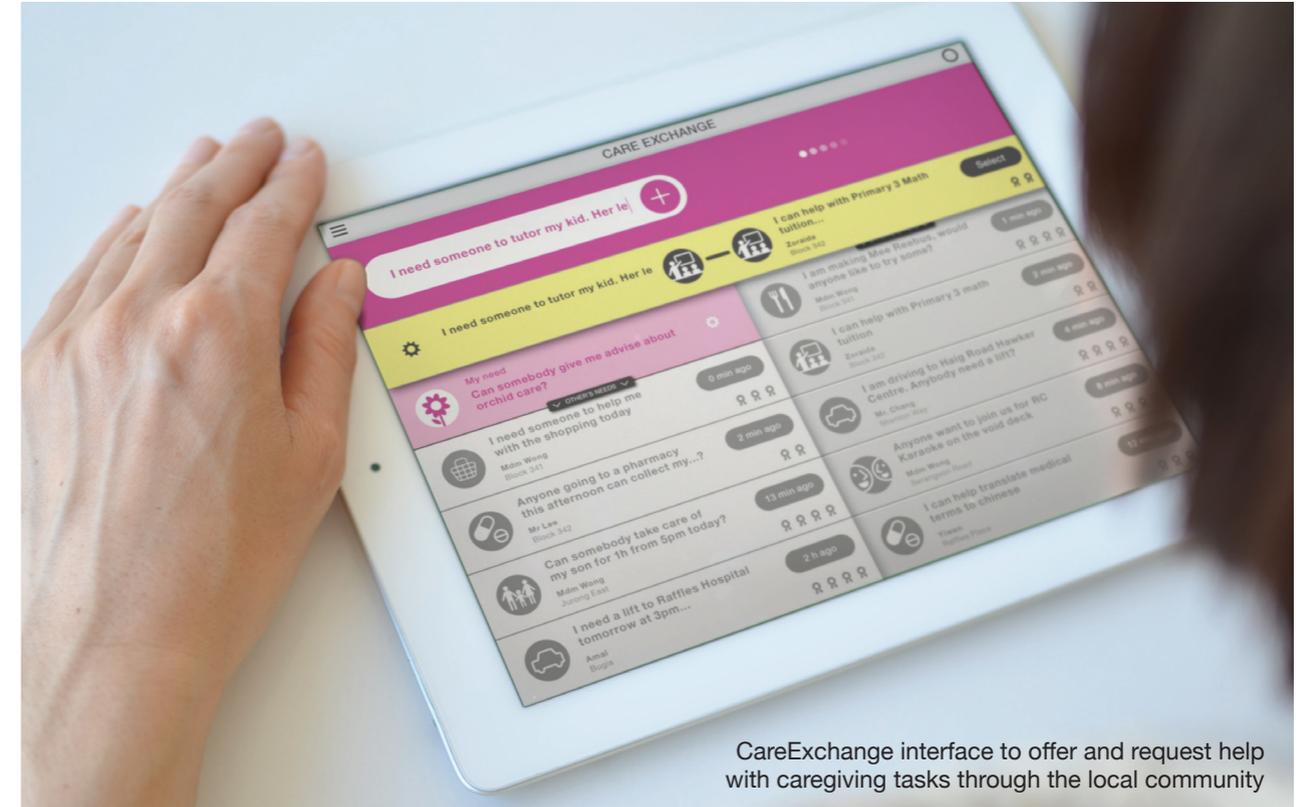
Many Singaporeans might be embarrassed about asking for help from social services, especially for mental health issues, which has a high stigma in Singapore. According to a study by the Institute of Mental Health (IMH), nine in ten people believe that those with a mental illness “could get better if they wanted to”, and that these problems were a “sign of personal weakness”¹². These stigmatising attitudes may prevent people from seeking treatment and getting diagnosed, for fear of being labelled as mentally ill.

By accepting that individual Caregivers might be afraid to ask for help, this concept seeks to normalise the giving of help to Caregivers, by creating new touch points in the community for Caregiver support services.

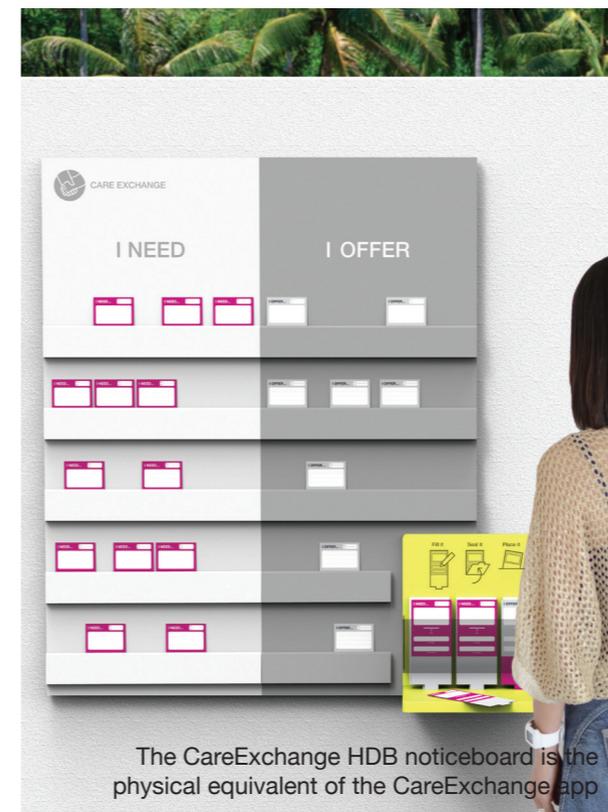
Taking advantage of places with frequent contact between residents, **Kind Eyes** is a service that helps to find and support Caregivers in the neighbourhood. Local shops are encouraged to use their direct social links to channel Caregivers to social services.

Digital tools offer convenience and a degree of anonymity. Hosted on the Care Cloud, the **CareExchange** has a digital platform where people in the community can post and accept requests for help with caring. Needs and demands of Caregivers can also be expressed and matched to garner support through a card exchange system on the community noticeboard at void decks or via a mobile app. The credibility of CareExchange can be kept through users rating, to build that all important trust in the help received. Those who are offering care can also be certified through training at the CareHub.

12. Lai, L. (2015, Oct 6). Straits Times. IMH study reveals stigma surrounding mental illness. Retrieved from <http://www.straitstimes.com/singapore/health/imh-study-reveals-stigma-surrounding-mental-illness>



CareExchange interface to offer and request help with caregiving tasks through the local community



The CareExchange HDB noticeboard is the physical equivalent of the CareExchange app



Filling in the I NEED request form to post a request for a CareExchange.

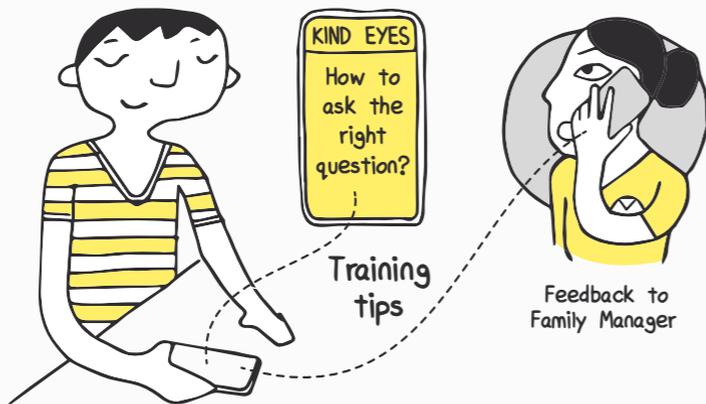


Kind Eyes is a service that helps to spot people in the community who need support. Local shops are encouraged to use their direct social links to channel caregivers to social services.



The shop assistant is a voluntary Kind Eyes mediator

The mediator offers her a copy of an EASY GUIDE which is published by the CARE HUB with the intention to help caregivers seek help more effectively.



Shop assistants can be trained to better recognise families that need special support



Care Exchange is a program initiated by social services to activate HDB communities. The Resident Community leader supported by FSC staff, introduces and manages the way residents can exchange services..

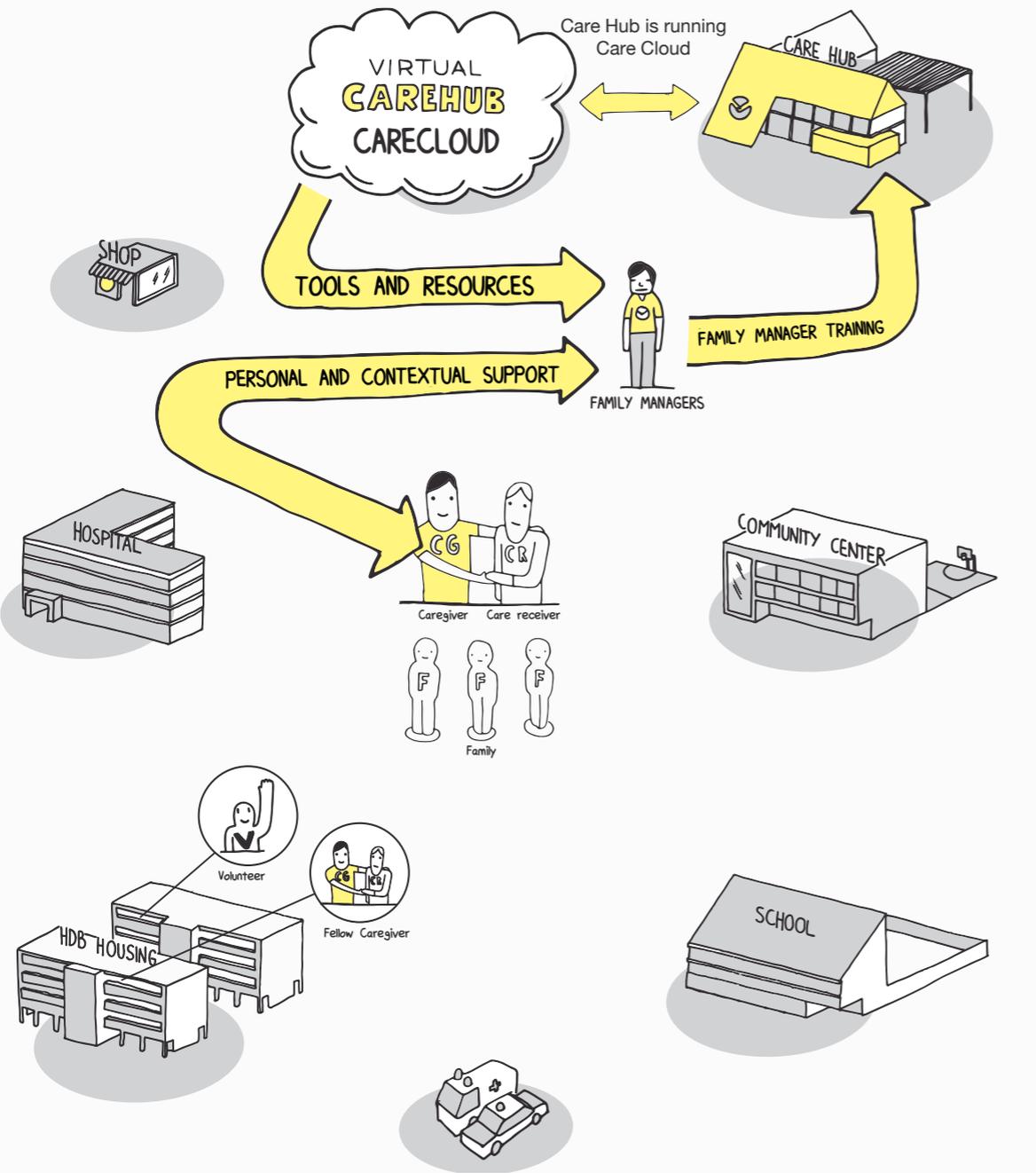


The residents can offer and ask for help from each other by the means of Exchange Cards. Each HDB building would have its own board to exhibit needs and offers.



Care Exchange has a digital platform as well. Help can be offered and searched via the caregiver application, the Care Cope App.

Your Call to Action



CITIZENS :

A caring compassionate community is a more liveable and loveable society. What would make you trust people in your community to help each other out?



PROFESSIONALS :

General Practitioners and shopkeepers work in the community, but social service workers seldom make contact with them as part of their standard practice. What if these members are given training and certification to identify blind spots in social care? What would be the incentives for the community to care for each other?



POLICY MAKERS and DECISION MAKERS:

There is potential in creating a system where different members and actors in the community can talk to one another. What if you could facilitate communities to care for one another by creating neighbourhood-level infrastructure and IT solutions? Who should provide these infrastructures? What will make people trust in these systems so that they may contribute without fear?

What's next?

Glad you asked.

If you are a healthcare or social service professional, you might already be overwhelmed with daily work, in a system which is designed not for Caregivers but for your patients or clients. It may be comfortable in terms of expectations and results to put in more resources to innovate on systems which are already working, however Singapore's healthcare infrastructure is reaching its limits.

One thing is clear. It is imperative for Singapore to pay attention to its Caregivers. Care needs to shift away from hospitals and into the community and home setting. Caregivers should be the ones being identified and given adequate resources and capabilities to be main carers for the vulnerable in our society. We need to uplift their role and support them.

The nine key insights found in this project demonstrate the rich learnings gained just by observing Caregivers needs and everyday experiences. The resulting ecosystem of concepts and opportunities pave the way for innovations that can transform the caregiving experience, improving both healthcare and social service systems.

Here are some next steps to take:

1. **Reflect** if the insights you have read do resonate with you. Think critically. Make notes.
2. **Tinker, pull apart and prototype** the concepts if you find them interesting and relevant. Get in touch with our project team, VWOs or key stakeholders to partner up and co-create.
3. **Try out** our prototype ProCare Journal if you are a social care professional who is keen to start working to support the Caregivers you know. Write to ncss_vwod@ncss.gov.sg and request a copy, try it and tell us how you would like to improve it.
4. **Share** about this project if you find it meaningful, head on to www.ncss.gov.sg/caregiving where you can access the following resources:
 - E-book of this publication to spread the insight and ideas in this book.
 - Prototype ProCare Journal with downloadable templates and tools.
 - Insight Movies, The Emotions of Caregiving.
 - Keep informed about developments of this project, sharing events, workshops etc.
 - Send us your feedback on the ideas presented in this publication, we would love to hear from you!



www.ncss.gov.sg/caregiving

Seeking caregiver support?

If you are a Caregiver yourself, or know someone who is a Caregiver with immediate needs, you can get in touch with:



AWWA Caregiver Service

AWWA strives to empower Caregivers and caregiving families through public education programmes, outreach initiatives, caregiving awareness talks, life skills training workshops, and psycho-social support programmes across the island. Find out more at <https://www.awwa.org.sg/our-services/family-caregiver-support/caregiver-service/>

Telephone: 1800 299 2992

Email: caregiver@awwa.org.sg



Singapore Silver Pages (SSP)

Developed by the Agency for Integrated Care, Singapore Silver Pages is a one-stop online portal offering information and resources on community-based care, financial assistance schemes and caregiving. The public can now easily access credible information and resources at their convenience to enable their loved ones to age well in the community. Learn more here: <http://www.silverpages.sg>.

Telephone: 1800 650 6060

Email: enquiries@aic.sg



SGEnable

SG Enable is an agency dedicated to enabling persons with disabilities. They offer Caregivers Training Grant (CTG)- approved training courses for Caregivers to learn more on topics such as day-to-day care, behaviour management, functional skills development and Caregiver self-care. Learn more here: <https://www.sgenable.sg/pages/content.aspx?path=/caregiver-support/>
Infoline: 1800 8585 885



caregivers alliance
limited

Caregivers Alliance (CAL)

CAL's Caregivers-to-Caregivers Education is a free training programme providing comprehensive and deep coverage on what mental illness is. Learn more here: <http://cal.org.sg/>
Telephone: +65 6460 4400
Email: general@cal.org.sg



TOUCH Caregivers Support

TOUCH strives to help you cope with the challenges of caregiving by providing a wide range of home-based and support services. Holistic care and support services are delivered by a team of doctors, nurses, therapists and care coordinators experienced in geriatric care. Find out more at: <http://www.caregivers.org.sg/>
Telephone: +65 6804 6555
Email: caregivers@touch.org.sg

How did we do this project?

Translating deep design insights into new solutions.



Watch the
"Making of... Movie"

1. Design Research: Understanding Caregivers Through Ethnography

- Understanding the brief and framing the context through secondary research.
- Identifying and recruiting suitable participants willing to share their experiences.
- Unpacking the experience of Caregivers through interviews, visual tools, and video-shadowing.

2. Analysis & Synthesis: Identifying key issues, needs & profiles

- Synthesised 9 Key Insights through rounds of discussions to derive the most distinct experience of Caregivers.
- Defining 5 Caregiver Typologies based on different behaviours and attitudes around caregiving.
- Visualising the Journey of Caregiving through models and graphs.

3. Ideation: Designing to meet Caregivers' Needs, Dreams and Desires

- Translating insights to Scenarios and Prototypes during a five-day design workshop in Barcelona.

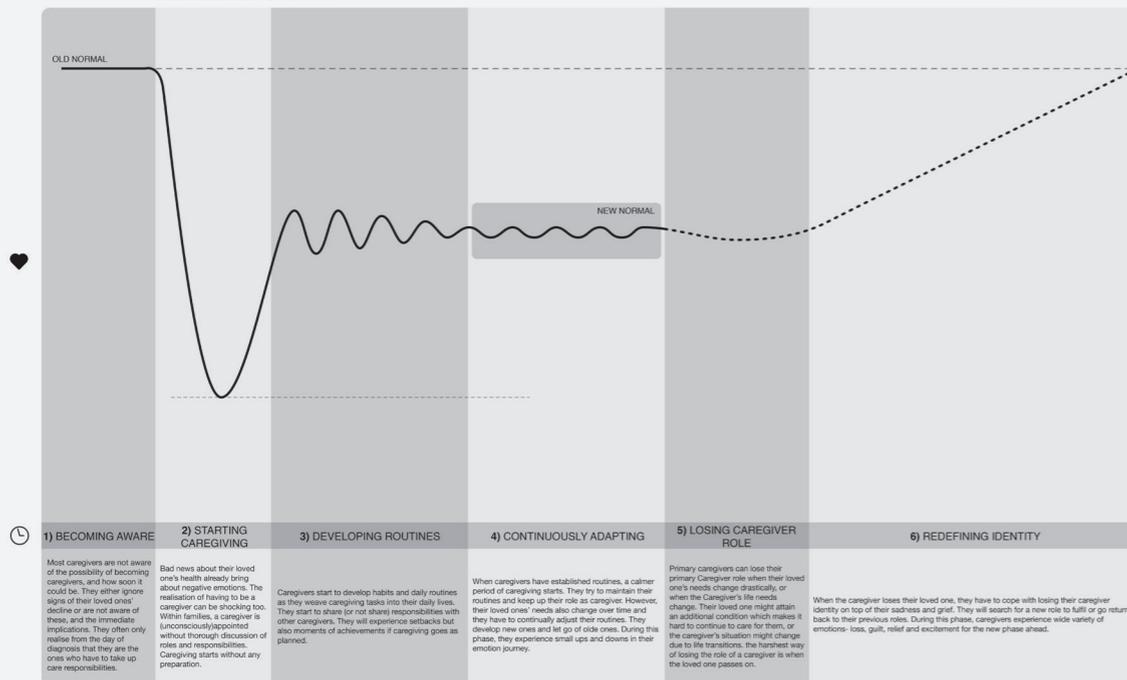
4. Co-creation: Checking ideas and strategies with stakeholders

- Enriching concepts with key stakeholders across various relevant sectors to refine proposed design concepts.
- Designing for communication through printed and online book, prototype ProCare Toolkit, 'Emotions of Caregiving' insight movies, Caring for Complex Needs website, and sharing sessions.



Caregiver Experience Journey

CAREGIVING EXPERIENCE JOURNEY - EMOTIONS

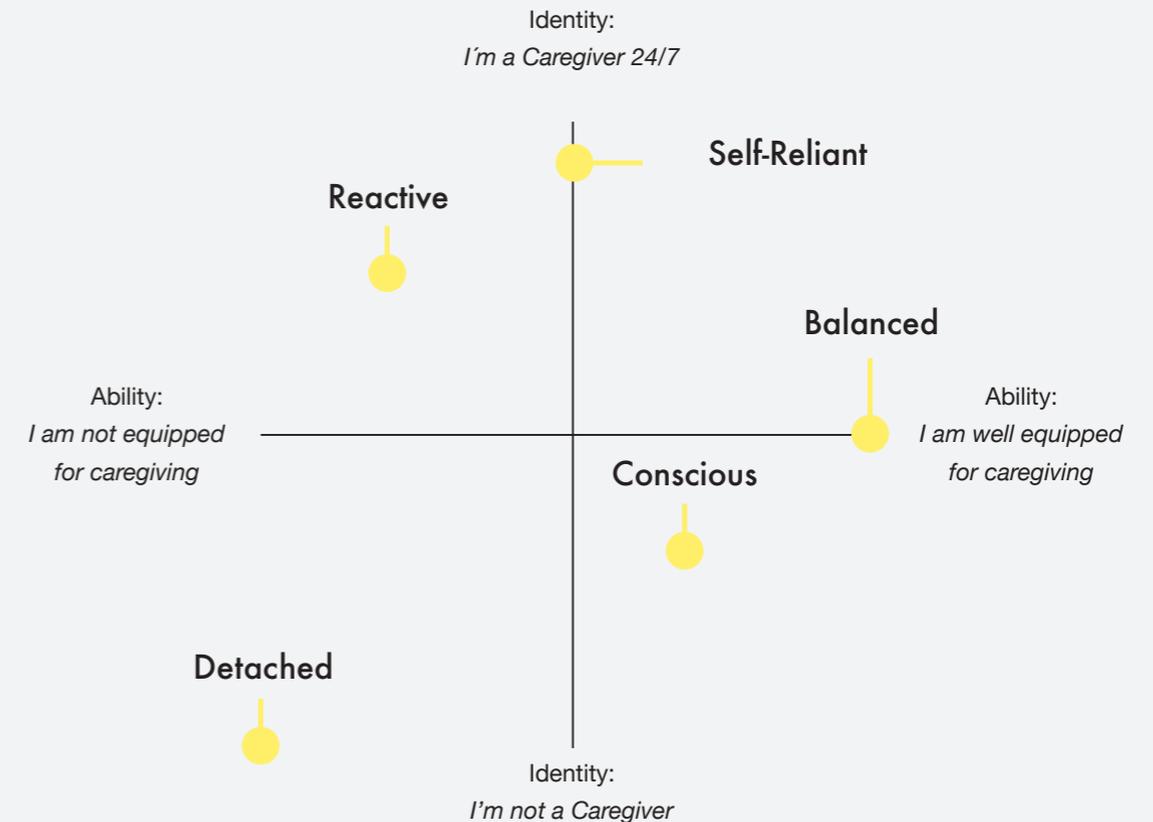


This journey model is a key research outcome of the project. It is the result of synthesising the ten unique caregiver journeys we understood to create a common journey framework that can be used to empathise with the overall experience of caregiving, as a series of emotional highs and lows. Seeing this journey over time opens up opportunities to support caregivers at multiple moments, as well as

reveals the greater impact that solutions offered at multiple touch points can deliver. As such, it is part of the prototype Toolkit for social care professionals that this project has developed, to enable them to have a more holistic and dynamic conversation with Caregivers that they support.

Caregiver Typologies

Understanding styles of caring



Each Caregiver is different and has their own unique needs. However, a few typologies or profiles do emerge when you map Caregiving Ability (x-axis) against Caregiver Identify (y-axis), as shown here.

Caregiving Ability takes into account: confidence, skills, supportive financial means, family and living context, knowledge, mindset towards learning & future-facing attitude. Caregiving Ability ranges

from being ill-equipped at the far left, to managing to 'survive' in the middle, to being well equipped at the far right. Identity describes how Caregivers link their personal identity to their role as Caregivers and ranges from an identity purely defined by being a Caregiver at the top, to balancing their role as Caregiver with their personal identity in the middle, to not identifying with being a Caregiver at the bottom.

Credits

Commissioned by



National Council of Social Service (NCSS)

NCSS is the umbrella body for over 450 member voluntary welfare organisations in Singapore. Its mission is to provide leadership and direction in enhancing the capabilities and capacity of our members, advocating for social service needs and strengthening strategic partnerships, for an effective social service ecosystem.

For more information, please visit www.ncss.gov.sg.

Conducted by



fuelfor

fuelfor is a specialist design consultancy creating award-winning health and care products, services, and experiences for clients in Europe, Asia and the United States. With close to 20 years of healthcare industry industry experience, their professional competencies span from ethnographic research and strategy, to user-centred design, and solution development. They have studios in Barcelona, Spain, and in Singapore. Say hello to them at contact@fuelfor.net.

For more information, visit www.fuelfor.net.

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Special thanks to our Caregiver participants for letting us into your homes and sharing your stories and thoughts; for showing us the beauty of caring.

Thank you to our project partners and stakeholders from across Singapore, for providing us with your support and essential feedback to co-create this project and its outcomes.

Many thanks to the incredible team at NCSS, you are amazing partners and we feel honoured to have worked with you on this important project - thank you! Finally, thanks to the fuelfor teams across Singapore and Spain for once again your hard work, commitment, passion and creativity.

Partners

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Caregiving Alliance Limited (CAL)
Institute of Mental Health (IMH)
SPD

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Dr Daniel Quah (National Cancer Centre Singapore, Assisi Hospice)
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