



# Case Study: **HAMILTON**

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

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CARDUS



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# Case Study: Hamilton

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

### Preface | Hamilton Demographics and Health Services

According to the Local Health Integration Network (LHIN), the city of Hamilton is considered a sub-region<sup>1</sup> embedded within the broader region of Hamilton, Niagara, Haldimand, and Brant (HNHB).

As of April 2017, 89.2 percent of Hamilton residents claim to be satisfied with their current health care,<sup>2</sup> which is slightly higher than the 85.4 percent average in the HNHB region and the 86.9 percent average across Ontario.<sup>3</sup> This is a healthy sign. Indeed, only 2.5 percent of Hamilton residents do not have a primary care provider (again, lower than the 5.5 percent average across Ontario).<sup>4</sup> According to LHIN data, Hamilton currently has 89.1 long-term-care beds per one thousand people aged seventy-five and older.<sup>5</sup> For perspective: Ontario has an average of 80.6 beds per 1000 residents aged seventy-five and older, while the HNHB region has an average of 86.3 beds.

However, Hamilton residents also have a very high level of Alternative Level of Care (ALC) days,<sup>6</sup> which are “days where a physician indicated that a patient occupying an acute care hospital bed does not require the intensity of resources/services provided in acute care” (LHIN glossary).

Hamilton’s average for Emergency Department (ED) visits that could best be managed elsewhere is 16 per 1000, while its rate of hospitalizations for conditions that could be treated in ambulatory settings is a mere 4 per 1000 people (on par with the provincial and regional averages).<sup>7</sup>

According to the 2014 census date, the most recent on record, Hamilton has a recorded population of 551,751,<sup>8</sup> with LHIN population estimates for 2015 at 556,359.<sup>9</sup> Hamilton thus represents 38.1 percent of the HNHB region, making it the most populous sub-region in the HNHB by a solid margin (the next closest is Niagara, at 385,345). Those aged sixty-five and older represent 16.4 percent of the population, and 7.1 percent reside in rural areas.<sup>10</sup>

Hamilton, like the rest of Ontario, is a place where **one in every four seniors** lives alone.

1. A sub-region is a smaller geographic planning region that helps LHIN better understand and address patient needs at a local level.

2. An important caution with the following data: LHIN notes that their data “may not reflect population.” Despite this caveat, the LHIN data provides a helpful snapshot of the palliative care landscape across the subregions of Hamilton Niagara Haldimand, and Brant.

3. LHIN, Comparative Table, April 2017, 2, file://DATA\_20170417\_Sub-RegionDataTables\_FINAL.pdf.

4. Ibid.

5. Ibid.

6. LHIN, Discharge Abstract Database for 2015–2016 Fiscal Year. Note: The number of ALC days as a proportion of the total length of stay in acute care.

7. Ibid.

8. Statistics Canada, 2014 Population Estimates.

9. LHIN. 2015 Population Estimates. April 2017.

10. Statistics Canada, 2011 National Household Survey.

The 2011 census indicates that 14.9 percent of the people aged sixty-five and over live in private households. Of those in Hamilton aged sixty-five and over, 65.9 percent are part of a census family; but only 5.3 percent live with relatives, 1.7 percent live with non-relatives, and 27.1 percent live alone.<sup>11</sup> For context, the Ontario averages show that 24.4 percent of those aged sixty-five and over live alone, 6 percent live with relatives, and 1.8 percent live with non-relatives. Hamilton, like the rest of Ontario, is a place where one in every four seniors lives alone.

Hamilton has 326 registered primary care physicians, which means about 6 primary care physicians per 10,000 people. They have 2 family health teams,<sup>12</sup> 10 family health groups,<sup>13</sup> 27 family health networks,<sup>14</sup> 3 community health centres, and 1 Aboriginal health access centre. In terms of community care service providers, Hamilton has 44 home- and community-care providers.<sup>15</sup> Hamilton also has 27 long-term-care homes comprising 3,866 beds, which equals 91 beds per 1000 people aged seventy-five and older. However, as the reports from various practitioners indicate, even this seemingly large quantity of beds is not enough to deal with current needs. There are two hospices in Hamilton and one public health unit. Given the resources available as of 2016, this has still resulted in an average of 762 patients each month who are waiting for long-term care.

According to the most recent 2014 LHIN report on palliative care in Ontario, there were 90,900 deaths in Ontario, 36 percent of which were seniors aged eighty-five or older.<sup>16</sup> This is only a slight increase from 88,200 deaths in 2008–2009 (32.6 percent being seniors aged eighty-five and over) and 88,800 deaths in 2010–2011 (34.7 percent being seniors aged eighty-five and over). Yet the upward trend in deaths and the increasing proportion made up by seniors aged eighty-five and over is notable.

When we become completely reliant on professional services for our care, **we do not recognize or use** the resources and abilities that exist in our natural communities.

In the HNHB sub-region, there were 12,11 deaths in 2012, which is a mortality rate of 848 per 100,000. It is also worth noting where these deaths occurred in 2012–2013.<sup>17</sup>

11. 2011 Canadian Census.

12. Family health teams are primary-health-care organizations that include a team of family physicians, nurse practitioners, registered nurses, social workers, dietitians, and other professionals who work together to provide primary health care to their community (LHIN glossary).

13. Family health groups are groups of at least three family physicians who agree to work together to provide primary care to a group of registered patients (LHIN glossary).

14. Family health networks are groups of family physicians who work together to give the patient timely access to quality primary services. Physicians receive monthly comprehensive care capitation payments for all enrolled patients. Capitation is based on a defined basket of primary care services provided to enrolled patients (LHIN glossary).

15. Based on data validated January 2016 for HNHB LHIN providers only. It should also be noted that service providers can deliver more than one service and in more than one sub-region; therefore, the number of home- and community-care service providers will be lower than the number of service types (LHIN glossary).

16. LHIN obtains this information from the following sources: Discharge Abstract Database (DAD), Chronic Care Reporting System (CCSR), National Ambulatory Care Reporting System (NACRS), National Rehabilitation System (NRS), Ontario Mental Health Reporting System (OMHRS), Registered Person Database (RPDB), and claims history.

17. Ibid.

- 39.9%—Acute Care (including psychiatric facilities)
- 10.8 %—Complex continuing care
- 5.3%—Emergency Department
- 20%—Long-Term Care
- 0.2%—Rehabilitation Facilities
- 23.8%—Home with/without Supports

The trend here across this sub-region indicates that in Hamilton there is **still a significant gap** between what we need and what we have.

What this reveals is that home death (even if that includes home death without proper medical supports) is a likely option for over one-fifth of the population in the HNHB sub-region, and that combined with long-term care, almost half of those who died would have done so at home or in a long-term-care facility. These numbers and how they have trended over the past five years are encouraging. However, almost half of all deaths in this region did occur in acute care settings. As the interviews will make clear, this is not necessarily problematic unless, of course, there were better alternatives available for them to have a natural death.

Using LHIN’s definition of a “palliative patient” as someone who “has died in an acute care hospital, excluding those who died of significant trauma or injury,”<sup>18</sup> it should be noted that those who did die of a significant trauma or injury in Ontario only composed 5 percent of the deaths in acute care hospitals in 2012–2013. This means that 95 percent of the acute-care deaths were palliative patients and of these 81 percent were aged over sixty-five.<sup>19</sup>

Zeroing in on the HNHB sub-region, we find that 84 percent of palliative patients were admitted through the ED. This is only 4 percent higher than the provincial average of 80 percent. What is perhaps even more interesting is that in 2012–2013, nearly “15 percent of palliative patients were transferred from long-term care home and 75 percent were living at home prior to acute admission.”<sup>20</sup> At 13.6 days on average, the length of stay (LOS) for HNHB patients is just shy of the 14.4-day Ontario average; however, this Ontario average is more than double the LOS of all other patients (6.3 days).<sup>21</sup>

According to the Ontario Ministry of Health, an ALC patient “is occupying a bed in a hospital and does not require the intensity of resources/services provided in this care setting (Acute, Complex Continuing Care [CCC], Mental Health or Rehabilitation).”<sup>22</sup> In 2012–2013, 10 percent of ALC patients used more than 52 percent of the ALC bed days. The HNHB sub-region does not deviate from this provincial story given that 50.7 percent of the ALC bed days are used for palliative patients.

When it comes to the final months of life, readmission into the hospital is quite common for palliative patients; in fact, nearly 39 percent of palliative patients in Ontario *will be readmitted* into a hospital in the last three months of life. In the HNHB sub-region, the numbers are slightly lower, at 36.3 percent.<sup>23</sup>

18. LHIN, Ontario Palliative Care Report, 2014, 11.

19. From the Discharge Abstract Database (DAD) MOHTC server.

20. Ibid.

21. Ibid.

22. Ontario Ministry of Health. Cancer Care Ontario. <https://www.cancercareontario.ca/en>

23. From the Discharge Abstract Database (DAD) MOHTC server.

Unfortunately the data here subsumes Hamilton proper into the larger HNHB sub-region; however, the trend here across this sub-regions indicates that in Hamilton there is still a significant gap between what we need and what we have. In many ways, then, Hamilton seems to present a case in point of the national narrative around long-term care: the current infrastructure is not enough to handle the future needs of palliative care as the “silver tsunami” of baby boomers draws near.

### **More than Infrastructure**

But while we need to address these potential infrastructure shortages, we also need much more than infrastructure. We need a change in our attitudes and dispositions, our habits and practices. We need a change in our conversations about the death and dying of our family members and neighbours, and we need a more robust understanding of how we are all—as individuals and institutions—implicated in this important issue.

In order to get a better understanding of just how such changes might take place and where some of them already are taking place, Cardus conducted interviews during the spring and summer of 2017 with some of the key stakeholders in the city of Hamilton and the health sciences. For a full list of the interviewees, please consult appendix A.

# The Palliative Care Landscape: Perspectives on the Ground

## An Overview of Hamilton's Palliative Care landscape: Tempered Optimism

After scanning the palliative care landscape in the city of Hamilton, and more broadly in the HNHB LHIN region, there was, overall, an encouraging tone of optimism across several sectors from the various stakeholders interviewed. This is not to suppress some strong criticism we heard, nor to deny that numerous improvements could be made. However, there is a shared sense that the city of Hamilton is really starting to address the gap between current infrastructure capabilities and the demands that will be placed on them in the coming years as the baby-boom population ages and dies.

The current vice president of oncology and palliative care in Hamilton Health Sciences (HHS) and the regional vice president for Cancer Care Ontario is encouraged by the possibilities of the recently formed Ontario Palliative Care Network (OPCN), “a partnership of community stakeholders” working to address the aforementioned gaps in palliative care in ways that will better serve all Ontarians.<sup>24</sup> According to their site, their mandate is threefold:

We often fail to ask **the more human question**: “What is the process of losing a loved one like?”

[First] Act as the principal advisor to the government for quality and coordinated palliative care in Ontario; [Second] Be accountable for quality improvement initiatives, data and performance measurement and system level coordination of palliative care in Ontario; [Third] Support regional implementation of high-quality and high-value palliative care.<sup>25</sup>

Although he is a key stakeholder of the medical profession, his tempered optimism is that the OPCN works from an understanding that end-of-life care is not *only* an issue for hospitals and the medical profession. Therefore, the HHS has a role to play, but it must be done in conjunction with the individuals, families, and communities in Hamilton who are served.

The OPCN, however, is only one piece of a more comprehensive strategy on palliative and end-of-life care in which the provincial government has invested \$75 million of its 2016 budget.<sup>26</sup> As someone on the front lines of this work, he admits that there are still real challenges, particularly for the HHS: “The question is how do we [HHS] take seriously our provincial and regional mandates? How do we instill the values of palliative care across all of the elements of care that are delivered across the HHS, specif-

24. See the Ontario Palliative Care Network (OPCN), Cancer Care Ontario, <https://www.cancercare.on.ca/pcs/palliative/opcn/>.

25. Ibid.

26. “Province Strengthens End-of-Life Care with \$75 Million Investment,” Government of Ontario news release, <https://news.ontario.ca/mohltc/en/2016/3/province-strengthens-end-of-life-care-with-75-million-investment.html>.

ically the interfaces with end-of-life care?” In other words, what does a provincial program to improve palliative and end-of-life care look like as it is embodied in specific communities, and has to address the concerns peculiar to a given locale.

A Hamilton-based home-care nurse shares the vice president of oncology’s sense of tempered optimism in Hamilton’s improving end-of-life-care landscape. She is a member of the Victorian Order of Nurses (VON) in Ontario, which is “Canada’s largest, national not-for-profit, charitable home and community care organization.”<sup>27</sup> “From my vantage point,” she remarks, “things are getting better.” Admittedly, she notes that since the days of Dr. Elizabeth Latimer,<sup>28</sup> VON nursing in Hamilton has been trying to recover its role in the palliative landscape. “Dr. Latimer taught fifteen VON nurses how to do palliative care at home, and was a resource for them and built up a whole team,” she recalls. “However, the government took a lot of this funding away so we had to fight for our ability to work in the community here.”

She is referring to one legacy from PC premiere Mike Harris’s wish to “introduce competition to the entire home-care sector,” which was met with fierce opposition since it threatened to have lean for-profit companies muscle out the not-for-profit VON.<sup>29</sup> The VON was, for a short period, not awarded the contract for home care in Hamilton for a number of years. However, in Hamilton, the health minister George Smitherman eventually cancelled the bidding competition under public pressure.<sup>30</sup> Yet the effects on the VON were already apparent. Some of the best nurses trained under Dr. Latimer had left, not to return. To this day, the interviewee notes, the VON lacks the leadership and team cohesion that Dr. Latimer gave it.

Talk to a health-care provider for a while and you soon learn that it is often a mentor and role model who influence their work. The director of the Bob Kemp hospice<sup>31</sup> talks passionately about the vision of Dr. Kemp, which was rooted in “never losing sight of the people we are caring for.” The palliative care landscape in Hamilton today, she laments, often loses sight of this. By being “disease driven” and “professionalized,” we often fail to ask the more human question: “What is the process of losing a loved one like?” The palliative care landscape in Hamilton could be greatly improved, she believes, if it managed to keep death and dying as human things that affect not only patients but also caregivers. Freeman also worries that Hamilton’s current system is too disjointed, and that more work needs to be done in coordinating care from homes and communities to hospices and hospitals.

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27. VON Canada website, <http://www.von.ca>.

28. Elizabeth Latimer was a distinguished member of the palliative care community in Hamilton, ON, as well as a professor in the Department of Family Medicine at McMaster University. For more, see the Award of Excellence web page dedicated to her at the Canadian Hospice Palliative Care Association website, <http://www.chpca.net/about-us/awards/dr-elizabeth-latimer.aspx>.

29. Kelly Grant and Elizabeth Church, “No Place Like Home? A Look Inside Ontario’s Byzantine Home-Care System,” *The Globe and Mail*, July 10, 2015, <https://beta.theglobeandmail.com/news/national/no-place-like-home-investigating-ontarios-home-care-shortcomings/article25409974?ref=http://www.theglobeandmail.com&#>.

30. For more on this, see “Is Competitive Bidding in Home Care Done? Let’s Hope So,” *Diablogue: News and Commentary About Health Care in Ontario*, September 17, 2012, <https://diablogue.org/2012/09/17/is-competitive-bidding-in-home-care-done-lets-hope-so/>.

31. To learn more about the Bob Kemp Hospice, visit their website at <https://kemphospice.org/>.

The director of critical care oncology and palliative care at St. Peter's Hospital shares some of these concerns, stating, "The key issues right now for Hamilton is that it's all quite fragmented. We have different physician funding mechanisms. We have physicians that align themselves with specific hospices or hospitals, and there's no integration of services." She adds that "in the next fifteen to twenty years, we do not have what we need to support the number of people that are going to be dying given the baby boomer generation. There are a lot more frail elderly that are out there surviving with many comorbidities. We have limited supports for them." It is worth noting that St. Peter's<sup>32</sup> currently has sixty palliative care beds, which is the most in any Canadian hospital. However, up to 80 percent of them, the director estimates, are used for oncology patients, not necessarily patients who require end-of-life care.

A family doctor of forty years in Dundas notes that his understanding of the end-of-life-care landscape has been shaped by his active involvement in making house calls. A disturbing trend he's noticed in his career is that fewer and fewer doctors are trained in making such visits: "Almost forty years ago every family doctor in town did house calls and delivered babies, but that's changed over the years. We've started to believe that bigger hospitals are better and can take on this role. But I think this has moved us in the wrong direction." And he minces no words when he claims that "end-of-life care needs to be moved out of the health-care system entirely, and communities, much like the compassionate community ideas of [Allan] Kellehear, need to be our goal." Yet there are some very exciting initiatives on the horizon, particularly in Dundas region of the greater Hamilton area, where his family practice resides. Perhaps the most encouraging of these initiatives is the Hamilton Family Health Team and the Dundas Health-Care Hub,<sup>33</sup> which is actively bridging end-of-life-care medical specialists to family doctors and communities, coordinating resources and gathering information and advance-care plans.

**"Almost forty years ago every family doctor in town did house calls and delivered babies, but that's changed over the years. We've started to believe that bigger hospitals are better and can take on this role. But I think this has moved us in the wrong direction."**

A clinical ethicist who deals with some of the most difficult decisions and tensions that face people during end-of-life care argues that one of the largest hurdles in the end-of-life-care landscape in Hamilton (and elsewhere) is how our language around death—particularly when it comes to oncology—is about "fighting" and "beating" whatever disease people might face. This can sometimes set up false hope, and it usually keeps people from learning how to accept death and start to think about "smaller miracles" that might surround the act of dying. There are infrastructure problems to be sure, but our very posture and language about death also needs to change.

Finally, another family physician we interviewed who also has a foot in McMaster palliative care research is optimistic about some of the developments taking place in Hamilton, particularly with Health

32. For more on St. Peter's hospital, see: <http://hamiltonhealth.ca/sphf-main/>.

33. Craig Campbell, "Dundas Family Health Team Starting Wider Public Consultation," *Hamilton News*, March 23, 2017, <https://www.hamiltonnews.com/community-story/7205926-dundas-family-health-team-starting-wider-public-consultation/>.

Tapestry.<sup>34</sup> This doctor is currently co-principal investigator of Tapestry, which is aimed at helping “a person stay healthier for longer where they live by bringing together interprofessional health care teams, volunteers, community engagement work and technology.”<sup>35</sup> He recounts how Hamilton was the testing ground for Health Tapestry, and how they had volunteers take iPads into the homes of 350 elderly adults. “They asked questions like, ‘Who are the people in life that matter to you? Who are the people that you would call on if you needed help?,’ which are non-medical questions, but important for their health profile. There were no questions about blood pressure and blood sugars because most eighty-year-old patients couldn’t give a darn about that, but they do care if someone is going to visit them that week.” In other words, end-of-life care is much more of a social phenomenon than a strictly medical one, an idea that will come up again later and that was corroborated by numerous stakeholders. As the data from these interviews comes in, this doctor notes, the team “comes up with a care plan, and we say to the client: ‘If your goals are A, B, and C, we need to start addressing that because so far nothing is being done to address any of them right now.’” This fusion of technology, volunteerism, and inter-professional communities is relatively new, but it is a growing initiative that has confirming the general tenor of tempered optimism shared by his colleagues invested in end-of-life care across Hamilton.

## Roadblocks to Improvement

The optimism in Hamilton is tangible, but this does not mean we should ignore the very real challenges facing improvements. Even the previously mentioned home-care doctor and researcher, as hopeful as he remains in the power of Health Tapestry to make real changes to the end-of-life-care landscape in Hamilton (and hopefully many other cities), is also well aware that “this project is not the answer to every problem. And keeping it running isn’t free; these programs need money to keep the momentum and to spread. They also should not just be coming from two doctors; it needs to be owned by others in the community.” This is a refrain for several of the interviewees. The VON nurse noted that “you put as much professional health infrastructure in place as you like, but that doesn’t take over the culture.” Again, the Dundas-based family doctor is ready for a renaissance of the community-led efforts to reform end-of-life care and wrest it from the hands of professionalized health institutions.

The director of the Bob Kemp hospice is a witness at the front lines of what this over-professionalization has meant for many elderly: “[When you leave the ER] they send you home with CCAC [community care access centre] support. We know that the government is in transition of closing down CCACs but, generally speaking, the care is pathetic. Sometimes you get great works and sometimes you don’t. The hospitals have a ‘home first’ policy, and if they want you out they will try to get you out. So then people want to go to a hospice, but we need proper referrals from CCAC and family physicians.” Her frustration is that the lack of coordination, the fragmentation of services, and the inability to put patients first results in numerous days of uncertainty for many elderly that could be avoided with a more streamlined, coordinated process. She is not advocating the removal of medical institutions and health-care professionals, but to find ways to connect them with people on the ground. She cited Brantford’s

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34. For more on Tapestry, see <http://healthtapestry.ca/>

35. Ibid.

Stedman Hospice<sup>36</sup> as one example of how the community and the hospital can be bridged together more seamlessly in Hamilton.

The vice president of oncology would agree that any solution which seeks to throw the baby of the health-care institutions out with the bathwater of community-based end-of-life care would pose larger problems. There are roadblocks to end-of-life care, he agrees, but simply putting end-of-life care “back” into the realm of the community is to ignore the very real good that the hospital can—and should—play for many at the end of life. “The location [of death] is as much a consequence as it is a goal,” he notes. “Framing it as a goal when there are goals that are of a higher priority can create a risk of a misplaced goal, so certainly death at home is highly desirable among many members of our community and their families and can be made possible. So you’ve got to be careful about it, and that’s not in any way to be defensive about not facilitating deaths at home to the optimum degree, because I’ll acknowledge we don’t. We need to do that. But it’s not either/or. It depends on the situation!” The larger roadblock to improving Hamilton’s end-of-life care is accessibility. We should not ignore the simple truth that “patients that die in hospices tend to be better educated, have better social determinants, are better able to navigate the system, are more socially advantaged.” The question of where one dies should not be divorced from questions of exactly who dies where and for what reasons.

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**The larger roadblock to improving Hamilton’s end-of-life care is accessibility. We should not ignore the simple truth that “patients that die in hospices tend to be better educated, have better social determinants, are better able to navigate the system, are more socially advantaged.”**

So this is the question that needs to be asked before we talk about planning. However, the lack of planning is also another barrier that many are trying to address. The ethicist we interviewed is particularly concerned about the problems that attend poor advanced care planning: “We know that probably 50 to 60 percent of the time, people are not able to make decisions when they are at the end of their life. They become incapable. That’s just partly because of the natural disease process. So when decision-makers are not clear what that patient would want for themselves, they really struggle. It’s a really, really difficult position to be in, more so than what people realize because oftentimes the decisions that are being made are decisions that will inevitably lead to somebody’s death.”

On another front, the director of oncology notes that a large hurdle for better end-of-life care is that we no longer confront death or feel comfortable talking about it. This is something Kellehear notes in his work, and was also reiterated by several stakeholders: “There’s a need for many to have the conversation [about death], and yet they don’t want to burden others. They don’t want their children to think, ‘Oh, Mom or Dad, they’re ready to die now and they’re giving up on life.’ So there’s this huge unspoken sense that it’s a burden to others to talk about the fact that you’re going to die one day.” In many ways, this fear inhibits proper advance care planning, but there’s also something else: “Are we really prepared for what death is going to look like? Smell like? Are we prepared to manage that? Do we have somebody who can come to our home?”

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36. See the Stedman Community Hospice website, <https://www.sjlc.ca/stedman-community-hospice-1>.

Both the vice president of oncology and the clinical ethicist, however, counter this point by also noting that much of the dying process is—and will always be—clouded by uncertainty. People do not know the date or the circumstances; those are out of their control. So there is also a delicate balance between “hope and uncertainty” that everyone must keep intact as they plan, and then re-plan based on new developments. In other words, advance care planning is good but is not the solution to more comprehensive roadblocks.

Another barrier noted by the Dundas-based family doctor is that the LHIN designations for Hamilton (and likely other areas) are rather large and can fail to account for the differentiations in micro-communities in a region. So when the sub-region of Hamilton claims to have plenty of hospice beds, to take one example, they also should note that there are no hospices (to date)<sup>37</sup> in Dundas, and for a dying member of Dundas to relocate to downtown or uptown Hamilton will require a whole set of commitments from “natural caregivers.” The problem, here, is that LHIN designations are a case study in how bureaucracies “see like a state,”<sup>38</sup> and can often fail to be humanized (and humanizing) institutions.

These, of course, are a few of the barriers to an improved end-of-life-care landscape in Hamilton as seen from the ground by various stakeholders. This list is in no way comprehensive of all the other hurdles facing Hamilton, but it provides a starting place for problem-solvers to begin from. It is also important to note that while some of the hurdles are matters of budgets, policies, and infrastructure, another common theme is that some of the hurdles are also ideological and cultural. What is needed, then, will not simply be solved by better policies, but by a cultural transformation in how we think about and prepare for death, and conversely, developing a more robust understanding of health.

## Thinking Differently About Death and Health

In the 2015 report, our attempt to reframe end-of-life-care conversations oriented itself around the idea of a “natural” death; however, in these case studies, we asked various stakeholders to share their perspective on what might constitute a “good” death. The conversations between various stakeholders were far-ranging, although there were overlapping concerns. But what became clear is that palliative care, and end-of-life palliative care in particular, requires us to think much more broadly about both death and health in Hamilton, and across Canada.

In his forty years of service, the Dundas family doctor concludes that a big part of a good death begins with simply “accepting the fact that we are going to die, and that that’s part of the life cycle.” The other side, though, is that many people are still completely unaware about what the end of life actually looks like for most Canadians today. “Most people I talk to,” he points out, “say they would like to die in their sleep at eighty-five. Of course, the reality is that most people will spend weeks or months in a hospital or a nursing home. Sometimes this is unavoidable of course, but most people I talk to seem unaware of this reality.” For this reason, he has committed himself to making home visits a priority of his practice, since having health care and the home integrated in a “good death” can only take place if

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37. There is currently a proposal to build a ten-bed hospice, St. Joseph’s Villa, in Dundas, ON: Sara Cain, “St. Joseph’s Villa Foundation to Build 10-Bed Hospice in Dundas,” *Global News*, September 19, 2017, <https://globalnews.ca/news/3756038/st-josephs-villa-foundation-to-build-10-bed-hospice-in- Dundas/>.

38. James Scott, *Seeing Like a State* (New Haven: Yale University Press, 1999).

our conception of health is broadened and these two worlds are integrated before it becomes too late. The difficulty, though, is that often it is the health professionals who are not in the best position to broach the topic of death and advance care planning; and he argues that the “power dynamic” at play often gets people defensive or a bit worried; therefore, what is needed—and what is being carried out in Dundas—is having more members of the community take on the role of bridging these conversations. “Unless there’s a kind of a cultural shift, unless it becomes the norm in communities to talk about death and dying together, it’s not going to happen on a kind of one-off basis as I go through my patient population.”

The VON nurse also champions the home visit as one of the central ways to improve end-of-life care and help more people have a good death. For her, a good death is when “I have all [health resources] in place at the time, so there’s no extra stress on the family and there’s no extra suffering for the patient.” This happens when a nurse or doctor and possibly a family caregiver are prepared and have taken the time to fully understand the situation and what it will require. This type of intimate knowledge—and empathy—cannot be attained in the hospital setting always because of the power dynamics at play. “That’s what I love about home care,” she remarks. “I really see what’s happening because I have stepped into their world. I’m the guest in their home as opposed to being the authority in my territory.”

What is needed, then, will not simply be solved by better policies, but by a **cultural transformation in how we think about and prepare for death, and conversely, developing a more robust understanding of health.**

Between the home and the hospital lies the hospice. And one of the reasons the director of the Bob Kemp hospice is so encouraged by the work of her organization is that it shows the broader community that dying is not just depressing: “The hospice is probably the most compassionate place,” she remarks. “It is the place where you find the most community support and the most people laughing. Laughing as you are crying. It’s a really beautiful testament of life, and it’s one of the few places where you can actually be proud of how the community comes together.” For the director, the good deaths that she has seen are about the legacy that is left for those who will survive. Therefore, she says people need to ask: “Who do you need to forgive? Who do you need to tell that you love? What were you holding on to that you really wanted to let go? How do you want people to remember you? Why?” These are the human questions that we care about at the end of life, which shows that a good death is always connected to a good life.

The ethicist largely agrees with these ideas, noting, “I don’t think it’s the actual act of dying itself; I think it’s the idea of not being here, that now we’re leaving our family, we may have unfinished business. Whether it be finance, whether it be relationships, whether it be accomplishments in life. We’re in a culture and an era where we want everything and sometimes we can’t have everything. And until we get everything, we don’t want to leave this world. I think there needs to be an acceptance, and when you live a good life and you have a good quality of life with the people around you and you feel like things that you wanted to accomplish have been accomplished, I think that leads you to a better death.”

The location for a good death ranged in importance among our interviewees. The director of oncology suggested that “a good death is one where the individual has some control over their environment if it’s possible. Where they’re able to control their own symptoms that might be associated with death, so that they can be pain free.” The Hamilton-based family practitioner and researcher concurs, suggesting that “smells matter. I would want smells of home like at Bob Kemp, where they almost always have cookies baking. Sounds and music matter. The visuals, and all the senses that give us pleasure. A ‘good’ death would be in tune with this.”

Yet the vice president of oncology argues that place is much less important since that will always be contingent on the circumstances and having a good death means balancing the tension between uncertainty and hope. The hospital, in some contexts, will be the best place to die, while in other scenarios it very well could be the home. What’s more worth our attention, though, is that practitioners of palliative and end-of-life care need to start thinking of health in much broader terms than they usually do, and this will involve facing the social isolation that is currently inflicting so many residents in Hamilton.<sup>39</sup> He argues that “as a society we need to ensure that we’re addressing social isolation because the manner in which it is addressed may influence people’s views about the goals of care that they see if they face an illness.” In other words, the social networks—the community—of people will affect their health and the type of end-of-life scenario they will have.

## Becoming a Compassionate Community

We framed these case studies around Kellehear’s notion of a “compassionate community,” and to close out these brief case studies it is worth briefly noting how our stakeholders understood this concept and where their hopes reside for the city of Hamilton.

In the VON nurse’s formulation, “the compassionate community is a beautiful church community, that’s just functioning really, really well. Obviously, it doesn’t always. When we see weakness in each other, we don’t always respond to that well. Someone might have a mental illness, and we do not know what to do with that. We don’t know how to really wrap around them and help them. But I think that’s the beginnings of it. I think Hamilton is a really good example of a compassionate city, from living here for the last ten years. The people who live and work here are very invested in Hamilton and very proud of this city. It has its challenges. We haven’t always dealt with the poverty well. We’ve had a huge amount of poverty compared to other cities. But people really care about each other.”<sup>40</sup>

For the director of the Bob Kemp hospice, there is a similar sense that the Hamilton community is a great resource for compassionate care. The volunteer force that Bob Kemp hospice draws on is only scratching the surface of the potential she sees in the Hamilton community to learn more about each other, to care for one another, and to give sacrificially of time to be near to those dying. Going forward, she would like to see more “hubs” start up: small, flexible hospices and care units that are adaptable

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39. For more information on this, visit the Hamilton Seniors Isolation Impact Plan website, <http://socialisolation.ca/>. This report notes that over twelve thousand seniors in Hamilton are socially isolated, and provides various initiatives to help remediate this.

40. Helen recommended the HMSMRT program as one of the most encouraging examples of its ability to be a compassionate community. To learn more, see their website, <http://www.hamsmart.ca/>.

and suited to smaller communities within Hamilton. We do not need dehumanizing superstructures to address end-of-life care needs in Hamilton; the future of our ability to become a compassionate community will be in how well grassroots organizations can thrive and then be resourced by a more coordinated, streamlined health system.

For the director of oncology, the effort to make Hamilton a more compassionate community is “geared at community citizens driving the change.” So when she hears about groups like the Carpenter Hospice<sup>41</sup> leading the initiative, she acknowledges that this is good but is less convinced that this is at the heart of a compassionate community. It has to be led by members outside of the health community, even if they are brought in later. “Churches are great examples of groups that, in some cases, have tried to make compassionate communities, for example, some have hired a nurse. They have developed their own way of managing the medical and the spiritual aspects of end-of-life care through that.” The problem, she sees, is that Hamilton is already too large for a compassionate community. What might be needed, she remarks, is a health authority like they have in Alberta, which might help coordinate all these smaller, grassroots movements.<sup>42</sup>

**“We have to stop thinking that death is about our health system because death is owned by everybody and we have made death into a medicalized event when in fact death isn’t a medical event. Yes, you can argue that it’s pathology, anatomy, but what about all the other things that go along with the dying process?”**

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The Dundas-based family doctor believes that the compassionate community does not need to be complex. “A lot of times, all people who are dying want and need is somebody to hold their hand at the end of their life, so you don’t have to be a trained professional to do that.” What we need to remember is that the heart of compassion is “to suffer with,” and it can be a very simple, beautiful thing. “Yet sometimes we see suffering,” he notes, “and we rush in to alleviate it. This drives a lot of the health-care system, and it’s good. But compassion might mean to share in the suffering.”

The clinical ethicist places the idea of a compassionate community into the realm of civil society. It is not, she argues as others have, just the health-care institutions, but it’s the whole community: “We have to stop thinking that death is about our health system because death is owned by everybody and we have made death into a medicalized event when in fact death isn’t a medical event. Yes, you can argue that it’s pathology, anatomy, but what about all the other things that go along with the dying process? I think that we need to stop putting it in the hands of the health system and say that this is your issue to solve. So by public health, by the medical system, by our police servicing system, by our education system, administrative health, administrative education, the ministry of social services, that’s ownership by everybody.” Schools, particularly, she believes can be doing better to foster habits of compassion in the next generation. Today they need forty hours of community service in order to graduate. That is only ten hours per year, and the motivations for this, she critiques, are often self-serving. A compassionate community would foster citizens who give more and do so without expecting to gain anything back. “Let’s have a sit-down with the kids and say ‘What does it mean to volunteer your time for somebody

41. See the Carpenter Hospice website, <https://www.thecarpenterhospice.com/>.

42. To learn more about this, visit the Alberta Health Services website, <http://www.albertahealthservices.ca/>.

else?’ and show them it doesn’t mean that you get something out of it; it means somebody else gets something out of it.”

Finally, the Hamilton-based doctor and researcher sees hope for Hamilton’s becoming a true compassionate community through the work of “the Integrative Comprehensive Care program from Hamilton Health Sciences;<sup>43</sup> right now, the ICC, is really the first hospital outreach program that really tries to engage communities and high-risk people that are discharged with congestive heart failure.” The most critical area where improvements can be made in helping more people receive care where they are, he suggests, is in the transitions between hospitals and homes. The “bounce-back between hospitals and homes costs hundreds of thousands of dollars and is not good for a patient’s health. When a person gets discharged, there needs to be a system in place that wraps around that individual in a meaningful way. That gives them an opportunity to set up their own circle of care, that has a case coordinator, a care coordinator that will connect all the important people to their lives and do everything in their power to keep that person out of hospital.”

## Compassionate Care Act and Beyond

New initiatives are already underway in Ontario to address some of the concerns raised by the on-the-ground stakeholders in Hamilton and other cities and regions in the province. Indeed, the Compassionate Care Act (Bill 182) has mandated that the health minister create a provincial framework designed to support improved access to hospice palliative care in the range of institutions from homes to hospitals. The next year will be a crucially important time for on-the-ground practitioners, health-care professionals, members of parliament, and members of a whole host of civil society institutions to come together, share their ideas and concerns, and work together to improve an aspect of our shared lives that will affect us all.<sup>44</sup>



READ THE PROJECT OVERVIEW: [go.cardus.ca/endoflifeContext](http://go.cardus.ca/endoflifeContext)

Case Study: Ottawa [go.cardus.ca/endoflifeOttawa](http://go.cardus.ca/endoflifeOttawa)

43. To learn more, read “Integrated Comprehensive Care (ICC) Program,” Hamilton Health Sciences, <http://www.hamiltonhealthsciences.ca/documents/Patient%20Education/ICCProgram-trh.pdf>.

44. To learn more about the Compassionate Care Act, visit the website, <http://ontariopalliativecare.ca/what-we-are-doing/>.

## Appendix A: Interviewees

**Helen t'Hart** | Registered Nurse, VON

**Kim Alvarado** | Director of Oncology, Critical Care, and Palliative Care

**Sandra Andreychuk** | Neonatal Nurse Practitioner and Clinical Ethics Consultant

**Dr. Ralph Mayer** | Vice President of Oncology and Palliative Care,

Regional Vice President, Cancer Care Ontario

**Clare Freeman** | Executive Director, Bob Kemp Hospice

**Dr. James Williams** | Family Doctor, Dundas

**Doug Oliver** | Associate Professor of Family Medicine, McMaster University,

Co-principal Investigator of Health Tapestry

## 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.