Good Care At Home
For Older People In Singapore

Jacqueline Chin, Michael Dunn, Nancy Berlinger and Michael Gusmano

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Cover and text design: The Press Room
Printed by C.O.S. Printers in Singapore.

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Executive Summary

Good Care at Home for Older People in Singapore is a product of a five-year collaboration among the Centre for Biomedical Ethics (CBmE) at the Yong Loo Lin School of Medicine at the National University of Singapore, The Hastings Center, and The Ethox Centre at the University of Oxford, to focus on challenges in Singapore that arise from the needs of ageing people, their families, and the healthcare and social care workforce. The generous support of the Lien Foundation has made this collaboration possible through project and dissemination grants to the CBmE.

The major product of this collaboration has been the *Singapore Bioethics Casebook* (www.bioethicscasebook.sg). Beginning in 2012, more than 70 Singaporean healthcare professionals, legal scholars, and other experts were consulted to develop a web-based casebook to support professional teaching and learning about typical uncertainties in healthcare work. Volume I, *Making Difficult Decisions with Patients and Families*, was published in 2014. Volume II, *Caring for Older People in an Ageing Society* launched in 2017, involved more than 180 Singaporean healthcare and social care professionals and a wide range of other experts.

This report complements and builds on the analysis undertaken to develop Volume II of the Casebook by exploring societal challenges that arise due to population ageing. It reflects existing Singaporean social policy as well as health policy, including the 'many helping hands' approach articulated in Singaporean social policy and reflected in current structures and financing of programmes for ageing people. It considers how an ageing society should acknowledge, advance, and balance the interests of older adults and of caregivers, with a focus on the everyday context of home and community. By describing frameworks for understanding challenges like these, and the home as a crucial setting for the giving and receiving of care, this report aims to support high-level reflection and discussion concerning social systems that support or hinder good care at home.

Section 1 explains the importance of good care at home, and why this is difficult to bring into focus when viewed from the perspective of healthcare. Section 2 describes caregiving relationships at home, and uses these relationships as a framework for understanding how to support good care in this setting. Section 3 describes the social systems involved in care at home, with attention to how these systems support or hinder the relationships described in Section 2.

In summary:

- Home is a distinctive kind of care setting, and healthcare is entering this space regularly in an ageing society. When it is not clarified what good care means in this unfolding context, problems can arise which cause suffering and harm to many different parties.

  Recommendation 1: A framework is offered in this report to support ethical care at home for older adults. The considerations that follow below should be widely debated to enhance support for older people and their caregivers at home. **(Section 1)**

- There are limits to setting professional standards in home care because many people who give care to older adults at home are not professionals, including family members, domestic workers, neighbours, and community volunteers.

  Recommendation 2: The relevant ethical standards that professionals and policymakers should use are the ones that support the human relationships that constitute the basis of care that adults growing older need in Singapore. **(Section 2.1)** They include:

  Supporting agency and preventing harm, with attention to balancing independence and safety, respecting privacy in the home, and setting appropriate limits and expectations when healthcare is delivered in the home. **(Section 2.2)**

  Respecting and sustaining care relationships, in particular supporting primary caregivers and shared responsibility for care work within families, and supporting the formation of social networks around older adults who have care support needs. **(Section 2.3)**

  Special considerations for caregivers who are foreign domestic workers, including protecting their welfare and rights in the work environment of the home. **(Section 2.4)**

  Addressing the developmental aspects of family life in an ageing society in public policy, including providing opportunities for sharing insights among peers, whether older adults, family caregivers, or domestic workers, so that people with common experiences and challenges may be strengthened by one another. **(Section 2.5)**

- Care relationships are affected by system-level priorities.

  Recommendation 3: Care relationships in ageing societies are bolstered by a social system's priorities. Appropriate measures of progress in social care should be developed and refined over time. **(Section 3.1, 3.6)**

  System-level efforts to support good care at home through policy and investments in appropriate services should ensure that older people and caregivers know about, and can readily gain access to utilise them over the course of care. This includes reducing duplication, siloing, and gaps in services serving older adults at home that can lead to confusion and ineffectiveness at the community level. **(Section 3.2)**

For older adults living in their communities, access to social networks is as important as access to health and social services. Ensuring training, supervision, and advisory support is necessary as more volunteer befrienders are recruited. Beyond volunteers, neighbours, hawkers, shopkeepers, and public servants play key roles in the social support of older adults, such as noticing unsafe situations or affording hospitable environments for older persons. Public education and outreach to this constituency can help strengthen this part of the social network. **(Section 3.3)**

The migration of medical technologies and clinical interventions into the home can complicate the lives of caregivers. Without the inbuilt supports of the hospital at home, caregivers should not be blamed for care issues they cannot manage on their own. To ensure an appropriate standard of care, hospitals may not only need to invest further in professional home care services but also identify clearer limits for the home as an extension of the healthcare system. **(Section 3.4)**

The system's heavy reliance on migrant workers as caregivers in the home raises many ethical issues and responsibilities relevant to social policy, including appropriate recruitment practices, fair and non-exploitative terms of employment, training and job support, recognition, and advancement opportunities. **(Section 3.5)**

The social system should recognise and support families who face multiple pressures in providing care to various parents and/or children at home while contributing to the workforce. Public policy should address unresolved tensions between these competing obligations, given that leaving families to cope on their own is neither sustainable nor ethically sound. **(Section 3.6)**

Information about financial responsibility for providing care in the home should be transparent. While families are encouraged to plan for the cost of healthcare in old age, clarifying the public provisions for social care is important for helping citizens to make the connections between good care and the good life. **(Section 3.7)**

Why Should We Think about Care in the Home?
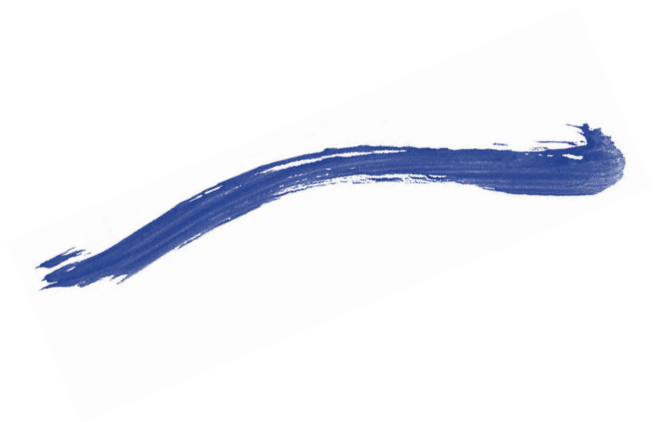
'*Care at home is crucial to care systems in ageing societies,*
yet it remains difficult to bring the nature of "good care at home" into focus.'

A good life and good care are intertwined. A person who needs some type of care is also a person deserving of a good life. A person who provides care also deserves a good life.

Care that enables ageing people to continue to live in their community, rather than be separated from it, is fundamentally important in helping people to thrive in old age despite frailty and illness. 'Home' in every culture and society means a haven, where vulnerability meets comfort, security, kinship, care, and concern. When an older person living with age-associated frailty or a serious illness is cared for at home, this care is an extension of a natural and enduring solution to human vulnerability and our need for care at any phase of life – indeed, from birth to death.

Care at home is crucial to care systems in ageing societies, yet it remains difficult to bring the nature of 'good care at home' into focus. This is in part because 'home', the most common care setting for most people throughout their lives, is different from other care settings. Unlike hospitals, clinics, nursing homes, and residential hospices, 'home' is not a healthcare institution staffed by physicians, nurses, and social workers, although these professionals may serve people who live at home. Unlike senior day care centres or community organisations that provide social services, 'home' is not primarily a social service setting. In 2013, the Minister of State for Health described a range of new policies concerning care at home.[1] These included standards for needs assessment; simplified access to government subsidies for medical equipment and services in the home and for transportation to medical appointments, dialysis, physiotherapy, and dementia day care centres; and subsidies for respite care programmes. In 2016, the government announced plans to pilot new bundled home and day care services,

train domestic workers in eldercare, enlarge the numbers of community befrienders in 50 communities by 2020, build active ageing hubs in at least 10 Housing and Development Board (HDB) estates by 2020, and improve transportation to care services.[2] Yet, it remains unclear how the formulation and delivery of services to the home translate into good lives for the person needing care and those giving care in this setting, and it is vitally important for professionals and non-professionals alike to have clear answers to these questions.

Efforts to describe good care at home within the framework of ethics have tended to focus on the regulatory standards, organisational values and obligations of home care programmes – namely, the delivery of medical and nursing services in the home – or on the experiences and interests of family caregivers.[3] This document, a companion to *Caring for Older People in an Ageing Society: A Singapore Casebook, Volume II*[4] offers a fresh analysis of the practical ethical considerations in providing everyday care for older people needing care at home, with attention to underlying social values concerning good lives for all, and how these shape social systems. This analysis is intended to be relevant to all forms of care at home for older adults, by family members, paid domestic workers, volunteers and friends, and by professionals.

In providing practical recommendations to professionals, non-professionals in caregiving roles, and to older adults themselves concerning what good care at home consists of, this document also invites readers to consider what a society with a strong commitment to investment in public services ought to do to provide ethical care for older adults in the places where they have built relationships, started families, and live their everyday lives.

[1] Committee of Supply Speech by the Minister of State for Health, Dr Amy Khor - 'Better Care for Our Seniors, Progress in Community Mental Health & Women's Health' (12 March 2013), https://www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2013/cos-speech-by-minister-of-state-for-health--dr-amy-khor---better.html, [accessed 9 July 2017].

[2] Committee of Supply Speech by Senior Minister of State for Health, Dr Amy Khor – 'Better Health And Aged Care Support For Successful Ageing' (13 April 2016), https://www.moh.gov.sg/content/moh_web/home/pressRoom/speeches_d/2016/speech-by-senior-minister-of-state-for-health--dr-amy-khor-at-th.html, [accessed 9 July 2017].

[3] See, for example, Guidelines for Home Care, https://www.moh.gov.sg/content/moh_web/home/Publications/guidelines/intermediate-and-long-term-care-guidelines.html, [accessed 9 July 2017]; C. Levine, S. Reinhard, L. F. Feinberg, S. Albert, and A. Hart, 'Family caregivers on the job: Moving beyond ADLs and IADLs', Generations, 27, no 4 (2003):17-23.

[4] Available at www.bioethicscasebook.sg

What are the Ethical Dimensions of Caregiving Relationships at Home?
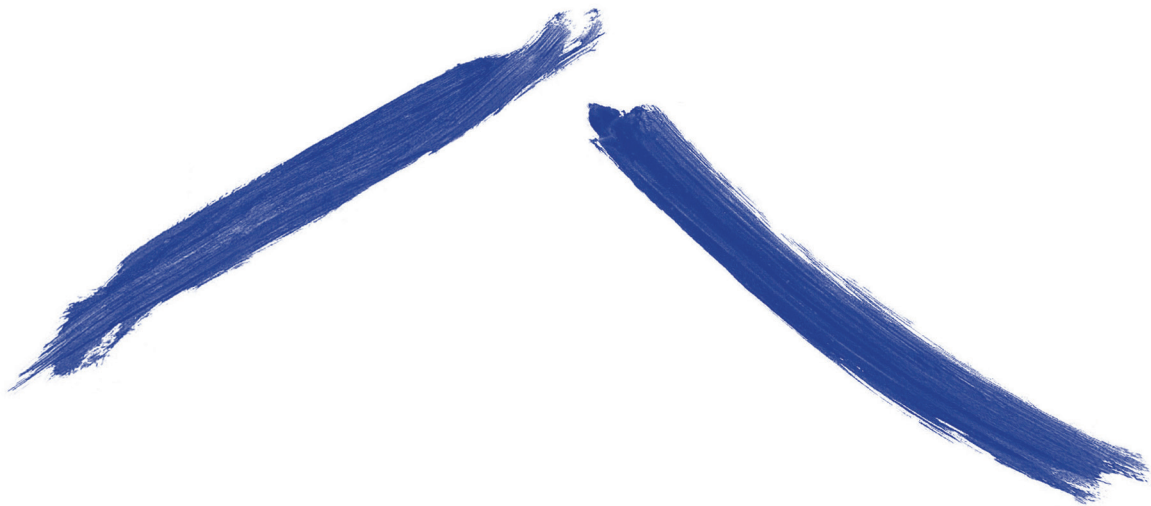
'Ethical standards designed for healthcare professionals working in clinical settings are not directly transferable to the care that is provided to older adults at home.'

2.1 – The Limits of Professional Standards in the Home

The care needs of people who are living with age-related frailty, serious illness, or both, cover a wide range, as do their resources and options for meeting these needs. Persons need care to accommodate age-related frailty and/or chronic conditions that may constitute serious illness.[5] This section explores the human relationships that constitute the basis of care, and specifically, the ethical dimensions of these relationships. The next section focuses on system-level efforts to support good care at home through policy and through investments in services.

The ethical dimensions of human relationships that involve the giving and receiving of care can be expressed through questions such as these:

- How should ethical standards for good care at home be thought about?
- What is owed to an older adult?
- What say should older adults have in decisions about their own care?
- What care relationships ought to be available to and established and maintained for older adults with different levels of frailty or other impairment?
- When might the obligations of different people in care relationships conflict?
- Who or what should be responsible for alleviating uncertainty or distress experienced by a caregiver at home?

In professional practice in healthcare, ethics usually refers to recognised standards or other guidance, such as principles, for doing work in a morally sound way. Examples of widely taught principles of biomedical ethics include respecting persons, doing good, avoiding harm, and promoting fairness. In the hospital, the clinic, the nursing home, and in home care programmes that employ healthcare professionals such as nurses, social workers, and physicians, it is appropriate to refer to 'professional' ethics. 'Healthcare ethics' is a helpful term in this context, as it covers the interprofessional nature of healthcare delivery. The interprofessional care provided in these settings encompass the related but not identical traditions of biomedical ethics, which are grounded in the practice of medicine, and of nursing ethics.

Ethical standards designed for healthcare professionals working in clinical settings are not directly transferable to the care that is provided to older adults at home. There are three main reasons for this.

The first reason is that the nature and purpose of care provided at home are different from the kind of care provided in a hospital or other clinical settings. This has important implications for how ethical standards are interpreted such that they are fit for purpose in the home environment. For example, people who are seriously ill foreseeably face choices about starting, continuing, stopping, or refraining from the use of potentially life-sustaining interventions. Ethical standards offer guidance to professionals on how to work with patients and families to plan for these decisions, and how the decision-making process itself should proceed when a patient is capable of making informed decisions, and also when a patient lacks the capacity do to this.[6] Ethical standards also clarify the basic obligations of professionals to patients – such as appropriate treatment of pain and symptoms – no matter what course of treatment a patient is pursuing. In the home, care usually unfolds over a longer period, and is not primarily focused on questions of appropriate treatment. Here, the nature of good care involves how best to support the agency[7] of the person in need of care – that is, their ability to make a range of choices about their own life, both in the present and into the future. These choices may include how, where, and with whom they want to spend their time.

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[5] Serious illness in an older adult refers to the presence of one or more life-limiting conditions, such as advanced cancer, congestive heart failure, chronic obstructive pulmonary disease, end-stage renal disease, dementia or other degenerative neurological illnesses. Other conditions in combination with age, such as hip fracture in a person of 80 or older, may also indicate serious illness. A seriously-ill person is chronically ill and may be hospitalised for acute episodes of illness.

[6] See: Jacqueline Chin, Nancy Berlinger, Michael C. Dunn, Michael K. Gusmano (eds.), *A Singapore Bioethics Casebook*, vol. i: *Making Difficult Decisions with Patients and Families* (Singapore: National University of Singapore, 2014; 2017), www.bioethicscasebook.sg.

[7] In this context, 'agency' refers to a person's ability to make choices and act on these choices, independently or through the support (or non-interference) of others.

Understanding how to support this aspect of an older adult's life, on a day-to-day basis, is different from the clinical focus on decisions to do with medical interventions and short-term transitions. Care at home may indeed reflect the continuation of goals established in a hospital or clinic, such as recovering function or managing a chronic condition. However, care at home will usually also involve recognising a moral obligation to do good for an older adult in ways that go beyond following a care plan, and that extend beyond a period of transition when caregiving at home is supported by medical and social services.

Secondly, additional questions arise concerning how to clarify moral obligations, and relevant ethical standards, within different human relationships that involve the giving and receiving of care at home. These relationships include self-care, caregiving by family members, caregiving by foreign domestic workers, caregiving by volunteers, caregiving by staff at non-health care organisations, and caregiving by healthcare professionals who work in the home. Some of these questions will concern privacy and respect. For example, the private nature of personal life at home means that showing respect for an older adult in need of care, often living in a household with other family members, will be expressed differently from the respect

that is owed to patients in a hospital ward, where there is less expectation of privacy. How should personal privacy be respected when an older adult at home needs help with intimate daily tasks? Other questions concern how principles that may inform intergenerational relationships within Singaporean families, sometimes expressed as being 'filial', are expressed through caregiving, and how these principles may at times conflict with the interests or preferences of the person in need of care. When a foreign domestic worker provides care to an older adult, the home is also a place of employment where standards concerning the treatment of workers apply. These and other issues add complexity to understanding care relationships at home, and a number of such issues are considered in the sections below.

The final reason that ethical standards designed for clinical settings cannot be directly applied to care at home is that people who provide care at home are usually not healthcare professionals, even if they are paid. This basic fact means that these caregivers at home cannot be held to the identical ethical standards that underpin professional roles in this setting. Instead, professionals must establish precisely what responsibilities caregivers have, given the relevant features of the care context, and support them

in meeting these responsibilities. At minimum, agreed responsibilities – such as the importance of listening to the voice and perspective of the person in need of care – need to be described to them in non-technical ways. In the following sub-sections, a discussion of how some commonly agreed ethical standards and responsibilities might be enacted in order to provide good care at home is provided.

This process of clarifying ethical standards and responsibilities is particularly important because it will help to ensure that problems of professional practice are themselves dealt with appropriately. Often, when problems of professional practice remain unresolved among healthcare professionals, these problems are passed along to caregivers at home, who have little or no opportunity to fix these problems or to channel their perspectives back to professionals in clinical settings. Therefore, as a question of fairness as well as avoiding harm, work on healthcare ethics should be especially attentive to professional problems that are at risk of being passed along to less visible and less powerful settings, such as family homes and nursing homes. Professionals working in hospitals and in the community should undertake to identify and resolve these problems.

2.2 – Supporting Agency and Preventing Harm

Most adults, and some children, can describe what a child needs from a family and a larger community to live a good life. In ageing societies, people should also be able to describe what an older adult needs to continue to live a good life, not limited to how to prevent calamities in this person's life.

An adult's agency is part of what differentiates an adult from a child whose capacity to act independently is still developing. Adults who retain mental capacity should be free to make a range of choices about their lives: where they will live, what kind of work they will do, whether they will have children, and how they will raise their children. Adults should also be free to act upon the choices that they make, and to change their minds or be ambivalent. Adults with impaired or fluctuating mental capacity, due to developmental conditions, psychiatric conditions, or conditions such as dementia, should also be supported to make choices about their lives as they are able to do so.

Promoting the agency of an older adult who is capable of living independently often involves supporting the adult in the management of risk. For example, preventing a fall that could result in a hip fracture is usually desirable: most adults would want to avoid the consequences – pain, surgical repair, rehabilitation – of a hip fracture. However, no environment can be made completely risk-free, and the home environment is far less standardised than a clinical setting. Limiting movement due to fear of falling could make a person less strong and less stable, therefore more prone to falling, and could also limit their agency in other ways. In the home, trade-offs between agency and safety are made continuously, and should be done so in a carefully reasoned way. In some cases, social systems can mitigate these risks by, for example, making it convenient and affordable for older adults to modify their flats in ways that increase safety while maintaining independence.

Making a judgement that an older adult is no longer capable of keeping himself/herself safe is a difficult matter. It would be wrong to misuse provisions intended to protect people who are incapable of protecting themselves from harm to restrict the personal freedom of a capable adult whose choices concerning his/her own life are different from what another person would choose, but are not harmful to himself/herself or others. Beyond that obvious caution, what is the right thing to do when an older person's choices or circumstances appear to put this person at some risk of preventable harm?

A family member or a professional may need to talk directly with the older adult about the potential harm and its consequences for the person's ability to do things this person values. Individual choices, and how a person exercises agency, are highly personal matters. It may take ongoing discussions, over time, before a shared perspective
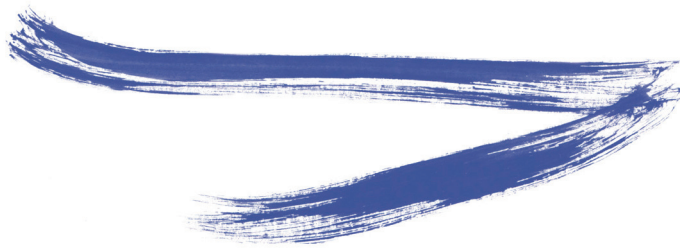
on a potential harm (such as how an older adult is managing a chronic illness, or personal finances, or household tasks) is reached. An older adult and a caregiver may agree to disagree about how well this person is managing his/her own life. For example, an older adult may opt to prioritise independence over safety, even at the risk of some harm to himself/herself, and the caregiver may decide to support the older adult's autonomy, even if the caregiver perceives the situation differently.

Caregivers may also need to acknowledge and discuss their differing perspectives, and, on occasion, agree to disagree about what is best for the older adult they aim to help. These can be challenging or unfamiliar situations for siblings, who may be uncertain how to manage or resolve disagreements among themselves. It is likely to be harder for a foreign domestic worker or a volunteer, both of whom have less status compared to a family member, to talk directly to an older adult about a potential harm. These individuals need to be able to turn to someone else to share potential problems they have observed.

Community bystanders – neighbours, local merchants, public servants – also need to know where they can turn to with concerns about an older person's safety, or ability to manage everyday tasks. Public information should aim to support broad understanding about the needs of older adults and about community services aimed at helping to meet these needs.

2.3 – Supporting and Sustaining Care Relationships

All people, including independent adults, have had experiences of being dependent on numerous people. These experiences arise during stages of life at home (during infancy and early childhood, for example), or through participation in social systems that serve the public broadly. Most people have had some experience of family life, of intimate personal relationships, and have both given and received care at home.

For an independent older adult, recognising interdependence may include new dimensions of longstanding relationships becoming established, or worked out within a family. For example, an adult child, niece, or nephew will stop by to help with heavier shopping or repairs, or otherwise notice an ageing adult's condition while supporting her continued independence. Formal and informal community services, such as volunteer 'befrienders' who may do light chores, or neighbours who help with meals or errands, can also support independence. Older adults with the mental capacity to make some decisions for themselves should have a great deal of say over these types of care relationships, which are woven into the fabric of their everyday lives. Some older adults, for example, may prefer not to participate in a befriender service even if it is readily available and might benefit them in some way that they value, or may be ambivalent about participating.

Older adults who have a greater degree of dependence on others are likely to need more care from other people, and also for others to make care arrangements, such as scheduling medical appointments. In these cases, it is highly likely for a family member, such as a spouse or an adult child, to become the default caregiver and care coordinator. This common arrangement contains many inherent challenges, some of them with ethical dimensions. For example, how should families recognise caregiving as a shared responsibility even if one family member bears the greatest day-to-day responsibility? How present is the older adult in need of care as a participant in these discussions? If the older adult is unable to take part in discussions about her care, who represents this person's perspective and preferences? How should financial responsibilities associated with caregiving be discussed and shared within a family?

Answering these questions is important, but these are not simple discussions for families to have. Compared to the decades-long experiences that parents accrue while raising children, adult children may have little prior experience of caregiving for older adults to draw on as they face their own parents' changing needs and greater need for interdependence. Siblings may disagree with each other about how best to help an ageing parent, with one sibling arguing for preserving independence, and another arguing for promoting safety, in ways that cannot be fully reconciled. Also, unfairness can seep into family roles when one family member bears an undue share of responsibility for caregiving, care coordination, or financial costs. This can be a challenging issue to raise directly within a family.

In an ageing society, these experiences should be recognised as normal, if inherently difficult, developmental aspects of family life, rather than stereotyped as problems of 'difficult families' or as 'crises'. This point has implications for how the government and other professional care providers frame recommendations about care at home in the formulation of their policies. It also requires the professionals who work for these organisations to provide appropriate support to families who need to address these issues in ways that serve the interests of both the older people at home receiving care, and all those involved in the care of these people. One way in which this could be realised is by developing productive, engaging ways to help people talk privately and publicly about how to provide good care to older adults as a normal, challenging part of family life. Again, reframing and enacting policymaking in such ways will require good care at home to be seen on its own terms, rather than as an extension of clinical medicine or transitional care.

2.4 – The Special Considerations of Caregivers who are Foreign Domestic Workers

The situation of migrant workers who often provide live-in domestic care for older adults in Singapore requires close attention to how responsibilities may become unbalanced or place caregivers in situations that are impossible to resolve. Foreign domestic workers are employees of families who are hired to perform hands-on caregiving tasks on behalf of an older adult: dressing, bathing, feeding, toileting, and accompanying the older adult to appointments and activities. While these paid caregivers live in the home and may work closely with family members, describing them as 'like family' obscures their role and status within a household. As employees, they are also like nurses in some ways, because of the nature of the work they do, and also like domestic servants, because of the terms of their employment and the de facto expectation that they will take on household chores in addition to caregiving.

Just as ageing societies need ways for people to talk about family caregiving as a part of family life, societies that include migrant workers need ways to talk about migrant workers as caregivers. These caregivers need support for a complicated role that takes place in the context of family and home, but differs from family caregiving, and also from home healthcare provided by an outside programme.

Foreign domestic workers are often introduced into a household via a recommendation from the healthcare system, in the aftermath of an acute episode (such as a stroke) or worsening condition (such as dementia), and may be trained for home care tasks by healthcare professionals prior to assuming responsibility for these tasks in a home. This means that the healthcare system has a stake in ensuring that foreign domestic workers are treated fairly, and are not viewed merely as extensions of the healthcare system who are responsible for ensuring that a care plan succeeds, or are not blamed if it fails.

Foreign domestic workers typically lack the authority to serve as care coordinators, but may be pressed into that problem-solving role. A family member who sees the role of the live-in paid caregiver in this way needs to have realistic expectations of what problems a foreign domestic worker can solve on her own, and what problems this employee will need to bring to a family caregiver's attention so that they can collaborate to resolve the problem. Training foreign domestic workers and family caregivers jointly to prepare them for collaboration is greatly preferable to training migrant workers in caregiving skills but overlooking preparation for working in a caregiving team that consists of an employer and employee.

One of the realities of the foreign domestic worker's role is that it contains a potential conflict between duties to the person in need of care and the worker's understandable desire to please an employer by carrying out the employer's instructions. This built-in conflict makes it genuinely difficult for a paid caregiver to bring problems to the attention of a family caregiver, if this means challenging the employer's instructions. Supporting the foreign domestic worker as caregiver starts with alerting the employer to the potential conflict and supporting the employer in this supervisory aspect of caregiving.

2.5 – Reframing Life at Home in an Ageing Society

Negotiating the balance between the independence and safety of an older adult, and between respect for personal privacy and the intrusion of caregiving into a person's privacy, are continual challenges in receiving and giving care. When older adults think of themselves as relatively independent and are perceived by family members as capable of managing on their own, they may be uncertain how to alert family members to their changing needs. They may worry about being a 'burden' to their adult children who are working and raising families, or worry about whether their children will respect or honour their values. For their part, adult children may find it genuinely difficult to understand the needs of an ageing parent, or of a parent who is the primary caregiver of a spouse in poorer health.

As noted above, framing these developmental aspects of family life in an ageing society as 'problems' does not necessarily help. Whether one is an older person receiving care, or a family member or migrant worker providing care, feeling that one's daily life is replete with problems is discouraging. Recognising that one's challenges are shared by other families in an ageing society, and that public policy aims to support families in this phase of life, may be more encouraging. Opportunities for sharing insights among peers – whether these are older adults, or family caregivers, or foreign domestic workers – should be supported as part of public policy in ageing societies so that people with common experiences can be strengthened by one another and can feel less isolated with the problems they face. Acknowledging just how difficult caregiving is, and how long this work may go on, is part of what an ageing society owes to the caregivers in this society.

What are the Ethical Dimensions of Systems Supporting Good Care at Home?

'Most countries have reached a consensus about the degree to which acute healthcare services are a public good worthy of government support. There is less consensus about social care that makes good care in the home possible.'

3.1 – Social Systems and Population Ageing

Care relationships at home are bolstered by social systems. These systems include investments in community-level services for older adults, and in the coordination of these services so older adults and family caregivers know about and can gain access to them over the course of care at home. Care at home for older adults is greatly affected by policy priorities in areas beyond health and healthcare, such as housing, planning and maintenance of public spaces used by older adults, and employment policies affecting family caregivers and paid caregivers.

A key question for Singapore going forward is how to integrate social systems supporting the ageing generation and caregivers at home, and the development and refinement of appropriate measures of progress in this area.

3.2 – Reducing Duplication, Siloing, and Gaps in Community Services for Older Adults at Home

Good care at home, which enables an older adult to remain in the community, requires robust social responses by government agencies working closely with local community members.

Singapore's extraordinary national commitment to public housing, and the broadly shared experience of HDB housing among several generations of Singaporeans, means that 'home' is not only personal and familial, but also a place where this society's commitments to inclusion, equality, and access to services are realised.

The Ministry of Social and Family Development offers various ways for HDB residents' committees and community centres, and social service organisations serving HDB estates, to work with voluntary welfare organisations (VWO) on behalf of older adults, most of whom live in housing estates. Professionals employed by VWOs often complete needs assessments of older adults and their families and help them connect with appropriate types of assistance, education, or advice.

However, other ministries also offer programmes geared to older adults in the community, and there is overlap among programmes that can lead to inefficiencies and confusion at the community level. Problems of duplicate services often arise due to 'siloing' habits during programme development: in complex administrative systems, professionals working on similar problems may be isolated in different ministries or organisations. A persistent 'siloing' problem that affects good care at home occurs when healthcare services that can potentially support an older adult's ability to continue to live at home are clustered in hospitals and triggered by hospitalisation or outpatient care. Looking at this problem from the perspective of the older adult at home is a priority: Is it possible for this person to gain access to community-based services that would help him or her to maintain health, without first deteriorating enough to be hospitalised or being treated as an outpatient?

3.3 – Developing Social Networks around Older Adults and Caregivers

For older adults living in their communities, access to social networks is as important as access to health and social services. Although families are central to caregiving in Singaporean society and usually constitute a major part of an older person's social network, friends and neighbours also provide support to older adults living at home. Volunteer 'befriender' services, often coordinated by VWOs, offer structure for social support and for tasks such as shopping or home repairs. The HDB system also offers a community volunteer programme that may benefit older residents of housing estates individually or through enhanced community activities. The expectation that healthier community members will volunteer to help older or more impaired community members suggests that the 'kampong spirit' persists within Singaporean social identity despite rapid development and urbanisation. Community members who have retired from full-time employment may be well-positioned to take part in the social support of older adults in the community; decades of evidence suggest that volunteering benefits the well-being of both parties.

At the system level, efforts to recruit, train, and supervise volunteers to work with older adults should be attentive to ethical considerations, including privacy of persons and families and confidentiality of information. Systems of support for volunteers should also provide a trustworthy supervisor or peer mentor to whom volunteers can bring their own questions. These may concern a volunteer's uncertainties about an older adult's safety or ability to manage everyday tasks, or about perceived needs that the volunteer is not able to meet.

Beyond volunteers, the typical HDB estate includes other people – such as neighbours, hawkers, shopkeepers and other local merchants, and public servants – who are not officially part of care systems for older adults but who may play key roles in the social support of older adults. These 'bystanders' may offer to help older adults when they see an opportunity to do so, but may be unsure of whether they should get involved in personal or family matters, or what they should do if they perceive that an older person is in an unsafe situation.

At the system level, public service messaging and outreach to specific community constituencies such as hawkers, about how to support older adults as fellow community members, may help strengthen this part of the social network. Providing members of the public with information about how to support caregivers in the community or bring up problems of suspected abuse or neglect to the appropriate authorities is important.

Another important issue at the community level is how older adults, family caregivers, and paid caregivers can bring needs and problems they may experience at home to the attention of community agencies that can provide help. As discussed in Section 2, framing these needs and problems as family 'crises' may be counterproductive and stigmatising, if the goal is to help older adults and their caregivers figure out how to manage family and household issues that may be new to them, or reflect a person's changing condition.

At the system level, helping caregivers at home, including foreign domestic workers who are part of the care system, to recognise frequently occurring problems in ageing societies, and to know how to access appropriate support, may be productive.

3.4 – Not Pushing the Hospital into the Home

In recent decades, the lives of caregivers at home have been complicated by the migration of medical technologies and clinical interventions into the home. Hospitals in Singapore and other developed healthcare systems prioritise discharge planning during hospitalisation, a process that can lead to an emphasis on skills training for caregivers who will be expected to take over medical and nursing tasks from clinical professionals. These tasks often include wound care, or the management of technologies ranging from artificial nutrition and hydration, to home hemodialysis, to ventricular assist devices, in addition to providing personal care and coordinating follow-up medical care and other appointments. Recreating the hospital in the home without the built-in structure of that institution can create undue burdens and hardships for caregivers at home, whether this caregiver is a spouse, an adult child with work and family obligations, or a foreign domestic worker who has been hired to provide hands-on care.

At the system level, professionals based in acute care and community hospitals, and medical and nursing home care programmes, should work to identify precisely what is owed to the older adult and to caregivers not only during transitions from hospital to home, but also after short-term 'transitional care' support ends while medical and nursing needs continue. This process should include insights from family caregivers and from foreign domestic workers responsible for delivering most care at home, so that healthcare professionals preparing patients for care transitions have a clear understanding of how care plans that succeed in clinical settings may become unsustainable at home despite skills training. Known problems, such as low post-discharge uptake of referrals to community-based
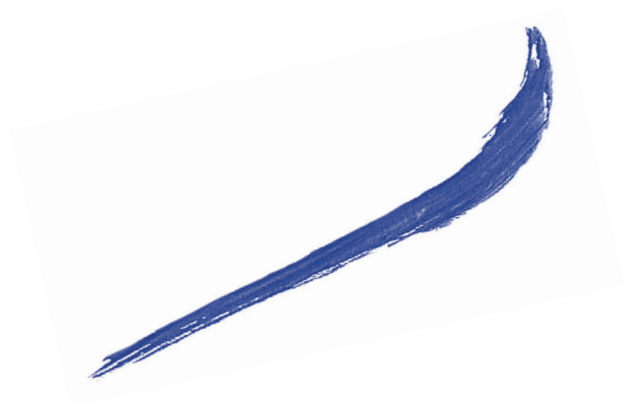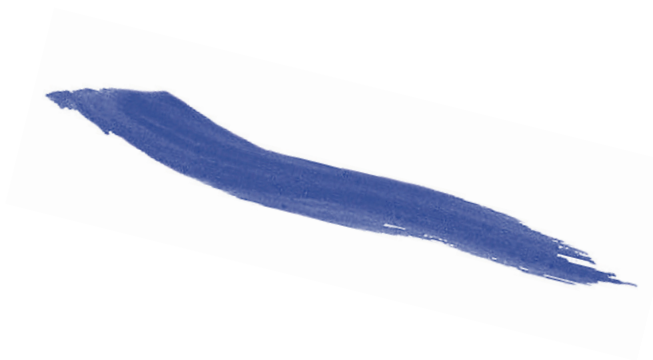
physiotherapy, may need to be rethought so that caregivers are not blamed for structural barriers they cannot overcome on their own. Unresolved problems in professional practice (such as appropriate and inappropriate use of feeding tubes) that affect care in the home also need to be tackled through clinical research and practice recommendations in different settings.

There may be no metric for what an older adult may value most about being able to live at home. Quality standards designed for the delivery of care by professionals in clinical settings may be a poor fit for home settings. Indeed, holding family caregivers or foreign domestic workers to professional practice standards concerning medical and nursing interventions is unjustified. Leaders of healthcare and social care systems should recognise that key performance index (KPI) targets are not met merely by referring family caregivers to services that will be difficult or impossible for them to make use of without help. To ensure that patients transferred home continue to receive care at an appropriate standard, hospitals may need to invest further in home care services to ensure that patients who need care from a nurse, physician, or other clinical professional can receive these services.

There are limits to what the healthcare system should expect of families as caregivers. As noted above, the home should not be appropriated as an extension of the healthcare system even when non-professionals can be trained in medical and nursing interventions. When this powerful system relies on unpaid, non-professional caregivers to perform tasks that in clinical settings would be performed by salaried staff, and also to subsidise the system through out-of-pocket fees, it is difficult to avoid seeing this situation as exploitative, rather than an expression of social values.

3.5 – The System's Obligations to Migrant Workers as Caregivers

The heavy reliance in Singaporean society on migrant workers as caregivers in the home (and also in nursing homes) raises important ethical issues relevant to social policy. As discussed in Section 2, foreign domestic workers are paid caregivers whose role and responsibilities should be considered on their own terms, rather than as extensions of family or professional roles. As a nation that structurally relies on migrant workers to meet the care needs of an ageing citizenry, Singapore has a range of responsibilities to this caregiving workforce, beyond providing opportunities to earn higher wages than in migrants' home countries and to contribute to home countries' economies through remittances. These responsibilities span different social systems, including recruitment, terms of employment, training, support for workers on the job, and recognition and advancement opportunities.

Policy concerning the recruitment and employment of domestic workers requires that these workers be recruited for a specific caregiving role – namely, caring for an older adult, a disabled person, or childcare. In reality their job is frequently conflated with all-purpose domestic work as a 'maid' or 'helper', and the recruitment process in 'sender' nations does not aim to recruit for specific types of care work. This means that training in caregiving for an older adult begins only after a worker arrives in Singapore and is matched with a potential employer. This process may put workers, employers, and persons in need of care at a disadvantage. The worker, under financial pressure to accept a job offer and pay back her recruitment fees, may accept a job offer with little knowledge of what caring for an older adult entails, or whether she will succeed in this type of work. The family member, under time pressure to put care at home into place ahead of a hospital discharge or other transition, may be unclear about what skills and types of experience are needed; for example, new employers may believe that they should hire a younger domestic worker, overlooking that a somewhat older worker may have accrued more experience and skill in caring for older adults. Tensions between an adult in need of care, and a caregiver, may be more pronounced when a caregiver is inexperienced.

At present, training for domestic workers is organised by a range of healthcare and social care systems, including the Ministry of Manpower (MOM), individual hospitals, and the Agency for Integrated Care (AIC). Because of domestic workers' limited power to acquire further training or

negotiate changes in their work responsibilities once they are placed in a job, further work in improving care at home in Singapore should include attention to how domestic workers are recruited, placed, trained, and supported in providing care to older adults and working within this type of family system.

While foreign domestic workers are provided some protection under the Employment of Foreign Manpower Act, they are not covered by the Employment Act, which regulates hours of work and public holidays. When migrant workers lack formal protections and enforcement mechanisms to safeguard days off and hours of rest, they are at high risk of exploitation, especially when they live in their place of employment. Even a well-intentioned employer may expect a domestic worker to give up her day off, without considering the worker's perspective, legal rights, and basic need for respite. At times, the tension and overwork created by such situations can result in cases of workers harming themselves or those in their care. The response to such reports should not be to blame individual 'bad apples', but rather to analyse where the system itself is producing problems, and to rethink and improve those aspects of the system. This analysis could lead to

recommendations aimed at improving working conditions through law, employer education, and services for migrants.

Ensuring that foreign domestic workers have some privacy in their living arrangements is a particularly difficult challenge. When considering a family's eligibility to hire a foreign domestic worker, the MOM looks for evidence that a person or family can provide 'sufficient privacy and sleeping space in the house where the foreign domestic worker will be staying'. For most families, who live in HDB flats, it will be impossible to provide a domestic worker with a private bedroom. Mindful that caregivers require respite, efforts to improve conditions for live-in migrant workers should consider how to provide more privacy and respite time for these caregivers.

Finally, the interests of domestic workers, the older adults they care for, and the family caregivers who supervise them should be recognised as closely and inextricably associated. Policies aimed at supporting family caregivers should always consider how these policies also support paid caregivers who are likely to work for and with family caregivers and experience household stresses related to caregiving.

3.6 – Addressing Multiple Pressures on Families

Caregiving is stressful, often exhausting work that can impair the health of a caregiver. Caregivers who are spouses are usually also ageing and facing age-associated conditions of their own in addition to the stresses of caregiving. Family caregivers who are not in the paid workforce often have other responsibilities, including to other family members.

How Singapore's social systems will recognise the multiple pressures on families who are contributing to society as workers while providing care to older adults, is a signal challenge in current and coming decades. The scale of this national challenge should be acknowledged by civic leaders, who should use their position to clarify that pushing the unresolved tension between these competing obligations into the home, for families to solve, is neither sustainable nor ethically sound.

More flexible working arrangements and expectations for caregivers is an example of a social policy that could support families in an ageing society. There is also a business case for structurally supporting family caregivers through their jobs. Lack of workplace support for caregivers has been demonstrated to result in substantial lost productivity to employers, as caregivers are forced to respond to family needs in ad hoc ways. Creating and promoting policies that offer family caregivers time off from work to take older adults to medical appointments, arrange for social services, or meet other caregiving needs may have economic benefits for an ageing society.

3.7 – Improving Transparency and Equity in Financing Care at Home

The metaphor of care for older adults as the work of 'many helping hands' suggests that good care in the home requires contributions from many different sectors, including government, healthcare and social care organisations, families, and community members. It is important to go beyond this slogan and describe what shared responsibility means in the context of good care at home. At a minimum, information about financial responsibility for providing care in the home should be transparent, as families are often surprised to learn that Medisave does not cover many services associated with care at home. The Singaporean government has started to address this issue by encouraging families to plan for the costs associated with ageing. Singapore should also reflect on whether there ought to be greater public support for social care, rather than suggesting that that the costs of an ageing society should be absorbed by families.

AIC has created the 'Singapore Silver Pages' (https://www.silverpages.sg) as a hub for information about programmes and services for older adults and caregivers, including financial eligibility and subsidies. Further efforts to share information and connect people with services should consider how to build 'navigation' capacities into systems that are typically being used by families under stressful or emergency conditions, as they grapple with the needs of an older adult who now needs help to continue living at home. These systems are not limited to web-based resources that older adults or family caregivers must first know about, then be able to use themselves.

Most countries have reached a consensus about the degree to which acute healthcare services are a public good worthy of government support. There is less consensus about social care that makes good care in the home possible. As Singapore grows older it is crucial for this society to reflect on this question, and to consider the relationship between good care and the idea of a good life.

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