SUPPORTING NATURAL CAREGIVERS

INNOVATIVE IDEAS FROM AROUND THE GLOBE NOVEMBER 2016

CARDUS HEALTH

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RESEARCH AND PROJECT SUPPORT

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ABOUT CARDUS

Cardus is a think tank dedicated to the renewal of North American social architecture. Headquartered in Hamilton, ON, Cardus has a track record of delivering original research, quality events, and thoughtful publications which explore the complex and complementary relationships between virtues, social structures, education, markets, and a strong society. Cardus is a registered charity.

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SUPPORTING NATURAL CAREGIVERS:
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Like many other Western countries, Canada is experiencing a demographic shift towards an aging society. This shift will create challenges for the health-care system as Canadians consider issues of aging, long-term care, and ultimately, end-of-life care. Aging and end-of-life care became medicalized during the previous century, but over the last few decades there has been a movement towards a public health model of aging. This model encourages everyone to take responsibility for care of older adults and seeks to enhance community support and engage other social institutions and structures. One facet of this has been a more thoughtful consideration of the role of natural caregivers and the relationships, networks, and social capital that sustain and empower them.

A 2016 public opinion survey of Canadians conducted by Nanos Research for Cardus found that Canadians highly value the ability to manage the health care of their parents. Yet, 60 percent of respondents believe society is doing only an average job in promoting the care of elderly parents.[1] The survey captured the urgency around this issue when respondents reported that they expected the number of seniors they would be providing care for in the next 10 years to double.

Currently, Canada assists caregivers through a number of federal and provincial initiatives. These initiatives primarily aim to offset the cost of caregiving and to protect employment status. While these provisions offer baseline support, the growing demand on caregivers will require the mobilization of community support systems. This paper acknowledges the current federal and provincial caregiver policies, but explores the potential social structures that could be mobilized to directly and indirectly support caregivers.

The central focus of the paper is to explore innovative international initiatives that build on community connectivity to support natural caregivers and those they care for. The initiatives are consistent with a public health approach and move towards the creation of a culture of care.

First, the paper develops the framework for supporting natural caregivers and examines the statistical profile of caregivers in Canada. Next, the current federal and provincial caregiver support programs are reviewed. The third section of the paper explores Canadian and international examples of innovative initiatives that support natural caregivers directly or indirectly. These examples are categorized under two headings: mobilizing supportive communities, and building caring living environments.

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1. Andrea Mrozek and Peter Jon Mitchell, "The Canada Family Life Project," Nanos Research Poll Results for Cardus Family (Hamilton: Cardus, 2016), 15. Retrieved from https://www.cardus.ca/research/family/publications/

1.FRAMEWORK

This paper approaches aging and end-of-life care through three lenses that are outlined in greater detail in the Cardus report, Death is Natural.

Natural death: Social systems should support the desires of Canadians for a natural death. By natural death, we mean a death by natural causes in the environment that is most natural to the individual, and surrounded by their natural caregivers. This approach seeks to identify the wide spectrum of stakeholders that play a part in supporting caregivers and those receiving care.[2]

Social architecture: We engage this term as a means of speaking of the full range of social institutions available to caregivers and those receiving care. Attention is paid to developing and sustaining community support, recognizing the challenges of social isolation and geographic separation. Constructing social architecture also means honouring the full human person beyond "beds" and "cost analysis" to uphold the dignity of the care recipient and their caregivers.[3]

Continuum of care: This lens recognizes that caregiving and care receiving are a journey. Care options should not be a series of alternatives but a continuum of care respecting the support structures and settings of those receiving care. The continuum of care lens also recognizes that the perception of aging and end-of-life care can be clarified through wider community engagement.[4]

Aging and dying are uncomfortable topics in our culture, yet the potential social capital that can be mobilized through broader community engagement is promising. A public health approach to aging acknowledges that everyone has a role to play and strives to develop a sense of community responsibility.

Compassionate Communities of Care
An emphasis on creating compassionate communities of care was derived from the World Health Organization's healthy cities initiative. The concept was advanced in the palliative care field during the late 1990s and 2000s.[5] The model focuses on community involvement with attention to the provision of social care. Integrating natural caregivers is an important aspect of the model. The values embedded in the compassionate care framework of connectivity, community mobilization, and social transformation towards a culture of care, animate Cardus' exploration of innovative models of care.

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2. Ray Pennings, *Death is Natural: Reframing the End-of-Life Conversation in Canada* (Hamilton: Cardus, 2015), 34. Retrieved from https://www.cardus.ca/store/4457/
3. Ibid., 35.
4. Ibid., 37.
5. Allan Kellehear, "Compassionate Communities: End-of-Life Care as Everyone's Responsibility," *Q J Med.*, vol. 106 (2013), 1072.

2.   WHO ARE CANADA'S NATURAL CAREGIVERS?

Natural caregivers shoulder a significant amount of the provision of care in Canada. About 46 percent of Canadians ages 15 and over have cared for a friend or family member with long-term health, age, or disability issues.[6] Among care issues, age-related issues are the most prevalent care need.

As might be expected, natural caregivers are often a friend or relative of the person receiving care. Of those providing care, almost half do so for a parent or in-law.[7] Of the 28 percent of caregivers who provide care to terminally ill care recipients, 41 percent provide such care to a parent.[8]

The age of the typical caregiver in Canada often reflects the care recipient. For example, the largest cohort of caregivers is ages 45 to 54, reflecting the fact that most care recipients are parents or in-laws. The chart below illustrates how the care recipient's age correlates with the caregiver's age.

CHART 1:   PRIMARY CARE RECEIVER; BY CAREGIVER'S AGE, 2012
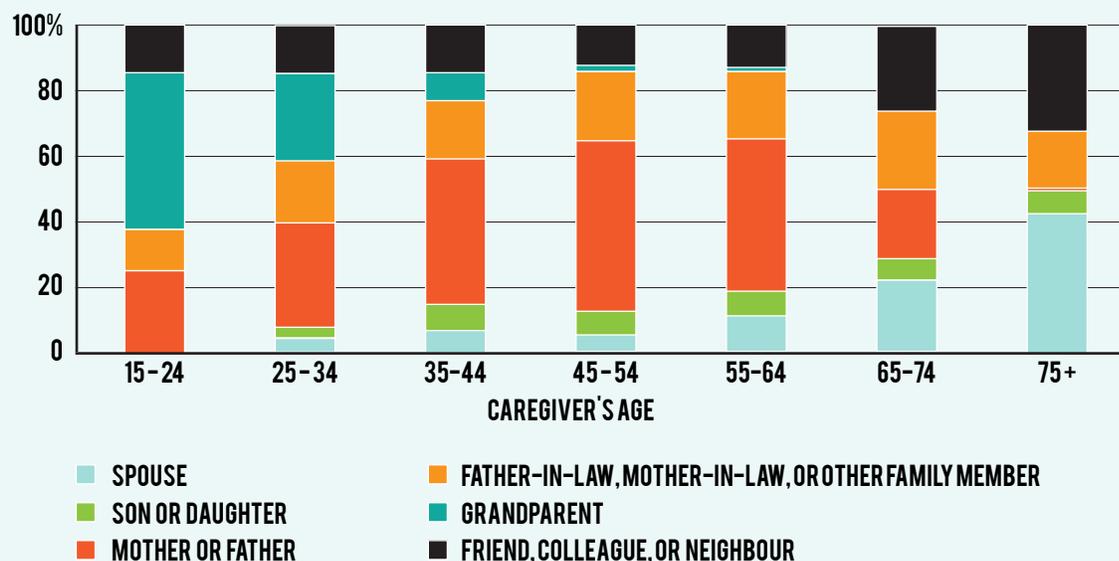
Source: Chart 2 in Martin Turcotte, "Family Caregiving: What are the Consequences?" Insights on Canadian Society (Ottawa: Statistics Canada, 2013) Retrieved from http://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.pdf

A 2012 study by Statistics Canada found that most caregivers had provided care for more than a year with about half of caregivers providing care for over four years. In most cases, these caregivers were

6. Maire Sinha, "Portrait of Caregivers, 2012," *Spotlight on Canadians: Results from the General Social Survey* (Ottawa: Statistics Canada, 2013), 3. Retrieved from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf
7. Ibid., 8.
8. Ibid., 4.

caring for an ill spouse or child.[9] Most caregivers spend under 10 hours a week performing caregiving duties, but 10 percent of caregivers are providing 30 or more hours a week of care.[10]

Most caregivers report that they are managing their duties, but increases in intensity and duration of care provisions take a toll. About half of caregivers report feeling anxious or worried, with other common experiences including disturbed sleep and irritability. About 35 percent of caregivers reported feeling overwhelmed.[11] A report published by the Canadian Medical Association suggests that caregivers are themselves at risk of poor health outcomes due to strain.[12]

CHART 2: TYPE, NATURE, AND DURATION OF CAREGIVING

	OCCASIONAL DAILY CARE	EPISODIC CARE	CONTINUOUS/ LONG-TERM CARE	PALLIATIVE/ END-OF-LIFE CARE	RECUPERATIVE CARE	HOME CARE
CAREGIVER INVOLVEMENT	Moderate to intense	Moderate to intense	Moderate to intense	Intense	Moderate to intense	Moderate to intense
DURATION	Long-term *May span years*	Short-to-mid-term *May span days, weeks, months*	Mid-to-long-term *May span months, years*	Unpredictable *Typically 3-6 weeks but could last months, years*	Short-to-long-term *May span days to years depending on condition*	Short-to-long-term *May span days to years depending on condition*
DEGREE OF CONTROL	High and predictable *Easy to plan in advance for changes to work and life responsibilities*	Limited and unpredictable *Impossible to plan for in advance*	Mid to high *Periods of high control can be disrupted with periods of mid-level control*	None	None to high *Depends on condition, e.g. pulled muscle vs. hip replacement after unexpected fall*	High and unpredictable *Easy to plan in advance for changes to work and life responsibilities*
EXAMPLE(S)	Groceries, yardwork, transportation	Treatment-related care *e.g. appointment in response to arthritis flare-up*	Chronic and/ or progressive illness or disability *e.g. Parkinson's, Alzheimer's*	Care in hospital, palliative care facility, community or home environment	Recovery following surgery, pneumonia, stroke	Supporting independent living *e.g. support service coordination, safety, and security assistance*

Source: Nathan Battams, Family Caregiving in Canada: A Fact of Life and a Human Right (Ottawa: Vanier Institute of the Family, 2016), 6.

Care requirements dictate the intensity of care. The Vanier Institute of the Family has created a chart that illustrates the diverse caregiving requirements based on the level of need. As reflected in the Vanier chart, those providing end-of-life or palliative care have no degree of control over a situation that requires intense involvement. About 3.7 million Canadians report having provided end-of-life care.[13]

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9. Ibid., 8.
10. Ibid., 7.
11. Ibid., 14.
12. Jasneet Parmar, Nathalie Jette, Suzette Brémault-Phillips, and Jayna Holroyd-Leduc, "Supporting People who Care for Older Family Members," Canadian Medical Association Journal, 186, no. 7 (2014), 487-8.
13. Statistics Canada, "End of Life Care, 2012," *Spotlight on Canadians: Fact Sheet (Ottawa: Statistics Canada, 2015)*. Retrieved from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2014004-eng.htm

It's clear that caregivers in Canada would benefit from an increased sense of support. It's also true that caregivers face diverse challenges that cannot be accommodated by a one-size-fits-all program.

Part of experiencing a natural death is the environments that are most natural to the person receiving care. Receiving palliative care in a home environment is preferable for many care recipients but it is also the preferred environment for many caregivers. Of the 621,000 people who provided palliative care in 2012, about 35 percent did so in their own homes. Another 17 percent said they would have preferred to have provided care in their own homes.[14]

Sources of support

The level of support a caregiver may require is conditioned by the intensity of the caregiving and the nature of the relationship with the recipient. A higher intensity of caregiving that involves many hours a week requires a greater degree of financial support.

When a helping hand is required, people naturally turn to those in their immediate social networks. This is true when caregivers seek sources of support. About one in five caregivers receives some form of financial support. About 12 percent of caregivers receive financial support from other family members while about seven percent receive assistance from a government program.[15]

Financial support is an important factor in caregiving, as one study suggests that this kind of support can reduce the probability of a care recipient entering a long-term care facility by 56 percent.[16] It is telling that social networks continue to be the first sources of financial support.

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14. Ibid.
15. Ibid., 16.
16. Samir K. Sinha, Bailey Griffin, Thom Ringer, Christina Reppas-Rindlishbacher, Emily Steward, Ivy Wong, Stephanie Callan, and Geoffrey Anderson, *An Evidence-Informed National Seniors Strategy*, 2nd ed. (Ottawa: Alliance for a National Seniors Strategy, 2016), 121.

3. SURVEY OF CURRENT CAREGIVER SUPPORT POLICIES

The federal and provincial governments have established policies in support of natural caregivers. These policies most often aim to protect employment status and offset financial costs in the form of grants, benefits, and tax refunds.

FEDERAL BENEFITS

The Compassionate Care Benefit (CCB)
The CCB was established in 2004 and expanded in January 2016 to cover a maximum leave of 26 weeks. The benefit is issued under Employment Insurance and eligibility requirements include a qualifying period in which caregivers must have accumulated 600 insured hours of work within the previous 52 weeks. One limitation of the benefit is that it is available only to caregivers providing care to the gravely ill or those at significant risk of death.

A pilot project initiated in August 2016 allows caregivers to receive some additional income while on claim. The Working While on Claim pilot project allows caregivers to keep 50 cents of their benefit for every dollar they earn up to 90 percent of their insurable earnings. Caregivers can agree to the terms of an earlier pilot project that allowed an earnings allowance of $75 or 40 percent of their weekly benefit.

Family Caregiver Relief Benefit
This benefit is a tax-free lump sum amount to support military veterans when natural caregivers are temporarily unable to provide care. The benefit covers the cost of care while a natural caregiver takes time off or addresses their own health and self-care needs.

FEDERAL TAX CREDITS

Family Caregiver Amount
Caregivers are eligible for this tax credit of $2,093 (2015) if they can claim one or more of the following:

- Caring for a spouse or common-law partner with a net income under $11,327;
- Caring for an eligible dependent;
- Sharing a dwelling with a dependent who meets certain criteria. In this case, caregivers may be eligible to claim an amount above $2,093.

Caregiver Amount
Caregivers can claim up to $4,608 or $6,701 when combined with the Family Caregiver amount.

Eligibility requirements include maintaining a dwelling where they live with a dependent or spouse/common-law partner's dependents who are 18 years or older, and for whom they have legal custody. The dependent must earn less than $20,343 (2015) annually.

Infirm Dependent Amount
Caregivers can claim up to $6,700 including the $2,093 Family Caregiver Amount for an infirm dependent 18 years old or older, for whom they have legal custody. The benefit can be divided among spouses.

Disability amount transferred from dependent
Under certain conditions a caregiver may be eligible to claim all or part of a dependent's disability tax credit.

Home Accessibility Tax Credit
The HATC is a non-refundable tax credit to assist in making homes more accessible. The aim of the HATC is to assist seniors and persons with disabilities to upgrade their dwellings to increase mobility and care. While the credit is targeted to seniors, it could reduce strain on caregivers by allowing care recipients to age in place.

AS OUR POPULATION AGES, WE WILL ALL HAVE TO CARE FOR FAMILY AND FRIENDS NEARING THE END OF LIFE.

#DOYOURPART

Graphic: Kira Lodder

PROVINCES AND TERRITORIES

There are various caregiver support programs offered at the provincial level, although eligibility requirements and benefit amounts vary from province to province.

All provinces and territories provide unpaid compassionate leave, with Alberta being the latest to do so in 2014. While qualifying factors can vary from province to province, most provinces and territories grant eight weeks leave to be taken within a 26-week period. Quebec and Saskatchewan offer more robust leave policies.

Quebec is the only province to offer refundable tax credits for caregivers where other jurisdictions promote non-refundable credits.

The chart on page 15 displays the provincial programs that correspond with federal programs. As the chart indicates, provinces fund respite services, though the degree of funding varies from province to province.

There are a few noteworthy provincial programs for caregivers. In 2011, Manitoba created the Primary Caregiver Tax Credit which recognizes the broad spectrum of caregiving relationships. Under specific conditions, the credit can be claimed by caregivers of spouses, relatives, and even neighbours and friends.

All provinces and territories offer coverage for at-home respite care as noted in chart 3, though there are no uniform criteria or standard amount of coverage. Home respite care is offered at no direct cost to First Nations and Inuit Health Branch programs, as well as the Northwest Territories, Nunavut, Yukon, Manitoba, and Ontario.[17] Partial cost for home respite services is available in British Columbia, Alberta, Saskatchewan, New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador.[18]

Federal and provincial grants and refunds are the most accessible policy levers available to the state in support of natural caregivers. The fact that these tools are available to caregivers communicates that governments recognize that natural caregivers are an important part of the care continuum.

According to a Statistics Canada report, as of 2012 only about 12 percent of caregivers providing end-of-life care have ever accessed the CCB.[19] This is below expectations and many factors may contribute to this including poor promotion of the benefit and the limited caregiving circumstances to which the benefit applies. Many assessments of the CCB have been conducted with a range of proposed improvements including converting the benefit to a refundable tax credit.[20]

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17. Samir K. Sinha et al., 122.
18. Ibid.
19. Maire Sinha, 4.
20. For example, see Sherri S. Torjman, *Policies in Support of Caregivers: Renewing Canada's Social Architecture, Research Paper no. 1.* (Ottawa: Caledon Institute of Social Policy, 2015). Retrieved from http://www.caledoninst.org/Publications/PDF/1071ENG.pdf

While policy adjustments are important, caregivers are more likely to turn to their own social networks for support, as shown above. In the next section, innovations that support caregivers and promote a culture of caregiving are explored. These innovations find their genesis not in state policy but most often within caregiving communities themselves. There is an abundance of opportunities for innovative thinking within the social institutions that function between the state and the market. This doesn't preclude the state or market as actors, but recognizes the social capital available in caregiving communities.

CHART 3: PROVINCIAL AND TERRITORIAL SUPPORTS FOR NATURAL CAREGIVERS

PROVINCE	COMPASSIONATE CARE LEAVE (# OF WEEKS OF PROTECTED LEAVE)	FUNDED RESPITE SERVICES AVAILABLE	SPECIFIC GRANT FOR FAMILY CAREGIVERS	CAREGIVER SPECIFIC LEGISLATION	CAREGIVER TAX CREDIT*
BC	8	Y			$4,318 at net income threshold of $14,615
AB	8	Y			$10,296 at net income threshold of $16,371
SK	12	Y			$9,060 at net income threshold of $15,473
MB	8	Y		Bill 42, The Caregiver Recognition Act (2011)	$3,605 at net income threshold of $12,312
ON	8	Y			$4,557 at net income threshold of $15,593
QC	8	Y			$775-1,131 no net income threshold defined**
NB	12	Y			$4,473 at net income threshold of $15,277
NS	8	Y	$400/month		$4,898 at net income threshold of $13,677
PE	8	Y			$2,446 at net income threshold of $11,953
NL	8	Y			$2,724 at net income threshold of $13,313
YK	8	Y			$4,530 at net income threshold of $20,002
NU	8	Y			$4,530 at net income threshold of $20,002
NWT	8	Y			$4,530 at net income threshold of $20,002

* Indicates Net Income of Dependent not Caregiver   ** Indicates Credit is Refundable

Source: Table 13 in Samir K. Sinha et al., An Evidence-Informed National Seniors Strategy, 2nd ed. (Ottawa: Alliance for a National Seniors Strategy, 2016), 124.

4. INTERNATIONAL INNOVATION

The creation of support structures for caregivers will become more urgent in the years ahead. The challenge presents an opportunity to engage in creative and innovative methods of supporting caregivers in their work.

This section examines innovative practices from around the globe that engage social institutions and contribute to the development of social architecture. The programs and models directly support caregivers, engage new supportive relationships, or indirectly ease the strain on natural caregivers. The models presented below address issues relating to aging or end-of-life care. The examples are divided into two broad categories: mobilizing supportive communities, and building caring living environments.

MOBILIZING SUPPORTIVE COMMUNITIES

As noted above, aging and end-of-life care has been undergoing a shift over the last few decades toward a public health model that encourages broad community engagement.

The compassionate community model is a legacy of this approach. The model seeks to engage the community as a place of understanding and a resource for caregivers and care recipients.

Dr. Allan Kellehear, one of the leading minds behind compassionate care communities, identifies the role of community and its absence in the modern experience of illness and care:

> In the last 100 years of western European cultural life we have witnessed a growing disconnect between the basic family unit and their wider connections with extended family and broader community networks. At the same time, we have witnessed a rising dependency on professional health services. Today, that set of cultural developments has led to a polarized view of care for older people, the chronically and terminally ill, as well as the bereaved. Care for these populations is now widely viewed as the responsibility of family or of health services. This polarized view is both an incorrect and unsustainable cultural and health policy position. Communities are able to do more to support families and health services and to bring practical resources and important supports to both.[21]

Compassionate communities aim to shrink the gap between communities and natural caregivers and health services. Kellehear argues that "care for one another at times of health crisis, and personal loss is not simply a task solely for health and social services, but is everyone's responsibility."[22]

Our current culture is uncomfortable and anxious about aging and dying, hindering a robust conversation about how to mobilize the community to care for the ill and for their natural caregivers.

The absence of robust community involvement in the care of the aging and dying has been accompanied

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21. Kellehear, "Compassionate Communities …," 1074.
22. Kellehear, Compassionate Cities Charter (undated), 1. Retrieved from http://media.wix.com/ugd/14d74a_c6e21bb0a3f047dfa4191382b784beae.docx?dn=CCCharter.docx

by "contemporary challenges of social isolation, the professionalization of dying, inequity of access to services and changing demographic trend."[23]

Research suggests that this lack of connectivity and the accompanying social isolation are detrimental to health. Professional health care alone is insufficient in meeting the challenge. Researchers Sallnow, Richardson et al write in their recent review, "Rather loneliness, stigma and other social problems are best tackled by friends or community members rather than healthcare professionals. A strong community response augments rather than supplants the professional response."[24]

Building compassionate communities encourages and supports natural caregivers in their role. One strategic step is to increase awareness about aging and dying within the community. Public awareness creates space for natural caregivers to speak about their experiences and to develop supportive relationships with other caregivers.[25]

A NOTE ON CAREGIVING AND FINANCIAL STRESS

Many caregivers experience financial strain. As noted above, federal and provincial policies aim to reduce the financial burden on caregivers through grants and tax refunds. The CCB is the central federal policy measure aimed at assisting caregivers. Yet, enrollment in the benefit has been lower than expected.

There is a large body of research on various instruments designed to ease the financial strain that can accompany aging, such as long-term care insurance and health savings accounts. These proposals reflect specific health-care jurisdictions and funding models. Savings and insurance instruments are primarily focused on medical and professional caregiving. Acknowledging the significant body of research and debate around these instruments, this paper focuses instead on initiatives that mobilize and enhance community responses to aging and dying.

Public awareness also counters social isolation, both for the care recipient and for natural caregivers. Raising awareness increases the capacity within communities to support caregivers, encouraging everyone to take responsibility for care and hands-on support.[26]

SEVERN HOSPICE, SHROPSHIRE, ENGLAND

Severn Hospice embodies the principles behind compassionate communities. It's an example of how an opportunity was identified and developed into a functioning initiative. The hospice serves a population of about 500,000 people dispersed in small to medium-sized towns. In 2007 the hospice began preparing for an anticipated flu pandemic, recruiting additional volunteers for responsibilities usually performed by paid staff. With a core of trained volunteers in place, the community identified a lack of

23. Libby Sallnow, Heather Richardson, Scott A. Murray, and Allan Kellehear, "The Impact of a New Public Health Approach to End-of-Life Care: A Systematic Review," *Palliative Medicine*, vol. 20, no. 3 (2016), 201.
24. Ibid.
25. Ibid., 205.
26. Ibid., 206-7.

social connectivity among the elderly and infirm. In 2009 the hospice was selected by the local health authority to operate a pilot project to address social isolation. The community of Church Stretton was identified as a community with an advanced aging population at risk for social isolation.

The philosophy behind the project was not to create another program, but to create a community. Family physicians identified potential individuals who would benefit from inclusion in the community-building initiative. A coordinator connected the individual with a volunteer based on similar interests.[27] As of 2014, Severn Hospice had recruited 1,000 volunteers supported by 350 staff. Trained volunteers assist with social needs and frequency of contact is negotiated between the volunteer and care recipient. Volunteers are encouraged to monitor changes in health and communicate any concerns with their coordinator.

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27. Paul Cronin, "Compassionate Communities in Shropshire, West Midlands, England," in *Compassionate Communities: Case Studies from Britain and Europe*, eds. Klaus Wegleitner, Katharina Heimerl, and Allan Kellehear (New York: Routledge, 2016), 33.

IT TAKES A VILLAGE FROM BIRTH TO DEATH

CARING FOR AILING FAMILY AND FRIENDS DOESN'T JUST HAPPEN IN HOSPITALS.

DO YOUR PART

Benefits

Follow-up evaluations found significant decreases in unplanned visits and phone calls to family physicians, and unplanned visits and admissions to the emergency room.[28] These results provide a measurable outcome of community connectivity in response to social isolation.

The benefit to the broader community beyond the reduction in medical services includes an awareness around aging and caregiving, and increased value on interconnectivity. When a significant portion of the community engages in caretaking activities, it raises the level of dialogue about issues of aging and end-of-life care within the community. Kellehear, who pioneered much of the philosophy behind compassionate communities, argues that such initiatives communicate to the wider community that end-of-life care is the responsibility of everyone.[29]

Another benefit is that the initiative equips people to be caregivers. The experience mobilizes people to support others who are providing care to neighbours and loved ones. The growth in awareness and mobilization are key elements of culture change in which community members see care for others as a personal responsibility.

THE GOOD NEIGHBOUR PROJECT, MILFORD CARE CENTRE, LIMERICK, IRELAND

The Good Neighbour Project is based on the compassionate community framework and promotes palliative care as a matter of public health. Consistent with the compassionate care philosophy, the aims of the program are to engage the broader community beyond medical care provision.[30]

The project has two aims. First, to enable people living with palliative care needs to identify their social and practical needs. Second, to enable these needs to be met within a person's circle of community.[31] Much like the Severn Hospice program, the aim is not to develop a service but to encourage a community support assisted by local organizations and the Milford Care Centre.

A "whole population approach" challenges the community to talk about death, dying, loss, and care. One way these conversations are facilitated is through online videos to assist people in learning what to say to those who receive hospice care and their families. The Milford Care Centre recognizes the need for conversations on death, dying, loss, and care. Public conversations about these issues also serve those who are providing care, creating an avenue to speak about their experiences.

At the practical level, the community assists in connecting those using palliative services and their families with local support in daily care activities such as picking up groceries, minor home maintenance, or sitting with a caregiver who needs a break.[32]

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28. Ibid., 37-40.
29. Kellehear, "Compassionate Communities ...," 1073.
30. Jim Rhatigan, "Compassionate Communities: Supporting People to Talk More Openly About Death, Dying, Loss and Care," (Lecture to the 14th Annual Education and Research Seminar of the Irish Association for Palliative Care, Kilkenny, Ireland, February 6, 2014). Retrieved from https://vimeo.com/88141620
31. Milford Care Centre Compassionate Communities, "The Good Neighbour Partnership," Milford Care Centre, http://www.compassionatecommunities.ie/good-neighbour-partnership (Accessed September 1, 2016).
32. Ibid.

Benefits

The program mobilizes neighbours to care for those who live in close proximity. It is a community-building and community-strengthening effort.

The community initiates culture change by challenging the silence and hidden nature around issues of illness and dying. The project empowers people to engage in supportive conversations with those experiencing illness, their caregivers, and those grieving the loss of a loved one.

IKI–IKI (VITAL) DAY CARE SERVICE, HAKUAISHA SOCIAL WELFARE CORPORATION, OSAKA PREFECTURE

This initiative in Osaka, Japan integrates care recipients into the local community while at the same time acclimatizing the community to their needs.

Operating since 2005, the program offers a day program for people with dementia. Iki-Iki intentionally avoids a heavy schedule, preferring to allow participants to maintain their own rhythm. The result is that people with dementia maintain some personal autonomy and are less likely to be considered "passive consumers."[33]

The anchoring event of the day is the noon meal. Those with dementia decide on the meal together, then shop in the local community for the ingredients. Shopkeepers were briefed ahead of time and the program publishes a regular newsletter for shopkeepers and the families of program participants.[34]

Benefits

Respecting the natural flow of the day by relying on less programming has altered how staff view their approach to care. For the seniors with dementia, the program respects a sense of autonomy and self-agency while integrating them into the life of the local community.

The shopkeepers willingly participate in the program and benefit in learning how to navigate the sensitivities and complexities of living with dementia.[35]

A key observation regarding the local community concerns the normalization of the disease. The integration of seniors with dementia confronts the notion of efficiency in daily interactions.[36] The inclusion of people with dementia into the daily life of the market creates ripples into the wider community, raising awareness about living with dementia and the responsibility of all community members in participating in the lives of these seniors.[37]

33. Kellehear, "Compassionate Communities …," 1074.
34. Libby Sallnow, Suresh Kumar, and Allan Kellehear, eds., *International Perspectives on Public Health and Palliative Care* (New York: Routledge, 2012).
35. Kellehear, "Compassionate Communities …," 1073-74.
36. Sallnow, Kumar, and Kellehear.
37. Kellehear, "Compassionate Communities …," 1074.

THE DIANE MORRISON HOSPICE, OTTAWA, CANADA

What happens when family caregivers are absent? The reality for many street-involved and homeless individuals is that they have little to no contact with their families of origin. When facing a terminal diagnosis, homeless and street-involved people enter a health system that may not easily accommodate some lifestyle and behavioural aspects of homelessness.

The Ottawa Mission, a shelter and service provider for homeless men, created a hospice in 2001. Patients referred to the hospice are homeless or street-involved and face a rapidly progressing terminal illness, or require help managing pain related to a terminal illness. The hospice is positioned to assist those whose behaviour or lifestyle issues make it difficult for other hospices to provide sufficient care.

The Diane Morrison Hospice recognizes the importance of natural caregivers, integrating them into patient care. The hospice welcomes clients' biological, adoptive, and street families and friends to help provide care."[38]

The Mission often hosts memorial services for clients who die in hospice, and has a plot at a historic Ottawa cemetery for those who are without family or have no involved family members.

Benefits
The obvious benefit of the Diane Morrison Hospice is that it understands its clients' unique challenges. The hospice contributes to a culture of caregiving by intentionally incorporating volunteers, family, and friends into the care of clients. The hospice honours the dying and ensures a dignified burial for clients who, through their experiences on the street, have not always been treated with dignity.

BUILDING CARING LIVING ENVIRONMENTS

Physical spaces can enhance or inhibit quality of life. Physical infrastructure must be considered when strengthening social architecture. This section explores innovations that utilize physical space and proximity to enhance care and support natural caregivers.

The detrimental effect of loneliness is not merely feeling down. Loneliness is linked to poor outcomes to personal health as well. A British survey concluded that "One in four young people feel 'left behind' in the world of social networking while 2.5 million elderly are secretly dreading Christmas."[39] Socially isolated older adults are at risk for poor health outcomes. Though young people may appear to be more connected, loneliness remains a significant problem regardless of age or stage of life.

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38. The Ottawa Mission, "Hospice," The Ottawa Mission, https://ottawamission.com/hospice/ (Accessed September 14, 2016).
39. John Bingham, "Connected Generation as Lonely as the Elderly," *The Telegraph*, December 12, 2014. Retrieved from http://www.telegraph.co.uk/news/uknews/11288047/Connected-generation-as-lonely-as-the-elderly.html

THE MEADOWS SCHOOL PROJECT, COLDSTREAM, B.C. AND WILLIAMS LAKE, B.C.

The Meadows School Project addresses the risks due to loneliness by bringing two generations together. The project also confronts attitudes about aging and older adults by integrating older and younger generations. In 2000, veteran teacher Sharon MacKenzie developed the Meadows School Project in Coldstream, B.C. and later founded the i2i Intergenerational Society in 2008. The project was inspired by language immersion programs and involved conducting elementary school classes for a total of five months a year in the Coldstream Meadows Retirement Community. Residents were welcome to sit in on classes in addition to meeting with students one-on-one after morning classes. Students also volunteered on site.[40]

As a result, residents discovered a greater sense of purpose in meeting with the children and were more active. The students were challenged to evaluate cultural stereotypes about aging. The program ran until 2008 in Coldstream and a second phase of the project was initiated in Williams Lake, B.C.

Benefits
The central aim behind the start of the initiative was to bridge generational divides. This act confronts stereotypes and discomfort around issues of aging. In this way, the program is an agent of culture change, instilling a sense of responsibility for caring for older adults. By holding regular classes in the facility, the Coldstream Meadows Retirement Community became a shared space.

For older adults, the initiative provides an added sense of purpose as they develop friendships that resemble informal mentorship. These relationships help prevent social isolation, providing secondary health benefits for participants.

HUMANITAS, DEVENTER NETHERLANDS

Around 2013, university student Onno Selback was fed up with the noise and conditions provided by the university housing. Selback contacted the Humanitas retirement home, which led to a new initiative. Today, students can live rent free in a small apartment at Humanitas in exchange for providing 30 hours a month of volunteer service. The volunteering includes a variety of interactive activities with older residents such as watching sports, celebrating birthdays, and providing company when senior adults experience illness.[41]

Humanitas accommodates six students and 160 senior adults. Similar programs operate in Cleveland, Ohio and Lyon, France.[42]

40. Jennifer Milner, "Programs to Bridge the Generations Engages All Ages," *The Journal of Active Aging* (2012), 32-42.
41. Carey Reed, "Dutch Nursing Home Offers Rent-Free Housing to Students," *The Rundown*, PBS NewsHour, entry posted April 5, 2015, http://www.pbs.org/newshour/rundown/dutch-retirement-home-offers-rent-free-housing-students-one-condition/ (Accessed August 25, 2016).
42. IAHSA, "Intergenerational Living," IAHSA The Global Ageing Network Blog, posted January 25, 2015, http://globalageing.org/intergenerational-living/ (accessed August 25, 2016).

Before the Humanitas project, a similarly inspired pilot housing project was tested in Barcelona in the 1990s that matched students with older adults. Versions of the program now operate in as many as 27 cities in Spain.[43]

Benefits
Similar to other intergenerational initiatives, this project confronts social isolation and the discomfort around issues of aging. Community is built between the generations and students take responsibility for small aspects of care. The opportunity creates a culture of care where both younger and older adults benefit from the shared space.

CO-HOUSING: DENMARK, THE NETHERLANDS

Intergenerational movements develop a culture of care among younger people. Another approach develops communities of care among aging adults. The co-housing movement has been around since the 1970s with origins in Denmark and the Netherlands. The movement has typically attracted young families, but as Western countries age, co-housing is becoming a more attractive option for older adults.

The premise behind co-housing is the formation of intentional community while maintaining a degree of individual space. Typically, the community shares kitchen, laundry, dinning space, and other common areas but people retain their own living quarters. The initiatives are self-governed and benefit older adults by preventing loneliness and social isolation, and encouraging active living and mutual care or co-care.[44] While care is not the primary motivation, there is a strong value placed on neighbourliness. As one observer writes, "The care stems from an interrelatedness members feel as good neighbours or friends."[45]

Co-housing older adults are attracted to the model because of the strong sense of community that avoids the institutional feel of other retirement living models. Some co-housing models accommodate caregivers when care needs become too much for other residents to provide.

One of the challenges facing the movement in North America is that co-housing requires both giving and receiving care from neighbours. One co-housing participant told the Globe and Mail that it is easier to give help than accept it: "This is really hard for us: to be open to accepting support and care from other people. We're practicing."[46]

Some proponents of older adult co-housing argue that public policy support is needed for the movement to flourish. Unlike usual development projects, new co-housing construction incorporates far more common space, limiting market appeal.

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43. Ibid.
44. Greg Bamford, "Cohousing for Older People: Housing Innovation in the Netherlands and Demark," *Australasian Journal on Ageing 24 no. 1 (2005)*, 44.
45. Ibid., 44-45.
46. Zosia Bielski, "Meet the New Golden Girls (and Guys): How Boomers Are Coming Up with Creative Living Arrangements," *The Globe and Mail*, November 11, 2015. Retrieved from http://www.theglobeandmail.com/globe-investor/retirement/retire-housing/for-retiring-boomers-co-housing-is-a-livelier-way-of-growing-old/article27212717/

A NOTE ON TECHNOLOGICAL INNOVATION

There has been significant technological development aimed at assisting older adults. Sophisticated monitoring systems and automated data collection have enhanced treatment and streamlined service. Technological advances can simplify many aspects of care, but these advances can also result in less physical contact between care recipients, caregivers, and other community members. Technology can help older adults maintain independence and a sense of autonomy, but it can it can also reduce face-to-face contact.

Benefits

Co-housing creates intentional communities that provide mutual support for participants. Being a good neighbour reduces the risk of social isolation and results in keeping active.

Co-housing broaches the topic of aging in society and requires participants to plan for the future. It offers a lifestyle of co-caring that can be attractive to individuals who do not have familial support.

TINY HOMES AND THE MED COTTAGE

The concept of the granny flat is undergoing a renovation for the 21st century. One modification on the established theme is the tiny-home movement. As housing prices in major urban centres continue to rise, tiny homes are gaining more media attention, offering a variety of sizes with an eye to affordability. Some models are mobile and others are modular in design, making them easier to set up on properties with existing structures. Tiny homes could potentially be built on a family property allowing for easy access to natural caregivers while maintaining personal space.

Some estimates suggest that 40 percent of people living in tiny homes are over age 50, leading some commentators to wonder if tiny homes will become a trend among older adults. Manufacturers are designing plans that are more suited to older adults, skipping lofts and ladders that have become popular in other designs.

Another variation on the tiny home is the MED cottage that is specifically designed for caregiving. The innovative idea of Reverend Ken Dupin, the 12 x 24 foot structures are akin to a high-tech hospital room that resembles a pool house. The small cottage is designed to connect to a home's existing plumbing and electrical supply and features a kitchenette and washroom with walk-in shower. There is a full range of caregiving technology from electronic monitoring equipment, overhead bed hoist and an automated medication dispenser. Dupin developed the idea as an alternative to the institutionalized feeling of a long-term care facility.[47]

Benefits

These options allow for caregivers and recipients to live in close proximity while respecting personal space. For some families, these structures make more sense than renovating a current home to fit the needs of an aging love one. The tiny-home movement isn't for everyone and it is easy to imagine municipal regulations and bylaws frustrating plans to install a tiny home or MED cottage.

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47. Med Cottage Granny Pod, "MEDCottage," http://www.medcottage.com (Accessed August 26, 2016).

CONCLUSION

Canada's natural caregivers are a central component of the social architecture supporting older adults and those at the end of life. As the population ages, the natural caregivers will be increasingly relied upon. Federal, provincial, and territorial governments recognize the contribution natural caregivers make, and offer grants and tax relief to offset the financial cost of caregiving. These programs are important both in the provisions they offer and for their acknowledgment of caregivers. Yet, it is clear that caregivers often turn to their immediate social networks for support.

Social institutions have much to contribute to supporting caregivers. Aging and dying are issues that are met with some reluctance, yet the innovative initiatives above demonstrate a positive contribution to the public discussion. The acknowledgment and encouragement of public conversations create spaces where caregivers can share their experiences, increasing awareness around aging and end-of-life care. The examples above view aging and end-of-life care beyond the medicalized context and encourage a wider community engagement. Social isolation can plague caregivers and care recipients, but creative social engagement has been shown to improve physical well-being.

What is clear from examples around the globe is that government initiatives are only one aspect of healthy community building and mobilization. Governments can, however, create policy environments where innovation and creative resourcefulness can flourish, all in support of caregivers and care receivers.

CANADA IS EXPERIENCING A DEMOGRAPHIC SHIFT towards an aging society. This shift creates challenges for the health-care system as Canadians consider issues of aging, long-term care, and ultimately, end-of-life care. How does this effect our social architecture? What structures can be created to support those who are supporting their loved ones? Cardus Health explores these questions and others. Follow the conversation: **cardus.ca/health**

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