

# Strengthening Palliative Care in Canada

A Ten-Point Plan

Oct 2018

#### Introduction

The purpose of this report is not to offer a comprehensive set of solutions to current deficiencies in palliative care in Canada, Rather, it aims to provide meaningful suggestions - drawn from both expert and grassroots insights - from Canada's lewish community on how palliative care can be improved for the benefit of all Canadians. Our hope is that, along with the professional knowledge and practical experiences shared by Jewish Canadians from coast to coast, the ten proposals in this report will provide elected officials and policymakers with a valuable foundation for strengthening palliative care across Canada.

This report was written by Cody Miller (Research Fellow) and edited by Steve McDonald (Director, Policy and Strategic Communications). CIJA is grateful to the University of Toronto Faculty of Law for sponsoring the research fellowship that made this report possible.

## **Summary of Recommendations:** A Ten-Point Plan for Strengthening Palliative Care

### A Better Strategy

- 1. The federal, provincial and territorial governments should adopt the World Health Organization (WHO) definition of palliative care. The WHO definition affirms principles CIJA found to be essential, including that palliative care should start as early as possible; it can occur alongside curative treatment; it extends beyond physical symptoms to address spiritual and psychosocial factors; and it considers the experience and role of a patient's family. Palliative care should not be defined or construed as including Medical Assistance in Dying (MAID).
- 2. The federal government should launch a national plan to address deficiencies in palliative care. This could be achieved through such mechanisms as a national Palliative Care Act with principles that are similar to the Canada Health Act or a federal-provincial health accord with explicit provisions to enhance palliative care. Whatever its form, the national plan should include specific goals, requirements and timeframes for improving education and expanding access to high-quality palliative care services.

#### **Better Education**

- **3.** Palliative care should become a mandatory part of medical education. Currently, many doctors who deliver palliative care in their practice have received no such training.
- **4.** Palliative care workers should receive enhanced education on the nuances of spiritual care and the variety of spiritual needs of patients in a diverse society. Greater training, education, and support for chaplains should also be explored.
- **5.** Provincial governments should promote greater public awareness of the nature of palliative care and the importance of advance care planning.

#### **Better Access**

- **6.** Federal, provincial and territorial governments should increase investments in homecare and hospice services. This will improve end-of-life care and alleviate the financial burden currently borne elsewhere in the healthcare system (such as use of relatively costly acute care facilities for palliative services).
- **7.** Provincial governments should set clear, evidence-based guidelines on palliative care spaces and wait times. This will enable more effective allocation of resources and precise identification of gaps in the system.
- **8.** Provincial governments should improve access for underserved or vulnerable communities. Particular effort should be made toward overcoming linguistic, ethno-cultural, social, and geographic barriers to palliative care. Strategic funding, creative use of technology, and partnerships with ethno-cultural community agencies can all help resolve this challenge.
- **9.** Provincial governments should make it easier for patients to cross provincial borders with minimal delay. Provinces should expedite information-sharing when it comes to health records of palliative care patients. Currently, Canadians who move provinces can be required to wait up to three months to receive insured healthcare services. Given their unique circumstances, palliative care patients moving provinces to be close to family members should be exempt from this waiting period.
- **10.** Provincial governments should foster caring communities by working with local organizations that mobilize volunteers to support patients. This includes ethno-cultural agencies with the expertise to meet the unique needs of patients from their respective communities.

## **Background: CIJA's Work on Palliative Care Policy**

The Centre for Israel and Jewish Affairs (CIJA) is the advocacy agent of the Jewish Federations of Canada. We are a national, non-partisan, non-profit organization, representing the perspectives of tens of thousands of Jewish Canadians across the country. CIJA is dedicated to improving the quality of Jewish life in Canada by advancing the public policy interests of Canada's organized lewish community. While working to build support for Canada's Jewish community on the issues that matter, CIJA's advocacy work also serves to improve Canadian public policy for the benefit of broader society. Our work on palliative care is a prime example of this, as evidenced by an interfaith statement on this issue that CIJA helped organize in partnership with major national Catholic, Evangelical, and Muslim organizations.

CIJA's work in this area grew out of the national debate surrounding Medical Assistance in Dying (MAID). While there is a diversity of opinion within Canada's Jewish community regarding MAID, there is a clear consensus that access to high-quality palliative care must be a viable option for patients approaching end of life. As noted by a respondent to our survey, a nurse with patients who have sought MAID:

I have had patients whose symptoms are not well-controlled and who want to "end it." By doing the work and finding out the underlying reasons, I have seen people change their minds about wanting their life to end.

Palliative care is an issue with the potential to touch every Canadian family. With an aging population, end of life is at the forefront of the minds of many Canadians. By 2036, seniors are expected to represent 23%-25% of Canada's population. With only 16%-30% of Canadians having access to palliative care<sup>2</sup>, and the vast majority of care providers having little or no training in palliative care<sup>3</sup>, there are significant gaps in the current framework that must be addressed.

CIJA actively supported the passage of Bill C-277, the Framework on Palliative Care in Canada Act (Palliative Care Act) and, as noted above, worked with a broad interfaith coalition to advance that objective. With such strong endorsement from a diverse array of Canadians, it was not surprising that the bill passed with unanimous support.

## **Report Methodology**

The purpose of this report is to provide federal and provincial policymakers – as well as other interested parties, such as media, NGOs, social service agencies and community members – with recommendations to strengthen palliative care in Canada.

This report was compiled with information obtained from existing literature, such as news articles, journal articles, and information published by governments and NGOs. We also consulted with key stakeholders across the country. This includes conducting a national, online survey of the grassroots lewish community - which garnered responses from 188 community members impacted by palliative care - and holding conversations with industry professionals, such as physicians, palliative care specialists, and chaplains.

The federal, provincial and territorial governments should adopt the World Health Organization (WHO) definition of palliative care. The WHO definition affirms principles CIJA found to be essential, including that palliative care should start as early as possible; it can occur alongside curative treatment; it extends beyond physical symptoms to address spiritual and psychosocial factors; and it considers the experience and role of a patient's family members. Palliative care should not be defined or construed as including Medical Assistance in Dying (MAID).

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."<sup>4</sup> Though this definition is generally accepted and can be found on the Government of Canada's website, each province has its own unique definition.<sup>5</sup>

There are four common elements among most provinces' definitions of palliative care: palliative care can start before end of life; it can occur along with curative treatment; it goes beyond physical symptoms; and there are elements of palliative care targeted toward members of the patient's family.

It is widely accepted by the provinces that palliative care addresses factors beyond physical symptoms and includes elements extending to family members. Almost all provinces and territories explicitly affirm that palliative care can begin before end-of-life care, which is often referred to as 'hospice care' or 'hospice palliative care.' One survey found that more than 90% of specialized palliative care physicians believed that, for all patients, referral should begin early, even if the prognosis is that the patient is likely to live longer than six months.<sup>6</sup>

The key disagreement between provincial definitions is whether palliative care can occur concurrently with curative treatments. With the exceptions of Saskatchewan, Newfoundland and Labrador, the Northwest Territories, and Nunavut, most provinces and territories hold that it can. Nunavut's most recent plan on continuing care, published in 2015, states that:

Patients may be considered for palliative care services if they are experiencing a lot of symptoms and treatment aimed toward a cure is no longer a goal.<sup>8</sup>

Dr. Gary Rodin, Director of the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC), stressed the importance of palliative care existing alongside curative treatment. Upon diagnosis, he notes that initial feelings are of suffering, dependency, hopelessness and loss of aspirations. For these reasons, the risk of suicide can increase. After just the first month of a cancer diagnosis, the risk of suicide increases by a factor of 12.9 Therefore, it is important that, in addition to physical symptoms, psychosocial and spiritual needs are also addressed upon diagnosis. The UK National Health Service definition, which explicitly defines palliative care as something which you may receive "while you are still receiving other therapies to treat your condition," may serve as a model.<sup>10</sup>

The federal government should launch a national plan to address deficiencies in palliative care. This could be achieved through such mechanisms as a national Palliative Care Act with principles similar to the Canada Health Act or a federal-provincial/territorial health accord with explicit provisions to enhance palliative care. Whatever its form, the national plan should include specific goals, requirements and timeframes for improving education and expanding access to high-quality palliative care services.

The healthcare system in Canada is, for the most part, governed provincially. The federal government provides funding to the provinces, subject to the conditions of the Canada Health Act (CHA). The CHA requires that insured health services of a province be subject to the conditions of universality, comprehensiveness, portability, accessibility, and public administration.<sup>11</sup> Despite the comprehensiveness principle, even a service deemed medically necessary may still fall outside the scope of the CHA if it is not a hospital or medical practitioner service. 12 Thus, many aspects of palliative care, such as psycho-social and spiritual support, could fall outside the act in its current state.

Though various elected officials, provincial governments, and organizations have pushed for the CHA to be amended to clearly include palliative care, 13 because the CHA does not require the provision of specific services or establish specific standards or guidelines for service delivery, we are not certain that this would be the ideal solution.

Australia's palliative care system places third on The Economist's palliative care ranking. 14 Like the CHA, the Australian palliative care plan is based on achieving general principles. While the Australian model has produced significant results, an evaluation of the strategy by the Commonwealth Department of Health determined that it was limited due to lack of defined baseline measures, measurable performance indicators, time-frames, and accountability frameworks.<sup>15</sup>

Palliative care should become a mandatory part of medical education. Currently, many doctors who deliver palliative care in their practice have received no such training.

The Canadian Society of Palliative Care Physicians conducted a national survey of more than 2,000 respondents on the state of palliative care in Canada. More than half of those who took part provide some sort of palliative care service and can be categorized as palliative medicine physicians (PMPs). 83% of these PMPs do not specialize in palliative care but offer it as part of their primary practice. Within this group, almost two-thirds received no palliative medicine training. Of the respondents who were family physicians with a practice focused on palliative care, 25% reported no such training. Even among palliative care specialists, 12% reported no training. Overall, this study found that an estimated 42% of all palliative care hours are delivered by untrained professionals.<sup>16</sup>

Doctors without palliative care training are more likely to recommend aggressive surgeries for patients at the end of life.<sup>17</sup> With proper referral to palliative care, the use of aggressive care to treat conditions with little hope has been demonstrated to decline. This can vastly improve the quality of end of life for many patients.<sup>18</sup>

Another study identified the stigma of the term 'palliative care,' as being one of the biggest barriers to early referral. Though significant numbers of palliative care physicians believe that there is a negative perception regarding 'palliative care,' only 28.5% of palliative care physicians favoured renaming the specialty to something such as 'supportive care.' Another 31.5% are neutral to the idea.<sup>19</sup>

Dr. Rodin suggested that a name change would avoid the stigma associated with 'palliative care,' communicate to patients that the concept of palliative care has changed, and, if implemented properly, with appropriate education, 'supportive care' would be a more positive term. Even without changing the name of the practice, proper education can be effective in reducing the association of the term 'palliative care' with 'giving up' at the end of life.

Palliative care workers should receive enhanced education on the nuances of spiritual care and the variety of spiritual needs of patients in a diverse society. Greater training, education, and support for chaplains should also be explored.

One issue reported in CIJA's community survey regarding experience with palliative care was a lack of appropriate spiritual care. One respondent noted that, although the chaplain was caring, the patient would have appreciated meeting with clergy from her own faith but did not know how to arrange this. Another respondent remarked that the chaplains provided were not appropriate for his father's level of faith:

While I think we both appreciated the effort, it was neither relevant nor appropriate for my father, and neither were the types of blessings or prayers offered.

Rabbi Adam Law, a chaplain at Baycrest Hospital in Toronto, suggested that such experiences are common, an unfortunate situation, as proper spiritual care has been shown to provide numerous benefits. In one study, patients (including those with no religious affiliation) completed three sessions with a chaplain. Most reported benefits while none reported any undue burden. These sessions were shown to increase positive coping when it came to religious concerns and decrease both feelings of helplessness and anxious preoccupation. Patients who felt that their spiritual or religious needs were supported by the clinical team were more likely to incur lower costs of end-of-life care.<sup>20</sup>

An interfaith model of chaplaincy is frequently employed, emphasizing the principles of providing comfort and support to patients of all faiths. Nevertheless, many needs remain that cannot be addressed by any individual chaplain, particularly in a multicultural society.

One study suggests that specific religious needs, the ability to access appropriate religious leaders to address these needs, and insensitivity are all barriers to appropriate spiritual care in an interfaith model.<sup>21</sup> Although Rabbi Law affirmed that this is a common experience, he also noted that, in an interfaith model, a thorough knowledge of other faiths was not crucial - so long as a chaplain is able to enhance a patient's hope, meaning and purpose. Rabbi Geoff Haber, the director of spiritual care at Baycrest, suggested expanding Clinical Pastoral Education or similar training beyond the chaplaincy team to community members who may wish to visit patients.

The need for improved education extends to all members of a palliative care team. For instance, one study of Inuit interpreters showed numerous difficulties, including ethical dilemmas of what to say to a dying patient. Ethical dilemmas can arise when interpreters feel it necessary to involve a community elder (which may be complicated by confidentiality requirements), or when deciding to translate a physician's words verbatim or to filter the message into a more culturally appropriate context.<sup>22</sup>

Cultural training is another crucial need that can range from learning to be sensitive to cultural needs at the end of life to specific understandings of cultural norms. For example, Aboriginal providers' general lack of local First Nation and / or Inuit cultural knowledge was found to create major barriers to the provision of culturally relevant and safe palliative care to these populations. As one participant in a study stated,

If a person that [a First Nation person] deems to be in authority, like a doctor, says well, for instance, 'you can't go home'; they truly hear that statement to be 'well, I'm not allowed to go home. 23

In one study, after a one-hour education session on Islam, palliative care clinicians showed significant improvement in their understanding of the Muslim faith.<sup>24</sup> Continuing education classes such as this could be beneficial not only in helping existing members of a palliative care team improve their ability to practice using an interfaith model, but also in addressing biases. As noted in the study:

Clinicians should not feel obligated to become – or expect to become – complete experts on an unfamiliar faith tradition. A better goal is to be open, present, and curious.<sup>25</sup>

In Judaism, there are many rituals at the end of life, including refraining from moving a body at certain times and maintaining vigil over the body until burial. By enhancing understanding, such needs can be respected and grieving families can receive more sensitive – and effective – support.

#### **Recommendation 5**

Provincial and territorial governments should promote greater public awareness of the nature of palliative care and the importance of advance care planning.

As mentioned, there is a negative stigma attached to 'palliative' care. According to the Canadian Hospice Palliative Care Association, despite belief by most Canadians in the importance of early care planning, only 13% have an advance care plan and only 9% have ever spoken to a health care provider about end-of-life care and their wishes. Less than half of Canadians have had such a discussion with family, and only 14% of Canadians have heard of an advance care plan.<sup>26</sup>

However uncomfortable, conversations about death must begin early. Both provincial and federal governments should work together to educate the public on the nature of palliative care and the importance of advance care planning. This can be done through government marketing and advertising alongside other relevant healthcare efforts already in place, such as organ donation efforts, to normalize end-of-life discussions.

Federal, provincial and territorial governments should increase investments in homecare and hospice services. This will both improve end-of-life care and alleviate the financial burden currently borne elsewhere in the healthcare system (such as use of relatively costly acute care facilities for palliative services).

Despite the general desire for patients to die at home, most deaths occur in hospital. Increasing funding and support for homecare and hospices can result in improved quality of life for palliative care patients and significant cost savings for patients, caregivers, and the public. The Canadian Hospice Palliative Care Association notes that:

compared to usual acute care, hospital-based hospice palliative care may save the health care system approximately \$7,000 to \$8,000 per patient.<sup>27</sup>

Though figures vary, a significant portion of costs are borne by family members of palliative care patients.<sup>28</sup> These costs can be substantially higher for patients living in rural areas.<sup>29</sup> The largest percentage of these costs derive from lost wages when family members must miss work.30

With improved access to hospice and homecare services, cost savings will result from reduced hospital admissions, fewer days in the ICU, and a decrease in hospital deaths.<sup>31</sup> An encouraging program launched in Catalonia, Spain, created homecare teams available to palliative care patients. The control group of patients without a homecare team was four times more likely to be admitted to hospital, spent an average of four days per visit longer in the hospital, and was three times more likely to visit an emergency department. The average cost per patient without a homecare team was 71% greater than those with such a team.<sup>32</sup>

Funding to expand access to hospice and homecare should not come at the expense of investments in hospital beds. Yael Ricquebourg, the Executive Director of the PalliAmi Foundation in Montreal, notes that hospital beds remain an absolute necessity for many individuals undergoing palliative care. Some patients prefer or require a hospital to enhance their feelings of security or due to specific needs that cannot be addressed in other settings. She points to a specific community hospital serviced by PalliAmi, where patients include vulnerable populations – such as addicts and mentally ill patients – who require care that hospitals are best suited to provide.

Provincial and territorial governments should set clear, evidence-based guidelines on palliative care spaces and wait times. This will enable more effective allocation of resources and precise identification of gaps in the system.

Several challenges within the palliative care system can be addressed through funding and proper policy. Due to a combination of insufficient beds, inconsistency in distributing palliative care hours that results from a lack of guidelines, patients and their caregivers are placed in difficult situations. CIJA contacted Local Health Integration Networks (LHIN) to determine exactly how hours were distributed. Although hours are given after a needs-based assessment, there are no guidelines in place to determine what services and hours are given in specific situations. In our community survey, one respondent described her experience caring for her mother with multiple physical and cognitive issues:

My mother was immobile, in bed, unable to look after any of her needs and very aggressive when one tried to look after her basic needs. My arms are filled with scars that will remind [me] of my mother's difficult time for the rest of my life. Due to the aggressive behaviours, I could not care for my mother's physical needs without the help of other hands. Three hours a day divided into two segments was not enough.

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Provincial and territorial governments should improve access for underserved or vulnerable communities. Particular effort should be made toward overcoming linguistic, ethno-cultural, social, and geographic barriers to palliative care. Strategic funding, creative use of technology, and partnerships with ethno-cultural community agencies can all help resolve this challenge.

Geographical isolation is a significant barrier to consistent care. One participant in a study stated:

[living] very far away from a larger centre, for us to get to Winnipeg which would be the place where most people would go for anything major... it's a nearly eight-hour drive.33

Studies show that those in rural communities are more likely to die in hospital, are less likely to receive home visits by a doctor, and have less access to healthcare professionals, 24/7 healthcare services, equipment, and medications. The monthly cost of palliative care per rural patient has been estimated as 16.4% higher and 29.1% higher for inpatient care.34

These cost disparities include out-of-pocket costs borne by families, such as transportation and missed work to bring a patient to a hospital.<sup>35</sup> In urban communities, one of the largest costs borne by patients and their families is private homecare costs, something that tends to reduce overall costs and hospital admissions.<sup>36</sup>

The use of technology to monitor and communicate with patients remotely (also known as 'telehealth') has been effective in managing symptoms and improving the experience of palliative care patients.<sup>37</sup> One such example is a virtual hospice, which has been shown to benefit patients and caregivers in accessing palliative, end-of-life, and bereavement information and support. For example, the Canadian Virtual Hospice, among other services, enables patients or caregivers to ask questions to a professional online.<sup>38</sup>

A study of telehealth in the UK found that, when used as a supplement to regular healthcare, especially for rural areas, it was a practical tool in advancing equitable care, including after-hours telephone support, advice services for palliative care patients, and videoconferencing for interactive case discussions.<sup>39</sup> Telehealth can also support caregivers in transmitting knowledge to patients. For example, the Nunavut Department of Health published an illustrated glossary of anatomy, which received positive feedback from Inuit interpreters for its use of 3D models.<sup>40</sup>

In addition to geographic impediments, linguistic, cultural, and social factors can also create barriers to palliative care. As mentioned, Indigenous patients often require translation services and there are cultural nuances to which palliative care staff must be sensitive. For Jewish patients who observe religious traditions, living in a new facility brings with it a range of ritual considerations – including Shabbat and holiday observances, as well as access to kosher food. The same can certainly be said of those who observe other faith traditions, such as Muslim, Sikh, and Hindu patients. Death rites also vary significantly across religions and cultures. Canadians with family origins in Africa or Asia, for example, may have perspectives on death with which many palliative care staff would be unfamiliar. And while Canada has made progress in advancing inclusion in recent years, LGBTQ+ patients continue to report fears of experiencing discrimination in long-term care facilities as a result of their sexual orientation and / or gender identity.<sup>41</sup> In many of these cases, the quality of care and patient experiences can be dramatically improved when palliative care teams partner with local ethno-cultural community agencies to address these unique needs.

Tailored solutions are also vital in supporting patients with socio-economic challenges. For example, a mobile unit known as Palliative Education and Care for the Homeless (PEACH) in Toronto may serve as a model for other cities. PEACH provides homeless patients with care wherever they are and recently teamed up with Toronto Hospice to launch the Journey Home Hospice, with four palliative care beds for homeless patients. Hospice care focused on this vulnerable community is especially crucial, given that homeless people are significantly more likely than other Canadians to contract serious illnesses such as cancer, heart disease, and Hepatitis C.<sup>42</sup>

#### **Recommendation 9**

Provincial and territorial governments should make it easier for patients to cross provincial/territorial borders with minimal delay. Provinces and territories should expedite information-sharing when it comes to health records of palliative care patients. Currently, Canadians who move provinces can be required to wait up to three months to receive insured healthcare services. Given their unique circumstances, palliative care patients moving provinces to be close to family members should be exempt from this waiting period.

Continuity of care can be negatively impacted and sharing of health records slowed by differences between provincial medical information systems.<sup>43</sup> Similarly, jurisdictional borders, which differentiate First Nation reserve (federal) and non-reserve (provincial) land, can also affect care accessibility. The federal government is responsible for providing healthcare services to First Nation peoples living on reserves. There are also, however, some provincial services provided to reserves. Poor coordination between federal and provincial entities can lead to compromised continuity of care and access to services.<sup>44</sup>

Dr. David Kesselman, CEO of the Louis Brier Home and Hospital, a Jewish community institution in Vancouver, stated that those who come to the facility from another province are expected to bring their healthcare records. Patients may experience difficulties in obtaining these documents in a timely manner, as demonstrated by the following excerpt from eHealth Ontario:

An electronic health record is a secure and private lifetime record of your health history. It gives your health care team, including family doctor, nurses, emergency room clinicians and specialists, real-time access to your relevant medical information, so they can provide the best care for you. As a patient, you – or your substitute decision-maker – have the right to access a copy of your personal health information.

Currently, patients don't have online access to their EHR...Until that time, a printed copy of the information in your digital health record is available from... the organizations listed below.<sup>45</sup>

One of the six organizations was the Freedom of Information & Privacy Coordinator Access and Privacy Office. When contacted, they informed us that this information is required to be released within 30 days, which is the average time range for delivery. Thus, despite "the right to access a copy of your personal health information," which will give one's healthcare team the ability to "provide the best care for you," one must go through a complicated process and wait over a month to receive relevant information.

Another delay in receiving proper treatment may be time spent waiting to qualify for healthcare in a new province. A reason for a patient moving provinces at the end of life may be the need to be near family members able to provide additional support. The CHA allows for a provincial health plan to deny coverage of a claimant if they have not resided in the province for three months.<sup>46</sup> Although one's previous province of residence continues to provide coverage during this transition period, gaps emerge in the form of disparities in the types of palliative care services each province insures. In some situations, patients have been unable to access proper support.<sup>47</sup>

## Recommendation 10

Provincial governments should foster caring communities by working with local organizations that mobilize volunteers to support patients. This includes ethno-cultural agencies with the expertise to meet the unique needs of patients from their respective communities.

Consistently, the UK is ranked as one of the top models for palliative care. 48 One initiative offered by most UK palliative care services is "compassionate communities", a community engagement initiative based on the idea that health is a collective responsibility.

Yael Ricquebourg has experience in a compassionate community model. PalliAmi collaborates with the Palliative Care Unit at Notre-Dame Hospital to provide end-of-life patients a climate of serenity. With more than 60 volunteers offering care through presence, reception and listening to patients and their loved ones, PalliAmi provides more than 7,300 hours of care to palliative patients. Ms. Ricquebourg sees significant value in government involvement to assist in attracting more volunteers.

Dr. Kesselman suggested that, if provincial governments support such a measure, specific needs must be researched to provide tailored services vs a one-size-fits-all approach. A needs assessment should be undertaken for each community and its facilities to identify gaps and determine how they would be best filled.

PalliAmi volunteers play a crucial role in addressing limited availability of doctors and insensitivity some patients experience. While physical pain is usually the focus of medical teams, psychological pain is often inadequately addressed. PalliAmi also addresses cultural and religious needs. By being present to understand and listen, volunteers have helped explain to hospital staff patients and families' nuanced cultural or religious requirements – such as those who observe Haitian mourning rituals, whose loud keening could otherwise result in unnecessary security interventions.

One respondent to CIJA's grassroots survey, who had experience with a community-based palliative team, thought that the compassionate community model should be adopted elsewhere in the healthcare system:

The model of home care provided by the community palliative team should be emulated by other community health services.

## **Conclusion**

How society treats its most vulnerable reflects its values. There are few more vulnerable – physically, psychologically, and socially – than those approaching the end of life. As part of our national commitment to universal healthcare, governments at all levels must do more to ensure that every patient has the option of accessing high-quality palliative care when they need it. We believe the ten proposals outlined in this report represent a meaningful contribution to this vital goal.

# **Endnotes**

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