# Case Study:
# OTTAWA

## A Look at the End-of-Life-Care Landscape

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# Case Study: Ottawa

## A Look at the End-of-Life-Care Landscape

## Preface | The City Of Ottawa and the Champlain Local Health Integration Network

The city of Ottawa is a sub-region within the broader Champlain Local Health Integration Network (LHIN), which is situated in southeastern Ontario and covers eighteen thousand square kilometres. The sprawling region stretches from Deep River in the north to Morrisburg and Cornwall in the south and Hawkesbury in the east. The region includes the nation's capital, the city of Ottawa, as well as a number of additional small towns, rural townships, and two First Nation reserves (Akwesasne near Cornwall and Pikwàkanagàn in Renfrew County).[1]

As of 2015, the Champlain LHIN had 1.3 million inhabitants.[2] Of these inhabitants, 20 percent live in a rural area, 19 percent are francophone, 19 percent are immigrants, 16 percent are over the age of sixty-five, and one in six residents reports using a language other than English or French (most common are Chinese, Arabic, and Italian). Three and a half percent of inhabitants in the region are Indigenous, though only 22 percent live on a reserve. Indeed, the city of Ottawa has Canada's largest urban Inuit population.[3] The Champlain LHIN is therefore large and diverse, with marked differences across the region, which translates into various challenges.

> Chronic conditions account for 21 percent of all admissions to acute hospitals and **61 percent of the total number of deaths** in the Champlain LHIN.

By 2025, the population in the Champlain is projected to grow from 1.3 to 1.5 million people, which represents an increase of 12 percent.[4] The region is also marked by a growing aging population, which will increase from 16 to 21 percent in this same time period.[5] Furthermore, over a third of Champlain residents (aged twelve and over) live with a chronic condition, and 15 percent live with multiple chronic conditions. Indeed, chronic conditions account for 21 percent of all admissions to acute hospitals and 61 percent of the total number of deaths in the Champlain LHIN.[6] Nearly 18,400 people over the age of sixty-five in the Champlain LHIN are living with dementia. This number is expected to rise by 30 percent between 2012 and 2020 to include 24,000 people. Dementia is the most significant cause of dependency and disability among older persons and the second leading cause of death in the Champlain LHIN.[7] Within the Champlain LHIN, the highest rates of chronic conditions are observed in the Renfrew County, Prescott-Russell, and Cornwall areas.

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[1] See appendix A for map of the Champlain Health Region.

[2] "Champlain LHIN Integrated Health Service Plan 2016–19," Ontario Local Health Integration Network, http://www.champlainlhin.on.ca/~/media/sites/champlain/Goals_Achvmnts/IHSP/201619IHSPEN.pdf?la=en.

[3] Champlain LHIN, "Local Environmental Scan," Ontario Local Health Integration Network, 2016, 6–7.

[4] Ibid., 9.

[5] Ibid., 9.

[6] Ibid., 28.

[7] Champlain LHIN, "Community Engagement Plan 2015–2016," Ontario Local Health Integration Network, 5–6, http://

Amid these growing pressures and needs, the Champlain LHIN mandate is "to ensure health services are well-organized, appropriately funded, and meet the health needs of the 1.3 million residents who call this region home."[8] The LHIN works with and funds roughly 120 health-service providers that offer about 240 health programs in hospitals, community support services, mental-health and addiction-service agencies, community health centres, and long-term-care homes. As of May 24, 2017, the Champlain LHIN also delivers home and community care services to support over 58,000 patients each year at home, at school, or in the community.[9]

The current palliative-care landscape within the Champlain region includes four main sectors—or spaces—of care: hospital-based palliative care, long-term-care facilities, community care hospices, and palliative care within the home setting. There are presently thirty-one hospital palliative-care beds in the Bruyère hospital, forty-two hospice beds within the city of Ottawa,[10] twenty-one hospice beds outside of the city,[11] and sixty long-term-care homes throughout the region.[12]

Looking at data collected between April 2014 and end of march 2015, a report by Health Quality Ontario reports that 58.1 percent of patients in the Champlain LHIN died in the hospital setting, below the provincial average of 64.9 percent; 46.2 percent received palliative home-care services in their last month (the provincial average is 43.3 percent); and 41.5 percent received a home visit from a doctor in their last month of life (provincial average 34.4 percent).[13]

The health system in the Champlain LHIN is therefore broad and complex, with many LHIN-funded health programs as well as non-LHIN-funded health-service providers. In addition, the region's sprawling geography brings with it special challenges in terms of coordinating services and ensuring their equitable access. The organization of the LHIN into sub-regions helps the LHIN to better understand and address these localized needs.[14] Technological advances are also playing an integral role in improving access in rural and remote areas, where online training and counselling programs increase the capacity of caregivers to provide the needed supports.

The Champlain region is experiencing similar pressures to other health regions across Canada; its end-of-life-care landscape is marked by a constrained economic environment, a rapidly aging population, and the growing prevalence of people living with chronic conditions and mental-health illness. According to a recent environmental scan, "Healthcare utilization rates have increased in the Champlain region over the last three years by 7% in acute care hospitalizations, 5% in emergency department visits, 13%

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www.champlainlhin.on.ca/~/media/sites/champlain/CE/PlnsRpts/201619CEPlnEN.pdf?la=en.

[8] Champlain LHIN website, http://www.champlainlhin.on.ca/AboutUs/Intro.aspx.

[9] The Champlain Community Care Access Centre (CCAC) is now part of the Champlain LHIN. Home-care services are therefore now coordinated by the Champlain LHIN.

[10] Hospice Ottawa has nineteen beds; Roger's House has eight pediatric beds; The Mission Ottawa serves the homeless population with fifteen beds.

[11] Hospice Cornwall has ten beds; Hospice Renfrew has six beds; Hospice Madawaska has two beds; Marianhill in Pembroke has three beds.

[12] See Champlain LHIN, "Wait List: Choosing a Long-Term Care Home," 2017, http://healthcareathome.ca/champlain/en/Getting-Care/Getting-Long-Term-Care/Wait-List.

[13] "Palliative Care At the End of Life," Health Quality Ontario, 2016, 4, http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf.

[14] See appendix A for a diagram of these sub-regions.

in admissions to mental health care beds, and 15% in home care visits."[15] Despite these increases, however, numbers are still lower than the provincial average by 5 percent in acute-care hospitalizations and 10 percent in home-care visits, though they are higher by 3 percent in emergency visits. They are also higher by 6 percent in terms of number of residents on a waitlist for long-term care, and there is a 16 percent longer waiting time for residents when compared to provincial averages.

Despite these growing pressures and the complexity of its health-care environment, the Champlain region is extremely fortunate to have a collaborative network of bright and passionate leaders working toward its success. Our conversations with community leaders made clear that strong leadership is an integral reason for Champlain's early successes in a number of areas. What's more, their collaborative and passionate spirits are key to the region's continual improvement. Despite representing various end-of-life spaces, they nonetheless demonstrate a deep recognition of the need to work together and an open and collaborative spirit to do so.

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The Champlain LHIN has been recognized for a number of early successes, including the implementation of the first regional palliative and hospice care program in the province, known as the Champlain Hospice Palliative Care Program, and the development of regional standards and indicators. In particular, Bruyère Hospital has shown to be an important leader in the area of palliative care. A more recent innovation is the creation of the Regional Palliative Consultation Team (RPCT).[16] The RPCT "is a partnership between Bruyère and the CCAC which supports health care professionals caring for palliative patients." The inter-professional team of consultants includes nurse practitioners, advanced-practice nurses, nurse specialists, and physicians with expertise in palliative care. The team offers consultation to primary-care providers and CCAC care co-coordinators, and those working in long-term-care homes, hospices, and retirement homes. The RPCT also serves as a central hub where physicians and practitioners from surrounding area hospitals can come together to learn and share their knowledge; it therefore plays an important role beyond consultation.

Yet despite these innovations, our conversations also make clear that there are critical gaps in the Champlain health-care region, especially as this relates to the notion of compassionate communities and end-of-life care. If compassionate communities are marked by a reversal of the trend to medicalize and professionalize death, where death is integrated within the community, where the community in fact shares in the "suffering" of the dying, where this shared suffering leads to a deeper awareness and capacity for care, where the dignity of those who are suffering is recognized, and where their emotional and spiritual as well as clinical needs are met, then there is certainly still much to do in Ottawa and the Champlain region.

Let us proceed by looking at these different spaces and by recalling the voices of those within the community.

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[15] "Local Environmental Scan."

[16] See "Regional Palliative Consultation Team," Bruyère, https://www.bruyere.org/en/regional-palliative-consultation.

## A Systems Approach to Compassionate End-Of-Life Care: Voices from the Community

Though there are spaces of compassionate care within the Champlain region, what is needed is a systems approach to compassionate end-of-life care. As one physician explains,

> We know that patients experience different needs across the illness trajectory, from the time of diagnosis of a progressive, incurable disease, to death, and then for family members thereafter as well with grief and bereavement. What we have to put in place are the different services and structures to meet their needs as they go across the illness trajectory, so that when they have a need, they will be able to find the right care in the right place at the right time by the right people.

But herein lies the debate. How do we best understand what this structure should look like? How do we effectively use constrained resources to build a comprehensive social infrastructure for end-of-life care? One that builds the capacity of, and effectively integrates, hospitals, long-term-care facilities, hospices, and the home within a community? And one that cultivates a compassionate culture throughout these spaces where the dignity of the dying and their caregivers are placed at the centre of our efforts?

Let's begin by looking at the different parts of the palliative care story within the Champlain region.

### The Hospital Setting and Compassionate End-of-Life Care

In an era of fiscal constraint, expensive hospital treatments, and expressed preferences by a majority of Canadians for a more natural death, there has been a somewhat natural tendency to look outside of the hospital environment for solutions. In many cases, funding has followed suit. The hospice movement has certainly emerged as an important and effective part of the solution. But in regions across both Canada and Europe where hospice movements are further advanced, there remains a dire need for palliative-care hospital beds where complex care needs can be addressed by an inter-professional teams. Therefore, the hospital setting will always play an integral role in the dying process for many people and remains an integral part of the social infrastructure for end-of-life care.

In Ottawa, the Bruyère hospital houses a thirty-one-bed palliative care unit and is the sole provider of this care in the Champlain region. Once a well-funded care unit with psychological and spiritual supports, the hospital has experienced a series of funding cuts that has severely reduced its capacity for both clinical care as well as psychological and spiritual support. As one physician explains,

> This palliative care unit can no longer see the most difficult cases. There's no psychologist. There's a part-time social worker. There's a chaplain who's only got one and a half days a week. How on earth—31 beds—can you provide the proper care for patients with the most difficult situations? The problem is, it's no longer funded and staffed as a PCU [palliative care unit], so in essence, we don't have proper palliative care.

"There is a terrible, desperate need for palliative care beds in this city!" the physician explains.

Another physician shares that policies have cut down a lot of essential programs within the palliative care unit: "It's like night and day from the time that I started to the way it is now." "This has been documented . . . cut-downs, both in the community and in patient services."

Hospital funding cuts may be part of a larger policy framework in recent years that aims to build the capacity of other sectors in the community to deal with end-of-life care. But savings often come from eliminating programs and services that address the emotional and spiritual needs of the patient. This, in turn, serves to cultivate a more clinical culture and experience within the hospital setting. As one physical shares,

> Studies show that between 40 percent and 60 percent of patients in our Western type of societies (so Canada, the UK, and the Anglophone ones), 40 percent to 60 percent of patients say that spirituality is important for them, and for many of them, it is religion. This is important for them in their lives, particularly as it relates to end of life. But very, very few doctors and nurses even ask about this.

He goes on to explain, “You will not find dictations by doctors and nurses of the patients they saw—where it says past medical history, medications, allergies, family history—you will never see their spiritual or religious care or needs. We need to start challenging that.”

In regions across both Canada and Europe where hospice movements are further advanced, **there remains a dire need for palliative-care hospital beds** where complex care needs can be addressed by an inter-professional teams.

Another interviewee eloquently explains,

> What I learned from people is that the most important part of death is probably to have peace. Not artificial peace. But a good death, I would say, is one with no regrets, or maybe there are some regrets, and then they are kind of reworked. Sometimes people may carry some mistakes and decisions they made in the past that keep bothering them. And then they come to the end of their life where often the stuff that has not been reworked in the past, let’s say like sexual abuse or abortion or divorce . . . all of this stuff, if it was not kind of processed, will haunt the person at the end of life.

Compassionate care within the hospital environment depends, therefore, on a holistic approach that values the spiritual and psychological needs of a patient alongside their clinical needs. Rather than shortchanging the quality of care and compassion within the hospital environment, our end-of-life care system must reorganize by building the capacity of the system as a whole (i.e., empowering long-term-care homes, home-care settings, and hospices) such that there is a *reduced need* for emergency-department visits, hospital admissions, and hospital deaths. The current reality in the Champlain region serves to exacerbate a system of growing inequality for end-of-life care, where compassionate care is relegated to certain spaces within the community, and the hospital offers a clinical and cold experience. Instead, the movement toward compassionate communities and end-of-life care *must recognize and include the hospital* such that a whole system of compassion is cultivated. In such a system, community compassion is enabled and integrated within the hospital setting, and conversely, clinical care is integrated within the community.

The current reality in the Champlain region serves to exacerbate a system of growing inequality for end-of-life care, where compassionate care is relegated to certain spaces within the community, and the hospital risks becoming a place that offers a clinical and cold experience.

## Long-Term-Care Facilities and Compassionate End-of-Life Care

**1. A growing care gap.** As medical advances enable people with chronic diseases and complex care needs to live longer, there is a growing need for compassionate, home-like spaces that can provide comprehensive and holistic care. Despite the preference by most Canadians for a natural death at home, the vast majority are unable to experience this. In the present context, as care needs increase and home-care supports (both publicly provided and through natural caregivers) become strained, many Champlain residents have little choice but to be placed on a wait-list for one of sixty long-term-care facilities within the Champlain region.

When an applicant applies for long-term care, the applicant is assigned a priority category that will affect their wait time. The average wait time to enter long-term care from home in the Champlain region is 134 days.[17] Many people wait much longer than this period as patients from hospitals are continually given priority to those applying from home. The period of waiting can be extremely stressful for the family and other caregivers. Indeed, often what drives seniors into long-term care is not their own needs, but rather that of their caregiver.[18] Another reality is that many of these needs then end up in expensive hospital visits. Leah Levesque, vice president of patient care at the Queensway Carleton Hospital, describes the situation in a 2016 article posted in the *Ottawa Citizen*: "It's not unusual for Queensway Carleton Hospital to have 50 seniors spread across the hospital and filling its 30-bed Alternative Level of Care (ALC) ward—a holding spot for patients whose acute illness is under control but who are too sick to go home and don't have a bed in long-term care either." Similar pressures are experienced in acute care, "where 14 percent of acute care space is taken up by non-acute patients," shares Dr. James Worthington, executive vice president of medical affairs.

Indeed, provincial numbers paint a similar picture. While long-term wait times for those applying from home have declined from their peak of 190 days in 2008, when Ontario's "Home First" program began, they have steadily increased in that same time period for those entering long-term care from the hospital.[19] The broader health system is not improving, therefore, so much as a different illness trajectory is transpiring in response to an acute-care gap, a trajectory where the hospital plays a larger role in providing care and access to long-term-care facilities.

**2. A need for emotional, spiritual, and psychological supports.** A number of recent reports and statistics paint a troubling picture of Ottawa's long-term-care facilities. An article posted in the *Ottawa Citizen* on August 15, 2017, reports that "the City of Ottawa has been slapped with an unheard of blanket order from the province to improve safety and care at three of its four long-term care homes following a string of incidents, including the repeated punching of one resident by a caregiver and head injuries suffered by another resident that was later covered up."[20] An earlier report by the Canadian Union of Public Employees argues that low provincial funding shortchanges Ottawa's seventeen long-term-care facilities by $1,460 hours of care daily, which equates to 273 full-time care staff.[21] And a recent Health Quality Ontario report indicates that 24.6 percent of long-term home residents in the

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[17] Health Quality Ontario, "System Performance Report," www.hqontario.ca/Portals/0/documents/.../hqo-2017-long-term-care-indicators.xlsx.

[18] Blair Crawford, "Ontario's Long-Term Care Problem: Seniors Staying at Home Longer Isn't a Cure for Waiting Lists," *Ottawa Citizen*, March 11, 2016, http://ottawacitizen.com/news/local-news/ontarios-long-term-care-problem-seniors-staying-at-home-longer-isnt-a-cure-for-waiting-lists.

[19] Original data source: Ministry of Health and Long-Term Care, reproduced in Crawford article cited above.

[20] Elizabeth Payne, "Ontario Issues Rare Order to Ottawa to Improve Failing Long-Term Care Homes," *Ottawa Citizen*, April 15, 2017, http://ottawacitizen.com/news/local-news/ontario-issues-rare-order-to-ottawa-to-improve-failing-long-term-care-homes.

[21] "Low Provincial Funding Shortchanges Ottawa Long-Term Care Residents by $1,460 Hours of Care Daily," Canadian

Champlain region experienced worsening depression between 2010 and 2016. [22] These indicators portray a system in need of reform, where formulas have overridden the focus on compassionate care, and where a medical model is simply not able to keep up with a changing landscape of needs.

As medical practices make it possible for those with chronic care needs to live increasingly longer lives, and as the rates of those suffering from dementia increases in our society, there is a dire need for compassionate, home-like spaces that have the capability of addressing complex care needs right up until the end of life. Long-term-care facilities can play an integral role in providing this compassionate care within the community, but there is clearly a need for improvement in some of these spaces. The Canadian Hospice Palliative Care Association explains that in the last fifteen years, there has been significant change in the responsibility of Long Term Care (LTC) homes despite their recognition of this:

> Providing care at end-of-life has become vital to LTC practice, however, palliative care has not been incorporated into the culture and self-perceived role of LTC. Further, homes are not equipped with some of the specialized knowledge and skills and dedicated resources to provide palliative care. Only once these gaps and barriers are addressed will we be able to create formal palliative care programs in LTC homes.[23]

**The average wait time to enter long-term care from home in the Champlain region is 134 days.**

Indeed, one physician shares that he met with senior leaders of a long-term-care facility to discuss opportunities to improve their capacity to provide medical care at end of life and thereby reduce reliance on expensive hospital visits, but was disappointed when the leaders replied: “This is too expensive, . . . and besides, families want their loved ones to go to the hospital at the end.”

While we do not suggest that all long-term-care homes in Ottawa and the Champlain region are void of compassionate care—and in fact, several conversations clearly portray the opposite—there are some important indicators in the Champlain region of a system under stress. Similar to hospital settings, long-term-care facilities seem to be experiencing a reduced capacity to provide holistic and compassionate care. Funding models that compartmentalize care needs do not easily fit alongside a compassionate end-of-life-care approach, and may in fact serve to overly professionalize and depersonalize the spiritual, emotional, and psychological aspects of the dying process. These aspects can only be detected by being present, actively listening, and showing compassion.

## Insufficient home-care and caregiver supports.

The province of Ontario has made home and community care a priority and has also identified the important need to support natural caregivers in these care environments. Many of these supports are

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Union of Public Employees (CUPE), April 19, 2017, https://cupe.ca/low-provincial-funding-shortchanges-ottawa-long-term-care-residents-1460-hours-care-daily.

[22] “Long-Term Care Home Performance in Ontario,” Health Quality Ontario, http://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance. 24.6 percent is in line with the provincial average of 24.2.

[23] “End-of-life Care in Long Term Care,” Canadian Hospice Palliative Care Association, http://www.chpca.net/projects-and-advocacy/eol-care-in-ltc.aspx.

publicly funded through the Champlain Community Care Access Centre (CCAC)24 and include home-care visits for nursing care, personal support care, occupational and physical therapy, counselling, and home visits from doctors and nurse practitioners. The amount and type of care that someone receives varies depending on the severity and nature of the illness.

In the Champlain region, 74.1 percent of palliative-care patients who were in the community in the last month of life received at least one home-care service in that period; 46.2 percent received palliative-specific home-care services, which typically involves more hours of care per week; and 41.5 percent of palliative-care patients had at least one home visit from a doctor in their last thirty days of life.[25]

But what is the story behind these numbers?

An article published by CBC News in December 2016 paints a troublesome picture of CCAC home-care supports.[26] The article describes a stressful family situation in which a mother nearing end of life is in need of more home supports but unable to access them. The high demands of her care is taking a toll on her family. One family member explains: "We get her out of bed, we get her into the bathroom in the morning. We have to lift her out of bed. We have to stay right behind her because she could fall. We have to lift her off and on the toilet." In the same article, Dr. Hacker, a palliative-care physician, explains that he and other palliative doctors were informed by the Champlain CCAC that it would have to cut back on personal support worker hours. The reduction means that palliative-care patients are being placed on a wait-list for sufficient home care. Dr. Hacker explains that "the government has been focusing on trying to get care out of expensive hospitals and into the community where costs are less, where patients want to be . . . but unfortunately the funding has not followed the patient home from the hospital."

To be sure, the Champlain LHIN and Champlain CCAC have recognized and sought to address this growing gap.[27] To understand root causes and strategies for addressing the growing demand, the LHIN commissioned a study by Preyra Solutions Group.[28] The study was completed in April 2017 and reports that in recent years, the wait-list for CCAC services has grown such that by December 2016, there were nearly 3,500 people formally waiting for CCAC services in the Champlain LHIN. While noting the CCAC's efficiency in administrative costs (7 percent less than provincial average) as well as its care and case-management model, the report finds that the substantial unmet need for home-care services in the Champlain region is primarily due to inequitable funding. Currently, the LHIN receives $240.5 million to fund home-care services. If the Champlain LHIN were funded for home care using a population-based model rather than one that is user based, it would receive an additional $31.5 million as its share of provincial home-care investments, which could then be potentially directed to 6,000 more

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24. The CCAC coordinates and delivers a range of home and community services across the region and is now part of the Champlain LHIN.
25. "Palliative Care At the End of Life," 4.
26. Simon Gardner, "Families Shouldering Burden as Home-Care Dwindles for Dying Patients," CBC News, December 12, 2016, http://www.cbc.ca/news/canada/ottawa/champlain-ccac-families-palliative-home-care-1.3889473.
27. These two entities have merged as of May 24, 2017. The Champlain LHIN will continue its current mandate while also delivering home and community care services.
28. Preyra Solutions Group, "Meeting Home Care Needs in the Champlain LHIN—Estimating and Managing CCAC Service Demand," April 26, 2017.

home-care clients.[29] As A user-based model, such as it is currently structured, does not account or adjust for a growing wait-list.

Ottawa has the highest number of residents with a post-secondary education, and more engineers, scientists, and PhDs per capita than any other city in the country, suggesting that it is also a **highly transient and mobile city**. Could the social character of the city present special challenges in terms of its capacity for informal care?

Interestingly, the report also finds that "available community support services—which substitute and complement CCAC services—are low in Champlain," and makes the further claim that "Champlain provides 1.7 % more personal support workers per day than the provincial average *because* there is 8.5% lower informal caregiver hours per client available in Champlain as compared to the rest of the province." Thus CCAC clients receive less informal care, which increases the need for CCAC services and increases the overall personal care gap in the Champlain LHIN. The finding of lower informal care rates, which relates to the community's social capital, is an interesting one, with broad potential implications for planning compassionate end-of-life care within the region. Ottawa has the highest number of residents with a post-secondary education, and more engineers, scientists, and PhDs per capita than any other city in the country, suggesting that it is also a highly transient and mobile city. Could the social character of the city present special challenges in terms of its capacity for informal care? And perhaps it is helpful to provide nuance to our understanding of "informal care" such that we better understand its composition of natural caregiver supports versus that provided by the community. Certainly the successful hospice movement within Ottawa, built on a groundswell of volunteers, suggests there is something deeper at play here. The distinction may be an important one when considering continuum of care strategies for the Champlain region.

Conversations with various professionals in the community served to highlight another concern with home-care supports, relating to the inequity in pay structures between home-care nurses and personal support workers (PSWs), on the one hand, and those working within a hospital setting, on the other. As one interviewee explains, "The inequities between home-care nursing and hospital-nursing funding is huge. And this drives retention, continuity of care, and engagement at the community levels, all of which for palliative care are critical. The remuneration models between the community and hospital nurses are vastly different." She goes on to explain,

> Many home-care nurses are very devoted to palliative care. But home-care nurses work in isolation. They have to go into people's homes and they don't know what they are going to meet. They don't have a colleague. They don't have a physician. They don't have resources with them at the bedside. And they have to travel; they have to travel in bad weather. So they are facing all of these special

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[29] The population-based method adjusts for population characteristics such as age, morbidity, and emotional determinants of health to allocate budgets across CCACs. Unlike the population- based model, the user-based model only includes the populations that receive services in its calculation—so the formula would never increase funding to CCACs even if it had a large wait-list because of historically poor access.

> challenges; they don't have the infrastructure or immediate help if they need it. And yet we pay them less; somehow we have decided this is a less valuable service.

The inequity not only serves to undermine the quality of home care but also affects recruitment and retention. "The home-care sector attracts new grads, but as soon as they are offered higher stability, better pay, better pension systems, and better benefits, they leave," explains the interviewee.

While a natural death is a preference for many Canadians, the reality is that this possibility depends on a circle of care within the community and a basket of compassionate supports that extend beyond the medical to include home care, respite, navigational, and bereavement supports. Unfortunately, this does not reflect present reality in the Champlain region. As one physician remarked, "While many Canadians would like to die at home, it is really only possible for large families and families with many resources." Certainly if we are to move toward a health care model that respect the wishes of Canadians to die at home, then we must ensure that the appropriate supports are provided regardless of these inequities.

"While many Canadians would like to die at home, it is really **only possible for large families and families with many resources.**"

The solution is complex, multipronged, and beyond the scope of this case study, but a 2016 report on the reality of caring by Health Quality Ontario recommends measures such as

> better preparation and instruction of caregivers for the responsibilities they are taking on; better coordination of home care services so that the burden of organizing care will not fall so much on caregivers; provision of clear information on what home care services are available and who is entitled to them; more consistent and reliable delivery of services; greater availability of respite services such as adult day programs; more services for high-needs patients; and more consideration of caregivers' needs and respect for the important role they play.

Clearly there is much work to do.

## Normalizing the Culture of Death and Dying

As fiscal pressures and end-of-life-care needs increase, there is clear need for improvement in the Champlain region. Ultimately, however, there is the need to get beyond institutional change to address the culture of death and dying itself. Caring for the dying is everyone's responsibility, and simply the right thing to do, but this also represents a reversal to some of the trends in our increasingly atomized society.

In 2013, the Vanier Institute of the Family released a report called "Death, Dying and Canadian Families." The report begins by describing the emotional aspects of death and dying between the years 1900 and 1950:

> Apart from deaths as a result of war and accidents, most people in this period died at home, cared for by family members and friends. Death was frequently a community event, with extended family, friends and neighbours attending to the dying person and then participating in rituals of visiting the family as the body lay at rest.[30]

Caring for the dying is **everyone's responsibility**.

The report references the work of historian Philippe Ariès who explains that "after death, a notice of bereavement was posted on the door. Windows and doors were closed except for the front door, which was left ajar to admit everyone who was obliged by friendship or good manners to make a final visit. The community generally joined the funeral procession to the place of worship and attended the funeral and burial."[31] Ariès continues, "The death of each person was a public event that moved, literally and figuratively, society as a whole." As a result, "the approach and attitudes toward dying meant that people were acquainted with death from an early age, as it was not shrouded in silence or mystery."[32]

As Ariès explains further, "The burden of care and unpleasantness, of dying, had once been shared by a whole little society of neighbours and friends."[33] With the shift from home to hospital, "this little circle of participation steadily contracted until it was limited to the closest relatives or even to the couple, to the exclusion of children."[34] As a result, death became lonelier with more people dying alone. The report explains that death, once an emotional and community event, became a largely individual and family event (and increasingly, family meant the nuclear family, with the decline of the extended family as the majority of the population shifted to urban areas and family members dispersed across the country).

### The Growing Epidemic of Loneliness

Though the intentions of our forefathers may have been noble, the unpleasantness of death was effectively removed from the community, and with this, also the opportunity for a community to journey alongside the dying, and for the dying to be surrounded by community and compassion. We are left

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30. Katherine Arnup, "Death, Dying and Canadian Families," Vanier Institute of the Family, 2013, 7.
31. Philippe Ariès, *The Hour of Our Death* (1981; repr., New York: Vintage, 2008), 559–60.
32. Arnup. "Death, Dying and Canadian Families," 7.
33. Ariès, *The Hour of Our Death*, 559.
34. Ibid., 570.

now with the growing epidemic of loneliness. As one interviewee explains: “The biggest challenge for me is to see when someone who in the process of dying is standing alone. It’s heartbreaking. It’s sad. Loneliness is probably the major disease of this society.”

A psychologist notes, “If you’ve ever been to a nursing home, this is a place of endless loneliness. People have visitors once a year. If you go there and say hello to someone, they love having visits. So you can change a person’s day or week by just being there.” He then explains,

> Cultures are different. Certain cultures tend to care for their elderly. I think our North American culture tends not to have as much of an interest. There used to be a time when as you go through stages of life, you look after your kids, then you look after your parents. And it’s a cycle. Your kids will end up looking after you kind of thing. I think we do less of that now. People are more apt to send people to homes, or leave them alone, or live their own lives. And they get busy, and just aren’t there. It’s part of the despair. Our culture is increasingly disconnected from each other. We are self-centered, and self-absorbed. Everyone’s trying to succeed. Get ahead. Perceive it as a competition. Who gets lets out of the competition? The people that have no competitive value. Which is the elderly.

These qualitative accounts are supported by statistics. As noted earlier, 24 percent of long-term-home residents had worsening depression in the Champlain region between the year 2010 and 2016. And recall the Preyra report, that the Champlain region has “an average of 8.5% lower informal caregiver hours per client available as compared to the rest of the province.”[35]

## The Culture of Death and Dying

The medicalization and professionalization of the dying process has served to sanitize our places of living such that suffering and the natural declines of life have been relegated to the sidelines, devalued and compartmentalized—and no longer considered part of life itself. But where are we going as a society if we are not demonstrating compassion toward our most vulnerable? This compartmentalization then leads to a particular discourse around death—or perhaps its lack—in some instances. One interviewee shares that after a family death, his son, who was still processing the whole experience, went to his Catholic school and spoke to his friends about what he was experiencing. “The school called my wife,” he recounts. “They tell her, ‘Oh we don’t want him to talk about that. We don’t want to talk about death at school.’” Another interviewee and physician, shares: “We are not always beautiful, and perfect, and running marathons. But it is important to allow people to have those natural declines, and it be okay, and not seen as a weakness or a burden, but seen as a value to the community, reintegrating those changes into those lives and into our society.”

What is needed, therefore, is a change in our attitudes about death and the overall culture of death, which begins with our conversations about death and dying. Advanced care planning is the term that is presently being used to advance this shift. But as one expert explains, “Advanced care planning is really a conversation like, What is this whole thing? What does this whole thing mean? What is important to

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35. “Meeting Home Care Needs.”

me? What's central to my life? What's the theme then that kind of holds it all together? And we don't have those conversations with each other about death, but they help you to focus."

Loneliness is probably the **major disease** of this society.

A new $2.7 million national study is aiming to narrow the gap between the care that frail elderly Canadians want and the care that they receive by evaluating ways to improve care planning conversations between patients, families, and health professionals.[36] "Canadians, especially the frail elderly, should be receiving person-centered care that is based on their goals and values," says Dr. John Yu, an associate professor of medicine at the Michael Degroote School of medicine at McMaster University and an internist at Hamilton health sciences. "Unfortunately this is not the current reality. Many are receiving unwanted treatments that can have a negative impact on them and their families." Research has in fact shown that "most frail elderly patients want to maintain quality of life rather than prolong it, but the use of invasive life-sustaining technologies in this population has been increasing."[37]

The need to deeply understand the values and wishes of those who are dying is integral to planning end-of-life compassionate care. Indeed, in the present context, where medical assistance in dying (MAiD) has become a medical option, there is even greater need to journey alongside the dying so as to understand *how* they are experiencing the journey of dying; what are their values, thoughts, and fears? This becomes even more crucial in an environment that offers medically assisted dying. *The crucial danger in the present context of fiscal constraint is that we provide MAiD as an option without having first provided equitable access to compassionate end-of-life care.*

## Medical Assistance in Dying (MAiD)

While medically assisted dying was not included in our interview questions, conversations with physicians and other care specialists made clear that this changing culture of palliative care was clearly on their minds. Data provided by the coroner's office shows that between June 17, 2016, and June 30, 2017, there have been approximately 550 medically assisted deaths in Ontario. Of these, available data shows that there were between 61 and 78 medically assisted deaths in the Champlain region. The Ottawa hospital has been a lead organization for MAiD; the hospital has been the provider in the majority (46) of these cases, including supporting 17 patients in the community, including in patients' homes and retirement homes.[38]

Conversation about MAiD made clear that a number of unforeseen consequences have transpired. First, an environment that offers medically assisted dying will have an affect on the recruitment and retention of caregivers and volunteers in end-of-life care. As one physician argues, "Government should be respectful of health-care providers' freedom of conscience to practice medicine/palliative care according to their well-formed ethics that may not necessarily include euthanasia. This has become a huge issue in recent

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[36] For more information on this emerging study, see "New Study Aims to Narrow the Gap Between the Care the Elderly Want and What They Get," McMaster Health Sciences, September 5, 2017, https://fhs.mcmaster.ca/main/news/news_2017/new_study_aims_to_narrow_the_gap.html.

[37] Ibid.

[38] "Board Meeting Highlights," Champlain LHIN, July 2017, http://www.champlainlhin.on.ca/NewsandEvents/NewsRoom/PressReleases/BdMtgHLs/20170726.aspx?sc_Lang=en.

months with a number of palliative-care physicians stopping or changing their practice due to conflicts with the college policy. This coercive environment must stop in order to attract more physicians into the already underserviced field." Another interviewee expressed deep concern about the palliative-care volunteer training offered by the Bruyère hospital. According to the interviewee, the presenter's opening remarks on the issue of MAiD served to make her feel instantly unwelcome and conflicted.

Where are we going as a society if we are not **demonstrating compassion** toward our most vulnerable?

A second potential impact of this new palliative-care environment is that it may serve to increase the levels of fear in many elderly patients. As one psychologists explains, "Fear is a very real sentiment among the elderly." The interviewee explains that according to Harvey Chochinov, a palliative-care psychologist, "a lot of things that people want at the end of life are more related to psychological problems. They fear the loss of autonomy or control. Fear of being a burden on other people. A lot of it is fear, rather than an actual lived experience. It's not that they're actually having pain. It's the fear of having pain." Two questions follow. First, are we doing enough as a society to understand and address these fears? And second, will the onset of assisted death, in a broader context of fiscal and family constraints, serve to increase this fear? In other words, does this new context of MAiD serve to undermine the confidence of a large portion of our population in our end-of-life institutions and increase fear? One physician shares that she has already had patients express these fears. And another interviewee argues that if we are to go down this path as a society, we should at least preserve some spaces without MAiD, in order to allow patients the choice: "Have another palliative facility," she argues, "but maintain this one [the Bruyère] for people who are more comfortable to be ensured that they're not going to be encountering that, or having any pressure about that."

And finally, a third potential impact is the consequences to family and community. "One of the things that has not been developed and predicted enough, that they didn't think about," shares the interviewee, "is the impact of the person who died as a result of MAiD on the family and community in general. They did not calculate it. Because we think that this is *just my own* decision, that, *I* decide about *my* own life. But the influence of the person who died with assistance from a physician has tremendous impact on the families."

The interviewee continues,

> There can be a lot of guilt and shame among families. And there is also the problems of what to do for such families. Do the people in the parish provide the funeral or not? How is the priest supposed to act? What is he supposed to do? To pretend it didn't happen? And then you have three hundred people who come for the funeral and half of the family is divided. Some say, we are okay with this, but the other half of the family are feeling burdened with this decision of guilt, feeling maybe, we didn't do enough. Something is wrong.

The onset of MAiD is a game-changer in many respects, and we are only at the very beginning of this journey as a society. Regardless of one's position on MAiD, there is a common need for conversations around how we understand it in relation to the need to normalize the culture of death and dying and to create compassionate end-of-life-care spaces. Unfortunately, these conversations are fraught with emotion and judgement in the present context, but we must eventually move beyond this to respectful dialogue aimed at developing a shared understanding of the potential pitfalls of MAiD in relation to our shared ideals for compassionate care.

## Promising Directions and the Community: Toward a System of Compassionate End-of-Life Care

"It takes a village to raise a child" is a popular ancient African proverb. The statement reflects the crucial role of the entire community in fostering the well-being of its children, understanding that this crucial role *is the stuff of life itself.* The same can be said in relation to our journey toward death, in that it is fundamental to the journey of life itself, and fundamental to how we live as a community. We have relegated the difficult things of life to the sidelines, believing that suffering and the natural processes of our decline are best taken care of outside of public view. Though our motivations may not have been wrong, the medicalization of death and dying has served to dehumanize a process that is most fundamentally about honouring life and providing dignity. For the dying, it is a spiritual journey, whether one identifies with religion or not, where one seeks peace within by having the needed conversations in a peaceful environment that not only manages pain but also respects and addresses their emotional, psychological, and spiritual needs. Death is natural; we cannot bypass it. As one interviewee explains, "We must all go through death—not around it." As a society, we speak volumes about our priorities and values by how we think about and deal with dying and death.

But there is hope on the horizon in the Champlain region. The needed cultural change takes strong leadership, and this is where the Champlain shines. Across both health-care and community domains, Ottawa's strong, compassionate, collaborative, and community-oriented leadership suggests that the region is well poised for the broader change that is needed. Leaders well understand the need for compassionate care in all end-of-life-care spaces, as well as the need to work together to achieve these ends. Leaders also understand the need to become creative and innovative, to learn from one another, to push through traditional boundaries, and to build the capacity of the community. And it is perhaps within this community domain that we see the most hopeful seeds of change.

Formed in January 2013, Hospice Care Ottawa is a community-based charitable organization that provides palliative and end-of-life programs and services to people living in the city of Ottawa. Services include community hospice-care programs such as in-home visits and day hospice, residential hospice care, bereavement care, and caregiver supports.[39] The delivery of programs and services is made possible through the support of a small dedicated staff, about 1,200 volunteers, and generous donors. With only 60 percent of funding being provided by the government, *the hospice model relies on the community*. Approximately 350 volunteers have received specialized training to provide direct client care, but other volunteers help with a host of other needs, including administrative, fundraising, gardening, and so on. Hospice Care Ottawa has been a "nursing-led and patient-centered model," which, explains its executive director, Lisa Sullivan, "has served to shape this care very differently than hospital based care." She explains further that "hospice becomes a hub, it engages people, engages people as volunteers. It engages communities. It engages commitment. And they create places. They are very special places."

The Maycourt Hospice in Old Ottawa South is indeed a special place. Set on the banks of the Rideau River, the hospice provides twenty-four-hour residential care in a beautiful and peaceful environment "where an interdisciplinary team provides physical, emotional, and spiritual support with a focus on

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[39] See the Hospice Care Ottawa website, http://www.hospicecareottawa.ca/.

pain and system management and quality of life."[40] The hospice's in-home volunteer support program offers both practical and emotional support for caregivers and patients in the home setting. "These volunteers provide someone to listen to, to read, to talk with, and to take patients shopping or to the bank, to assist at meals or to simply watch over while the patient rests. This program allows caregivers to do errands or to rest knowing that their family member is being cared for."[41]

These promising practices and efforts must be able to scale outward and upward, to **include all spaces of end-of-life care** such that we create a complete system of compassionate end-of-life care.

Interestingly, a recent study published by McMaster University, and one of few quantitative examinations of the care experience of patients who accessed multiple care settings in the last months of life and died in a specialized setting such as residential hospice, indicates that most caregivers (84–89 percent) rated the relief of physical pain, relief of other symptoms, spiritual support, and emotional support by hospice as either "excellent" or "very good." These proportions were less favorable for home care (40–47 percent), cancer center (46–54 percent), and hospital (37–48 percent).[42] According to its authors, "these findings suggest that the hospice approach, including the greater attention it places on emotional and spiritual dimensions of care, may be worth replicating in other spaces of end-of-life care within the community." The long-standing and collaborative relationships between the Champlain LHIN, CCAC, and the Ottawa Hospice are certainly a positive factor in this regard. Various conversations attested to the fact that these explorations had already begun.

A more recent grassroots initiative within the city is called Compassionate Ottawa (CO). CO is somewhat unique in that it is being launched as a broad community initiative supported by key service-provider organizations.[43] CO will not deliver any direct services but will focus on linking the skills in the community with areas of need. Its aim is to build community capacity to better support those in need of palliative-care services across the life spectrum and to normalize the death process in the community. From December 2016 to April 2017, a volunteer group visited some thirty-five community organizations to seek support and to explore possible partnerships. The response was very positive, and initial partnerships were formed with the Champlain Hospice Palliative Care Program, Hospice Care Ottawa, and Age-Friendly Ottawa.[44] Perhaps what is most impressive about this grassroots initiative is the degree of support it has already received from the community.

Therefore, in the Champlain region, despite current challenges, there is also much reason for hope. The Champlain region is blessed to have an array of strong and passionate leaders working toward improved end-of-life care. Furthermore, a constrained fiscal environment and rising needs have perhaps

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40. Ibid.
41. Ibid.
42. Daryl Bainbridge and Hsien Seow, "Palliative Care Experience in the Last 3 Months of Life: A Quantitative Comparison of Care Provided in Residential Hospices, Hospitals, and the Home From the Perspectives of Bereaved Caregivers," *American Journal of Hospice and Palliative Care* 35, no. 3 (2017): 456–63.
43. See Jackie Holzman, "Compassionate Ottawa: A Case Study," September 22, 2017, http://conference.chpca.net/compassionate-ottawa-a-case-study/.
44. See "The Beginnings of Compassionate Ottawa: Reimagining Palliative Care," Pallium Canada, August 2017, http://pallium.ca/cc/canadian-compassionate-communities-projects/cc-ottawa/.

cultivated a heightened interest among the community and its leaders to work across divides toward a more compassionate and holistic system of end-of-life care. The Ottawa Hospice and Compassionate Ottawa are promising examples of two organizations seeking to cultivate compassionate end-of-life care from the bottom up, so to speak. What's more, their early partnership ensures a greater return on their efforts to build capacity within the community. *Early indicators for both of these organizations demonstrate the power leadership and the power of community.*

But these promising practices and efforts must be able to scale outward and upward, to include *all* spaces of end-of-life care such that we create a complete system of compassionate end-of-life care. Our conversations have made clear that despite Canadians' preference for a natural death, the Champlain health-care system is not yet providing the right kind of supports in the right places and at the right time for this to be possible. Moreover, these stresses are being borne by patients and caregivers. In our present context, compassionate care at end of life risks being relegated to only a special few. The social infrastructure of a compassionate community must, therefore, include *all* spaces of end-of-life care within the community, including hospitals and long-term-care facilities, where a majority of Champlain residents spend their final days. Our desire for a culture of compassion in these spaces must outweigh our acceptance of current realities, and usher forth creative approaches that break down these traditional divides and harness the capacities and compassion of our communities. Compassionate end-of-life care is really about our life—and our values as a society. We must find new ways to work together to ensure that the journey toward death is surrounded by dignity and compassion.

READ THE PROJECT OVERVIEW: go.cardus.ca/endoflifeContext

**Case Study: Hamilton** go.cardus.ca/endoflifeHamilton

## Appendix A: Interviewees

**Michel G. MacDonald** | Executive Director: Catholic Organization for Life and Family (COLF)

**Nancy Lefebre** | Senior Vice President and Chief Clinical Executive, St. Elizabeth Home Care

**Madonna Gallo** | Head of Public Affairs Corporate, St. Elizabeth Home Care

**Dr. Jose Pereira** | Director, Research, the College of Family Physicians of Canada;
Professor, Department of Family Medicine, University of Ottawa;
Clinical Professor, Division of Palliative Medicine, Department of Family Medicine,
McMaster University; Scientific Officer, Pallium Canada

**Carol Dailey, RN** | Recently retired, Carleton Lodge long-term care.

**Marcia McGuire** | Palliative Care Volunteer, Bruyère–St. Vincent Hospital

**Father Roman Rytsar** | Pastor, Ottawa Hospital

**Dr. Sephora Tang** | Psychiatrist, Ottawa Hospital

**Dr. Rene Leiva** | Family and Palliative Care Physician, Bruyère Hospital

**Dr. Tim Lau** | Geriatric Psychiatry, Royal Ottawa Mental Health Centre;
Associate Professor, University of Ottawa.

**Mr. John Fraser** | MPP, Ottawa South,
Parliamentary Assistant to Minister of Health and Long-term Care

**Dr. Andrew Mai** | Medical Director, Medical Director Hospice Care Ottawa,
Assistant Professor University of Ottawa, Division of Palliative Care

**Dr. Jill Rice** | Acting Director, Division of Palliative Care,
Champlain Regional Palliative Consultation Team, Champlain Regional Palliative Care Lead

**Lisa Sullivan** | Executive Director, Hospice Care Ottawa

# Appendix B: Interview Template

How would you define a "good death"? How does your work hope to help more Canadians in x (city) achieve this?

What prompted you to undertake this work?

How do you think the landscape of palliative care can be improved? / What aspects of palliative care are not being addressed well?

What are the barriers to achieving a good death in x (city) today?

What work, if any, are you doing to help address these barriers/change the current "emotional architecture" around palliative care?

Do these strategies include public awareness building and education?

How important are partnerships and collaboration in terms of the work you are doing? Who are some of your key partners? How did you forge these relationships?

Does your organization engage in advocacy work with other organizations/levels of government? Which ones?

Are you aware of other models like yours that exist in this city? In another city?

As more Canadians, esp. the baby boomers, age and near death, what is the advice you would give to them and to their families?

What advice do you have to Queen's Park and Ottawa when it comes to addressing palliative care needs?

If cities can really be labelled "caring" as Kellehear argues, what do you think x (city) still needs to do in the next ten years to really be a place known for its compassion and care, particularly palliative care?

**ABOUT CARDUS HEALTH |** Cardus Health is an emerging program advancing research on Canadian end-of-life care through three lenses:

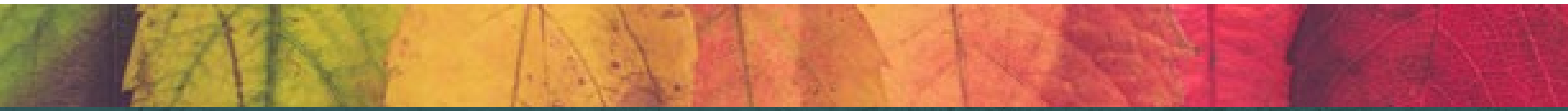
1. Natural Death: We need to build a social system that supports the desire of Canadians for a natural death, which we understand to mean dying of natural causes in our natural environment surrounded by our natural caregivers.

2. Social Architecture: We need to think of this system in terms of more than health, recognizing that not only the patient but also the natural caregivers need to be the focus of support, and thus the full range of social institutions best equipped for natural deaths need to be made more available to more Canadians.

3. Continuum of Care: We need to think of the delivery of care not as a series of alternatives to be chosen between, but rather as a continuum of care in which there is a seamless continuity of end-of-life care supports and settings as our fellow Canadians and their loved ones travel the journey through to the end of their natural lives.

Cardus aims to build on the good work done by the 2011 Parliamentary Committee and the hundreds of good organizations in this field, toward the common goal of bringing the best care to some of the most vulnerable among us.

**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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