



Winnipeg Regional
Health Authority Office régional de la
Caring for Health santé de Winnipeg
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End-of-Life Care: Public Awareness and Perspectives

Local Health Involvement Groups May 2021

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Acronyms

ACP	Advance Care Planning
LHIG	Local Health Involvement Group
LTC	Long Term Care
PCP	Palliative Care Program
WRHA	Winnipeg Regional Health Authority

Main Messages

- The WRHA's Local Health Involvement Groups (LHIGs) are a large component of the WRHA's broader public engagement strategy and provides one mechanism for ongoing community input. LHIGs are advisory to the WRHA Board.
- Between April 19, 2021 and May 6, 2021, LHIGs met to explore end-of-life care issues, focusing mainly on public awareness and perspectives.
- Given the anticipated increase in demand for end-of-life care services as a result of the Winnipeg Health Region's aging population, ongoing discussions with the public are needed to determine and meet future needs and expectations.
- The recent LHIG meetings revealed that various aspects of the topic were new to a lot of members including: places of care options; the variety of supports and resources available to patients, families, and the general public; advance care planning and goals of care, and; understanding palliative care as an approach to care.
- Comments shared acknowledged the inevitability of death and dying. A number of members opined that the lack of awareness might be due in part to the taboo nature or discomfort in discussing the topic by patients, families, and even healthcare providers.
- However, most members strongly believe that these are important conversations for families to engage in, especially well before being confronted with a health crisis.
- There was consensus across the LHIGs that the general public needs to be more aware about end-of-life care so that individuals and families are better informed when considering, discussing, and making decisions regarding their end-of-life wishes.
- Most suggestions made by LHIG members about the WRHA's role in raising public awareness relates to making information easier to access and disseminating practical information more broadly.
- LHIG members further suggested that the WRHA consider efforts to improve the public's awareness using a combination of media campaigns, having print material available more broadly, and through strategic outreach initiatives targeting specific groups.
- Lastly, members identified the following as the most significant end-of-life care issues for patients and families:
 - knowledge of relevant information, resources, and supports;
 - timely, open, and honest communication with care providers;
 - ensuring places of care meets the needs and desires of patients and families; and
 - the need for individuals to make their end-of-life care wishes known and to have them honoured.

Executive Summary

According to a 2019 Winnipeg Health Region Community Health Assessment report, the region's population is growing and aging.¹ The population is projected to reach 966,760 in 2030, with the proportion of older adults 65+ projected to be 18.9%. The same report also acknowledges that "despite an improvement in life expectancy, residents of the Winnipeg Health Region continue to experience a substantial and increasing burden of illness due to largely preventable chronic diseases" (p.12).

With an aging population and higher prevalence of chronic conditions, the topic has become increasingly important to patients, families, service providers, and the healthcare system overall. It is therefore important to continue the public discussion about end-of-life care in order to meet the anticipated increase in demand for services and to respond to future needs. By increasing our understanding of public views and current experiences, the Winnipeg Health Region is better positioned to make impactful decisions regarding the coordination of health system and community-based services as well as how resources are managed.

The WRHAs LHIGs provide an opportunity for members of the public to share their views and ideas to address important issues impacting healthcare services. Their perspectives and input enhance the region's understanding of these issues and allows for planning and decision-making that better meets the needs of the populations receiving these services. With this mandate in mind, each of the WRHA's six LHIGs met between April 19, 2021 and May 6, 2021 to explore, discuss, and share perspectives and input on end-of-life care issues. The goal of each 90-minute meeting was two-fold: to determine members' knowledge and awareness of end-of-life care and to gain insight into patient and family needs and expectations.

This report aims to summarize the valuable input and unique perspectives shared by LHIG members. Although it does not reflect everything shared at the recent meetings specific to end-of-life care, it does highlight the themes that emerged while exploring the topic.

The main findings from this report about *public awareness*:

Public understanding about key palliative and end-of-life care *terms* and *core concepts* appear to be limited.

- Although most members had heard the terms *palliative* and *end-of-life care* before, there was limited knowledge about its actual meaning among some members.
- There continues to be a misperception about palliative care being a *place of care*, rather than an *approach to care*.
- Some members understood palliative care to be a place where someone goes to die or as a last resort when there are no other treatment options available to try.
- Others were under the impression that the primary goal of palliative and end-of-life care was to help people die comfortably, not knowing that services also focus on comfort and quality of life for those affected by life-limiting / life-threatening illness.

Public awareness of palliative and end-of-life care services and places of care varied among members.

- Awareness appeared to be greater among those with personal lived experience, either by having a close relative or friend who used palliative care services in the past.
- Conversely, group discussions revealed that most members with little-to-no personal lived experience were the least familiar with the topic.
- Consistent with the misperception about palliative care being a place of care where someone goes to die, a number of members were unaware that the WRHA Palliative Care Program (PCP) provided services at home for those registered with the program.

Information about end-of-life care, advance care planning, and goals of care planning are available to the public. However, *most of these resources appear to be largely unknown* to those who have not been connected to the WRHA PCP or CancerCare Manitoba.

- The WRHA's website houses a lot of information about services offered in the region and provides links to numerous regional and national reputable resources.
- Most of this information is either offered or made available to patients and families registered with the WRHA PCP or receiving services from CancerCare Manitoba.
- However, when a number of these resources were shared during the LHIG meetings, almost all of the resources were new to members with little-to-no personal lived experience. Some of the resources were even new to those with lived experiences.
- Specific to Advance Care Planning (ACP), *Goals of Care* generated a lot of discussion and questions as many members were hearing about it for the first time.

Members feel *it is important for the general public to become more aware* of end-of-life care and that information about the topic should be easier to access and disseminated more broadly to improve awareness.

- There was general consensus that knowledge and awareness are key factors in promoting and facilitating meaningful discussions between patients, families, and care providers about end-of-life care wishes.
- LHIG members expressed a desire to see resource and informational material specific to services and resources available in print and electronically.
- Information should be available at more places, especially places where people access health and social services (e.g. primary care physician office, access centres).

A number of members believe that *conversations about dying and end-of-life wishes need to occur earlier* across life stages.

- Numerous suggestions were made about various healthcare professionals taking more of a lead role in initiating discussions about end-of-life care or ACP with patients and families, especially when sharing a diagnosis of a life-limiting / life-threatening illness (i.e. well before their health starts to decline).
- A number of LHIG members suggested that discussions about death and dying should occur earlier in life and that we (as a society) should consider introducing the topic in non-health care settings (e.g. schools).
- Despite the acknowledged inevitability of death and dying, members theorized that the topic might be considered taboo for certain segments of society to discuss openly.

Suggestions for consideration to improve public awareness about end-of-life care:

1. Consider making enhancements to the WRHA website that make it easier to navigate and find information being sought by patients and families. Detailed suggestions can be found on page 17 of this report.
2. Build capacity within relevant program area's in the WRHA (e.g. PCP, Spiritual Care, Social Work) and community groups to engage in outreach efforts and provide educational workshops in the community.
3. Consider public awareness media and / or marketing campaigns purposed with promoting ACP and its benefits and improving the publics understanding of palliative care. Start by building on existing and ongoing initiatives and awareness campaigns.
4. Make key resources easily accessible and available at low-to-no cost. Consider disseminating this information more broadly in health and non-healthcare settings (e.g. senior centres, work places). Make key resources such as the *ACP Patient Workbook*, *Practical Matters*, and the *PCP Brochure* available throughout the community in an effort to reach those with no internet access or limited access to mass media.

The main findings from this report about *public perspectives*:

Informational and communication needs emerged as the top two significant end-of-life issues.

- A number of LHIG members shared personal stories about not having timely information, not understanding what was communicated to them, or not feeling heard.
- Good communication with patients and families was identified as being essential.
- LHIG members feel that it is important for families and patients to be aware of relevant and practical information, resources, and supports.

Regardless of the setting, services and supports should be culturally appropriate and safe in an effort to respond to the Region's diverse communities.

- Members stressed the importance of care providers being knowledgeable and respectful of cultural differences.
- This includes an awareness and understanding by service providers of ethnic, racial, religious, and other cultural factors which may impact patient and family care.

Efforts aimed at achieving equitable care should also involve flexibility, adaptability, and additional considerations on the part of healthcare teams when delivering services to certain groups. Groups mentioned by LHIG members include:

- Youth
- Newcomers
- Older Adults / Seniors
- Those experiencing poverty and homelessness
- Canada's Indigenous peoples
- Immigrant and refugee populations
- Individuals with cognitive impairments
- Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) communities

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- i. Cui Y, Zinnick S, Henderson A, Dunne L. *Winnipeg Health Region Community Health Assessment 2019*. Winnipeg, MB. Evaluation Platform, Centre for Healthcare Innovation (CHI) & Winnipeg Regional Health Authority. December 2019.

Introduction

Local Health Involvement Groups

Connecting to the community and engaging the public continues to be a priority for the Winnipeg Regional Health Authority (WRHA). “Involve the public” by partnering and collaborating with those we serve is one of the region’s six strategic priorities. There are six Local Health Involvement Groups (LHIGs) throughout the health region that have been providing feedback and their unique community perspectives on significant health issues to the WRHA Board for 18 years. They are comprised of 80-90 residents of the geographic community area pairs (Appendix A) that each Group represents. The LHIGs are diverse in terms of culture, socio-economic status, professional backgrounds, work experience, age, and gender. Their discussions, feedback, and any associated recommendations related to the topics they explore are captured in a report that is shared with the Board, WRHA Senior Leadership, relevant program areas, and are available on the WHRA website (<https://wrha.mb.ca/engagement/lhig/reports/>). Suggestions from the LHIGs are used in a variety of ways to address important issues impacting healthcare throughout the region.

Background

Every year, members of the LHIGs (Appendix B) share ideas for topics that are a priority to them and these are presented to the WRHA Board of Directors for review and support. In recent years, *end-of-life care* continued to emerge as a topic that LHIG members expressed interest in exploring at future meetings. The topic was brought forward to the Board in 2020 and subsequently became one of the two topics approved to explore in 2020-2021.

Approximately six meetings were held between April 19, 2021 and May 6, 2021 where 45 members of the public met to explore, discuss, provide input, and share their perspectives on end-of-life care issues. WRHA leadership, including *Community Area Directors* (Appendix B), *Board Chair* Pat Solman, and *Board Directors* Kiran Kumandan, Lisa Pormeister, Dr. Judith Scanlan, and Major Gordon Taylor were also in attendance at meetings to observe and hear firsthand the comments, input, and experiences shared by LHIG members.

Key Terms and Concepts: Used in the exploration of this topic

The following terms and concepts were used in the exploration of this topic.

Palliative Care:

- Is an approach to care which focuses on comfort and quality of life for those affected by life-limiting/life-threatening illness;
- is much more than comfort in dying; and
- is about *living*, through meticulous attention to control of pain and other symptoms, supporting emotional, spiritual, and cultural needs, and maximizing functional status.

– World Health Organization, 2020

End-of-Life Care:

- Falls under the broader continuum of palliative care;
- often refers to palliative care for people with a life-limiting illness who are in decline and nearing the end of life; and
- processes for addressing medical, social, emotional, and spiritual needs continue.

The WRHA offers a robust palliative care program (PCP), which includes access to care 24 hours a day for those registered with the WRHA program and consultative services to patients and health care professionals across Manitoba. Palliative and end-of-life care is delivered in all care settings, including individual homes, long-term care (LTC) homes, hospitals, and hospices.

Advance Care Planning and Goals of Care:

Advance care planning (ACP) is a way to help you think about, talk about and share your thoughts and wishes about future health care. It gives you a "voice" in decision making, helps you determine who would communicate for you if you are unable to communicate for yourself and should include conversations with your health care team. *Goals of care* refers to the intended purposes of health care interventions and support as recognized by both a patient or substitute decision maker and the health Care Team.

– Winnipeg Regional Health Authority 2021

Questions pertaining to an individual's goals of care are asked by healthcare teams when a patient goes to a hospital, LTC, or when being transferred from one healthcare facility to another (e.g. from hospital to LTC). However, patients and their families can also initiate the discussion at any time. The ACP Patient Workbook is available for download on the WRHA's website - <https://professionals.wrha.mb.ca/files/acp-workbook.pdf>. It is a guide to ACP, with thought-provoking questions to answer, and important details about various health-care treatments, as well as tips on developing and sharing your advance care plan.

Engagement Process

Consultation with Subject Matter Experts

Prior to the LHIG meetings, program leadership and specialists from the WRHA's PCP, Spiritual Care Services, Social Work, and Patient Relations met with LHIG staff to provide relevant and up-to-date context and information on end-of-life care in the Winnipeg health region. The feedback from staff helped to inform the content and focus for the LHIG meetings.

Presentation and Questions for Input

The LHIG meetings focused on providing members with general information about palliative and end-of-life care, followed by the opportunity to share their input, ideas and perspectives. Each meeting included a presentation by subject matter expert Janice Nesbitt, a Clinical Nurse Specialist with the WRHA Palliative Care Program, who also remained available to

LHIG members to answer questions and observe the group's discussion and feedback. The presentation covered key terms, considerations, services, places of care within the Winnipeg health region, and resources related to the topic. Following the presentation, members were presented with six questions for input. Questions focused on gauging member's awareness and understanding of palliative and end-of-life care as well as gaining insight into their perspectives pertaining to patient and family needs across the palliative continuum of care.

Public Awareness: Key Themes

Public awareness refers to communication activities designed with the intent to raise awareness, influence behavior changes, and from a health care perspective, improve health outcomes for individuals and the population. A general familiarity with key terms and availability of services has the potential to empower individuals and families in accessing palliative care if needed and encourages important discussions about their own future care. That is to say that awareness of palliative and end-of-life care helps improve knowledge of, and access to services by patients and families that better aligns with their needs and wishes.

Following a presentation entitled *Palliative and End-of-Life Care* by subject matter expert Janice Nesbitt, LHIG members were asked two questions related awareness on the topic. The questions and responses are listed below. Responses have been organized by theme. Under each theme are individual responses to provide further insight.

Question 1: What was new to you?

Theme 1. *A number of LHIG members commented on various aspects related to palliative care services being new to them, especially the option of receiving services at home.*

Individual responses:

- Did not know that you could receive palliative care in the home.
- Did not know that palliative care was an option in the home with access to 24/7 support on call.
- Was not aware that access to a team 24/7 was available for those receiving services in a home setting.
- First time hearing about the different classifications of palliative care.
- Didn't know that there was a cap for home care hours for patients receiving palliative care at home.
- Wasn't aware how much of the load would be expected to be carried by family and friends if someone decides to opt for palliative care at home.
- Didn't know there was end-of-life care protocols at LTC homes.
- Didn't know that LTC offered palliative care.
- First time hearing that up to 70% of people state that they would prefer to die in their homes than in hospital.
- Didn't know that you could deliver palliative care where the person lived. How do we get the word out?

"would it be more efficacious for the system and the person if a change could be made in terms of resources available because it would seem to me that it makes more sense to keep as many people as possible out of hospital if that's their preference. Has any investigation been done to see if we could go a different route? Just a thought." – LHIG member

Theme 2. A number of LHIG members were unaware of the type and variety of resources available to patients, families, and the general public.

Individual responses:

- Learned about most of the resources listed on the final slide in the presentation for the first time.
- All of the resources shown during the presentation were new.
- Wasn't aware of the Employment Insurance Compassionate Care Benefits
- Wasn't as familiar with the resources in spite having lived experience supporting a loved one in palliative care.

Theme 3. A cluster of comments also centred around hearing palliative care being described as an approach to care rather than a place of care.

Individual responses:

- Didn't know that palliative care wasn't a place.
- Didn't think there was this sort of consideration around life expectancy.
- Thought palliative care was more or less when there weren't any other treatment options available or the person didn't choose to have other treatment options.
- Thought it was a special place you could take someone to that had a very chronic condition or disease.

"I used to think that palliative care was a place. I didn't know that it was an approach. Knowing that it's an approach is an eye opener."
– LHIG member

Theme 4. A number of aspects related to Advance Care Planning (ACP) was new to some LHIG members, most especially the Goals of Care categories.

Individual responses:

- Didn't know about the different ACP Goals of Care levels (C- Comfort Care, M – Medical Care, R - Resuscitation).
- First time hearing about the goals of care levels.
- Didn't know about the levels of resuscitation connected to palliative care.
- Didn't know once a patient is enrolled in the WRHA Palliative Care program, cardiopulmonary resuscitation (CPR) will not be attempted under the Goals of Care.
- Had never heard of goals of care (a few members asked for the goals of care to be explained again).

Theme 5. Most of the information was new to members who have had little-to-no personal experience with end-of-life care.

Individual responses:

- Everything was very new.

- Pretty much all of it was new
- A lot of this was new.
- Everything presented tonight was new.
- Didn't know any of this - probably because of the lack of exposure personally.

"I didn't know any of this was available." – LHIG member

Additional individual comments:

- Didn't know what the term hospice meant.
- Wasn't sure how Grace Hospice and Jocelyn House operated (i.e. in terms of what's included, costs, how they differ from St. Boniface Hospital or Riverview Health Centre palliative care units).
- Didn't know that someone who's receiving aggressive treatment for cancer isn't a candidate for palliative care but would instead be followed by Cancer Care Manitoba.

Question 2: What are your ideas about how we can better inform people about end of life care / palliative care services and options?

Theme 1. *Disseminate the information about palliative and end-of-life care more broadly. Information should be available at more places, especially places where people often go for healthcare services (e.g. primary care physician office, access centres).*

Individual responses:

- The information about Advance Care Planning is beautiful on the website but this information needs to be available in print for people who can't access it online.
- There should be a media campaign about where to go for information about end-of-life care – there should be media ads and billboards about where to call, where to go.
- Create a publication similar to what they do for newcomers (e.g. how to open a bank account, how to apply for a mortgage, how to access or do a number of things). Could there not be an educational brochure of some sort that could speak to this kind of health service?
- Could this be combined with a few other health topics at information centres or health fairs?
- Something else that might go into a pamphlet – information about how Advance Care Plans or how Power of Attorney's work– a lot of people don't understand or know where to begin.
- Whatever information is conveyed, make sure it's honest and complete – dying in palliative care isn't pretty. It can be ugly.
- More work is needed around general dissemination of the information by family physicians.
- Leverage the visits or interactions with family doctors – they can start having these discussions or sharing the information at their place of practice.
- Is this information available in doctor's offices? Consider those kinds of basic places. Make sure the information is nice with easy to read language so that people can understand it. Consider material that's been translated into other languages.

- This information will be needed by everyone at some point. Put information where people can get it before they need it so that they're not scrambling when the situation arises.

“The more you know about these things before you need them, the better off you are when you do need them.” – LHIG member

Theme 2. Normalize talking about death and dying and consider taking strategic measures that would prompt or encourage families to have conversations about these life events and end-of-life care.

Individual responses:

- The public needs to talk more about death.
- We need to talk about death more.
- It shouldn't be uncomfortable or embarrassing to talk about death. But there is some that not all cultures might feel this way.
- This conversation might be uncomfortable for those people in a position to talk to us about it, people like physicians or teachers. Therefore, training might be needed for them to be able to talk to us about it.
- Anything that the WRHA can do to encourage families to have conversations about this. We need to talk to our family beforehand and not when there's a crisis.
- Make material available that will get people thinking about this on their own, planting the seed that you might need this at some time.
- Have information like this available at a DRs office, with nice easy to read language. While waiting, people who have not thought about this before might read it and consider talking to their families about this stuff.
- Having this information available in a doctor's office or other healthcare places, might encourage people to have these conversations with their family members, to talk about those difficult things before it is on their doorstep.

“We need to talk about death more. I think the lack of awareness comes from discomfort in talking about death.” – LHIG member

“make it normal somehow to talk about these issues before they actually become an issue. So that people not in the midst of, or at the beginning of a crisis are now suddenly having to face these conversations. It's so much better I think, if people have these chats with their family members, or friends, or both, before anything actually happens” – LHIG member

Theme 3. Conversations about dying and end-of-life wishes need to start earlier.

Individual responses:

- Schools would be a good place to start the conversation about death. If sex education is covered in schools, why not death since we all die?

- Have the conversation at diagnosis - the conversation needs to happen earlier.
- Family physicians could start the conversation with their patients earlier.
- When the diagnosis is first made in the DRs office, it should generate an automatic referral to the palliative care program where the family can choose whether or not to accept an appointment or a meeting with someone from the program. Just so that they know that there's someone out there that could explain all the stuff that's often found in the booklet. That way if the patient and family needs help to understand the information or navigate the different parts of the program, they have it. If this happened right at the beginning, it would make things a lot easier for families.
- As soon as a person is diagnosed, there should be a follow up meeting scheduled to tell people about all the things that are there to help them.
- A lot of the audience you're trying to get to is the family of the patients – families are often wondering where they can get this information when they're searching. Online is an option but the contact points in the healthcare system (home care, access centres) can be really good starting points. These contacts should also be knowledgeable about this instead of just handing out reading material.
- We need to prioritize talking with our families to get some idea about what kind of comfort care we might need and / or want – have the conversation early, especially before the point of where someone can't speak for themselves. It sure saves a lot of problems.

Theme 4. Consider doing *community outreach. Host presentations and workshops.*

Individual responses:

- Do more outreach, presentations or workshops about the topic (e.g. at seniors centre's or other groups)
- Have a nurse come out to speak to newcomer groups.
- Target specific groups for presentations such as newcomer groups, seniors, and retirees.

Additional Individual Comment:

- We often don't come across this information until the time arises where we need it. Therefore, it might help to have this added to the role of a patient advocate.

Public Perspectives: Key Themes

End-of-life care requires a significant investment in resources, funding, and coordination of health system and community-based services. Ongoing discussions aimed at understanding public perspectives and experiences is needed in order to ensure that the healthcare system responds to the needs of patients and their families, as required.

LHIG members were asked to consider their responses to the questions below based on a combination of what they know about palliative and end-of-life care, what they learned from the presentation, and where applicable, their personal experiences. Responses have been organized by theme. Under each theme are individual responses to provide further insight.

Question 3: What care or supports do you think family members or primary supports should receive when their loved one is (a) nearing end of life; (b) at the time of death and (c) afterwards?

Theme 1. *Informational Needs.*

Individual responses:

- Clear information on what to expect.
- For the family, it would help to have an explanation of the process of dying, so that the family understands what may happen throughout the process.
- Accurate information about what you're dealing with so you can have the right information to make the right decisions about whether or not to pursue a treatment or not.
- Information on what you need to do or consider when your loved one is dying or has died - similar to what a number of funeral homes give out in terms of what you need to do. It would be helpful to have this information beforehand, especially for legal matters, because there is often a lot of paper work to fill out and submit.
- Handouts or books that explain things.
- Family, caregivers need to have honest and direct information with the options that are available to them.
- General information about legal considerations.
- It's important to have legal advice, especially for those who are an executor or Power of Attorney and especially when their loved ones are nearing the end of life. They all have a powerful role to play. If everyone has a clear understanding about who's responsible for what, it would resolve a lot of family issues if roles are identified and in place legally.

“A patient will want to know what is going to happen to them and what their care will look like. The family will want to know what their role will be in that care and what they'll need to do during the end-of-life process” – LHIG member

Theme 2. Communication Needs

Individual responses:

- Good communication with and between healthcare providers, patients, and families.
- Knowing who to go to with questions or concerns.
- Clear, easy communication that helps families really understand what is going on.
- A volunteer to walk alongside the family (preferably a volunteer from the medical field) so they can help communicate certain difficult to understand terms.
- Don't sugar coat messaging. Patients and families deserve to understand how invasive certain procedures can be and the risks of prolonged suffering. The healthcare team should tell it like it is so families can prepare better.
- Healthcare providers involved in a patient's care should keep the family members informed because the patient might not always keep the family members updated.
- In addition to honesty, clarity. That is, if the medical staff know how dire a situation is, don't hold back communicating clear, accurate, honest information because of not wanting to hurt someone's feelings or cause someone pain.

Theme 3. Knowledge, Awareness and Offers of Resources and Supports

Individual responses:

- Offers of spiritual care or support groups or one-on-one counselling.
- Family members should know whether or not they're eligible for paid leave or compassionate care benefits.
- Caregivers need to know what financial benefits exist and to know if they're eligible so they can have the option taking care of their loved ones at home.
- Options of therapy, support groups.
- Access to an advocate – someone who knows the system, inside and out.
- More access to advocates with personal experiences.

Theme 4. Respite for Caregivers

Individual responses:

- Supports to come into the home to give caregivers a break.
- Palliative care at home – respite for family caregivers taking care of both their loves one's at home and children.

Theme 5. Check-Ins

Individual responses:

- Important for a healthcare team to check up on the families periodically because their needs will change over time and they won't need just one thing all the time. While they're providing the checkups, they can offer applicable resources at the time.
- Checking in periodically to better meet the needs in the moment.
- Have someone ask if they're doing ok.

Theme 6. A Primary Contact Person on the Healthcare Team.

Individual responses:

- If there is a healthcare team with different experts that provide different support, it helps if there's one person who's a coordinator for that group. The family can then build rapport with that person because every time you get a call from a different person, it feels disjointed.
- Having a person who is a primary contact that could arrange calls or discussions with other members of the interdisciplinary team.
- Have one person to contact when with questions or concerns as they arise. Whether it's what to do when certain symptoms appear or to help understand what each medication is supposed to do, it helps to have someone provide guidance to caregivers and explain what all this means.
- Have a point person to speak to at any given time when questions or concerns arise. A point person would help, especially for those who are in palliative care for awhile (e.g. 3 months).

Theme 7. Support with Administrative Tasks

Individual responses:

- A person to help navigate the administrative work and filling out forms.
- Help understanding and filling out the health care directive. The jargon on it isn't easy to understand. Maybe more people would fill them out if it was easier to understand or if there was someone to help.

Additional individual comments:

Individual responses:

- Privacy – it can be very awkward when your loved one is dying and has to share a room with another patient
- A quiet and soothing physical environment
- An “end-of-life care doula,” similar to what’s there for childbirth. Have a similar option available for those at the end of life.
- Culturally sensitive and appropriate supports.
- Ease of navigation – we want things to move smoother and faster when dealing with the health care system.
- There’s a very “western medicine” outlook on what support looks like. A good diverse group is needed when creating end of life care programming.
- Patients and families should ask about coverage that might cover a private room (e.g. blue cross).
- 24-hour access to see loved ones in palliative care facilities.
- With the current situation during the pandemic, it's even more important for staff involved in care to demonstrate care, compassion and encouragement for those who can't have visitors due to current restrictions and to the family members who can't visit.

Question 4: For family members or friends of an individual who has died: what care or support did you NOT receive and wish you had received?

Theme 1. Information – General, Resources

Individual responses:

- Reading material to help prepare for what was to come.
- Information about all of the resources that are out there.
- Relevant, practical information – e.g. a list of funeral homes, where to go for grief counselling.
- A checklist about what to do next or what to think about.
- Awareness about the kinds of information and resources available to families.
- General information about resources and asking if or what would be helpful.
- Information about where to go, what to do, who to approach.
- A set of guidelines on what to expect across the various stages of end-of-life.

Theme 2. Better Communication.

Individual responses:

- Professionalism and better communication. The healthcare team could've done a better job of giving more honest and accurate answers.
- A better understanding of what was done and why.
- Communication about what's being done and by who (i.e. who's providing the treatment and why).
- Timely communication from long term care staff when they were aware that a loved one was nearing the end of life.
- The issue wasn't the information that was communicated but how it was communicated. Things just could've been explained better and could've been more personal.
- At the time of diagnosis, it would've helped to have someone there to explain some of the stuff that was shared by the presenter (this is where the ball was dropped).

"As someone who has worked in the educational system I know firsthand how challenging our systems are for people to navigate. As professionals, I believe it is incumbent on all of us to remember that fact when we are dealing with the consumers of these systems. Everyone is overworked - but that is just not a good enough excuse for insensitive behaviours. Fortunately, I am able to say I have received the best of care for my loved ones - but have also had some tougher encounters." – LHIG member

Additional individual comments:

- A break from caregiver responsibilities.
- Help with taking care of young kids and knowing how best to explain to them what was going on.
- A comfortable place to sit or rest when staying overnight in the hospital. It would've helped to have a room that facilitates comfort when staying overnight as a visitor.
- An exit interview by the LTC home to discuss the families experience.
- An opportunity for family follow-up with the healthcare team after the passing of a family member.
- A more consistent display of compassion.
- More personal attention.
- An idea about what kinds of questions we should be asking of the health care team.



It is worth noting that there was a cluster of statements made by numerous LHIG members who shared their belief that those who work in the palliative and end-of-life care field really do have the patient's "best interest at heart." A number of LHIG members with personal experiences also shared stories about the small acts of kindness displayed by staff, acts that went above and beyond their formal duties. One member shared that although it was a challenging experience for the family:

"Whatever they did at Grace Hospice was exactly right on target – they were really wonderful, the whole team, everything. They explained everything. They knew his name. They treated him really really nicely. He had a really great room. They allowed us to bring food in and spend as much time. They had a bed in there that we could stay overnight if we wanted to. I mean, it was a lovely experience – I would want to be there at the end of my life." – LHIG member

Question 5: Should different approaches or types of support be considered for family members/friends that experience language barriers, socio-economic challenges, have disabilities, mental health issues, etc.?

Theme 1. Addressing language barriers.

Individual responses:

- If it's a language barrier, a liaison that understands the language and the health care system should be available to help patients and families.
- Access to interpreters and translators are important in order to avoid any misunderstandings or miscommunications.
- Print material (e.g. pamphlets) should be available in as many different languages as possible.
- Bare minimum - have translation services available in many different languages.

Theme 2. Take into account a number of considerations for specific groups.

Individual responses:

Newcomer Groups:

- Newcomers may need translators, help connecting to others in their community.
- Consider outreach to newcomers - network with agencies that work with newcomers to collaborate on providing this information to them.
- As someone new to this country, it can take 5 to 6 years to understand how systems in a new country works. Newcomers need resources that can help facilitate or make it easy to navigate the system – perhaps a volunteer working in palliative and end-of-life care should be made available to work with newcomers.

"You have to reach out to different communities and see what they would feel is appropriate for them, what their expectations would be as to how they could best support their family or friend in a time like this." – LHIG member

Older Adults / Seniors:

- Reach out to various community groups (retirees associations, senior's groups, etc.) as they are often looking for information and content to share with their members.

Immigrant Population

- Different cultures have different rituals, practices but it's about letting them know the resources that are available are to help you live and not die (i.e. understanding palliative care as an approach to care).

Individuals with cognitive impairments:

- For certain types of cognitive impairments, it can take longer to explain what is going on and they may need more time understand what is going on. Certain groups just need more time.
- Extra supports for patients or family members with cognitive impairments – support that helps them comprehend the information being shared.

Youth:

- Consider programming and mental health supports specific to youth who have experienced a loss and are grieving.

Additional individual comments:

- The Western medicine approach doesn't fit everyone – educate people working in palliative and end-of-life care on cultural differences and rituals and to respect the cultural differences.
- This should apply to everyone but especially for those who identify as low-income, make sure that they're aware of any benefits they might be entitled to (benefits covered by our healthcare system) and share information about free resources and supports.
- Create the necessary policies and ensure that staff are trained and able to display competencies regarding different cultures, religion, and sexual orientation.

Question 6: Based on what you've heard tonight, what do you see as the most significant end-of-life issue(s) for patients and family members?

Theme1: Knowledge of, and timely access to relevant information, resources, and supports.

Individual responses:

- Access to information.
- Access to information and resources.
- Getting concrete, accurate information.
- Access to Information – it sounds like there's a lot resources out there, but there's uncertainty about how much the general population is aware of.
- Have important material available in multiple languages.
- Knowing what support is available and where to go for assistance.
- Educating people and getting the word out there as to what services are available.
- Knowing where to go for information at least to get started.
- Knowing what the options and choices are out there and what it all means.
- Access to psychosocial and mental health supports.
- In addition to information, education, communication and advocacy, add spirituality / spiritual services as an option for people.
- Easy, open access to the services that the family wishes to have.

"Being informed and being prepared. That doesn't all have to come from the system – making it more acceptable for people to talk about this by giving them the information they need so they can talk to family and friends in advance when they feel ready."

– LHIG member

Theme2: Communication that is timely, honest, informative and by a limited number of qualified individuals involved in a patient's care. In addition to being able to display care and compassion, these individuals should be knowledgeable about end-of-life care.,.

Individual responses:

- Communicating essential information in a timely manner with patients and families.
- Communicating in an empathetic and respectful manner. This needs to be part of a broader effort to create an atmosphere of compassion.
- It is critically important to have a person to speak to once you are in that spot and need information, rather than be referred to a website or given a pamphlet.
- A point person that understands the totality of a patients concerns who can communicate effectively with the family throughout their time in palliative care.
- Communicate with compassion and not with assumption.
- A translator or interpreter would be very important for people who don't speak the English language.
- When palliative care is triggered, the point of contact person should be a knowledgeable and caring individual.

- On a 24-hour shift, it would help to have the same three healthcare team members to talk to. There needs to be consistency on a team. We can't keep telling the same story over and over again to different healthcare team members.
- All of us need:
 - to be listened to and heard
 - to be valued for our input and concerns
 - to be given some time without feeling we are chasing after the medical staff
 - to have our loved one dealt with compassion, dignity and respect - not as someone that just has to be "fit" into a system
- We need a well-functioning health care and support team and an integrated approach to care for the patient and the family.

Theme 3: The need for individuals and families to anticipate and discuss their future care and make their end-of-life care wishes known, respected, and honoured.

Individual responses:

- It is important to have the patient and families wishes met – important for families and patients to have these conversations early, making decisions early.
- Make sure you know what the person wants, what's their wishes so that no one is guessing and giving them something they don't want or need.
- Complete your Advance Care Plan.
- Make death part of the conversation \.
- Have Emergency Response Information Kits (E.R.I.K) on your refrigerator. Everyone should have them and information about them should be something the caregivers are aware of.

"I'm a big believer in making your wishes known – fill out those forms, give it to your doctor, give it to your family members, let them know what you want for your end of life."

– LHIG member

Theme 4: Ensuring places of care better meets the needs and desires of patients and families.

Individual responses:

- having a comfortable location and the support of staff or volunteers to assist the family during this difficult time – i.e., having volunteers help with the families heavy lifting.
- some facilities should consider animals as family.
- For people in hospital, having a comfortable environment. Having your own space and space for people who are there for you. Privacy is very important during the last days.
- a place where you want to be but at the same time it also being a place that provides what you need.

Additional individual comments:

- Everyone should see their death as a release.
- We need to focus on acceptance.
- Expand Medical Assistance in Dying (MAiD).

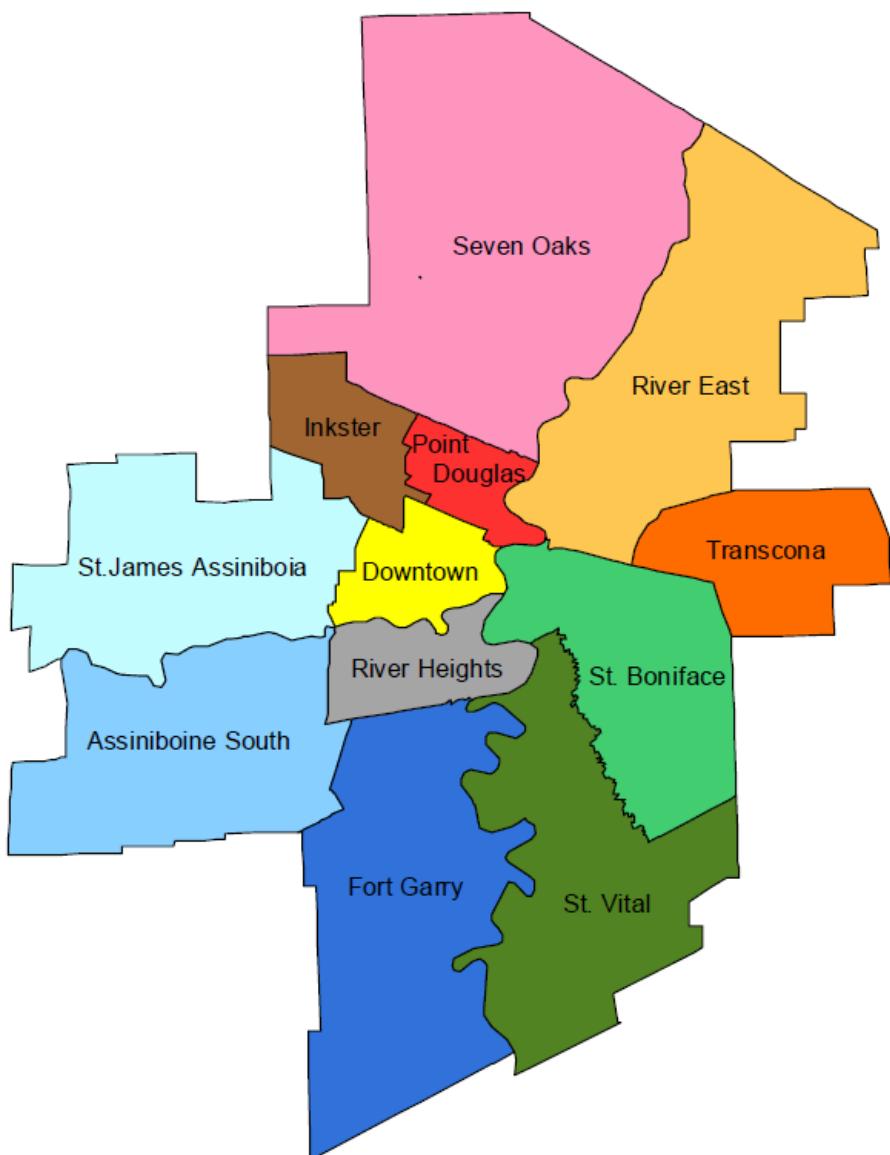
Suggestions to Improve Public Awareness

LHIG members were asked to share their idea's about how we can better inform people about end-of-life care and palliative care in general. Their input resulted in the following suggestions to improve public awareness:

1. In an effort to better inform anyone visiting the WRHA website seeking information about palliative care or ACP, consider making the following enhancements that will inform the public and make it easier to navigate and find information being sought by patients and families.
 - Develop a video library of brief informational videos available directly on the website that convey general information about palliative care and ACP. These video's can be housed on the WRHAs ACP and / or the PCP webpages. Rather than providing links to view these video's on other websites, consider embedding key video's directly onto the WRHA webpages highlighted above.
 - Suggested videos include an *Overview of the WRHA Palliative Care Program*, *An Overview of ACP*, *An Overview of Goals of Care Designations*, a *testimonial from families discussing end of life care wishes and the benefits of an ACP*, and *interviews with healthcare providers explaining the importance of knowing a patient's goals of care designations*. A number of these video's already exist on the Canadian Virtual Hospice website (<https://www.virtualhospice.ca/>) – consider importing key content from this site.
 - The ACP patient workbook is available for download but not everyone has a printer. Provide an option on the same webpage that provides people with information about how to order a copy of the workbook (by phone or online).
 - The ACP patient workbook is only available in the English language. Consider making this workbook available in French (an official language), major Indigenous languages, and other widely spoken languages.
 - It takes quite a bit of navigating between webpages on the website to find key information. Consider providing one downloadable document on all relevant webpages (PCP and ACP webpages) that collates general information about related services, resources, and contacts.
 - Wherever possible, key informational resources listed on the WRHA website should be available in other languages to the greatest extent possible. These resources include the brochure about the WRHAs PCP, the *ACP Patient Workbook*, and *Practical Matters* (a guide intended to help with bereavement and logistics following a loss of a loved one).
2. Build capacity within relevant program area's in the WRHA (e.g. PCP, Spiritual Care, Social Work, Community Development) and community groups to engage in outreach efforts and provide educational workshops in the community.
 - Provide information and instructions on the WRHA website about how to request an information session or workshop. The WRHA PCP offers this service but it is not advertised anywhere.

3. Consider public awareness media and / or marketing campaigns purposed with improving the publics understanding of palliative care and promoting ACP and its benefits.
 - Start by building on existing and ongoing initiatives and awareness campaigns such as ACP Day (occurs annually on April 16) or World Hospice and Palliative Care Day (second Saturday of October annually). Some healthcare facilities set up booths and engage in other activities on ACP Day. Consider partnering with community groups to bring similar activities into the community.
 - In order to reach all those that could benefit, campaigns should include as many platforms as possible (e.g. TV coverage, interviews, talks on radio, an online presence, use of social media)
 4. Make key resources easily accessible and available at low-to-no cost. This is especially important for those without access to the internet. Consider partnering with groups to disseminate this information more broadly in health settings (e.g. Access Centres, Primary Care Clinics) and non-health care settings (e.g. schools, senior centres, work places).
 - Opportunities exist to make key resources such as the ACP Patient Workbook, Practical Matters, and the PCP Brochure (a bilingual resource) available more broadly.
 - In an effort to educate and raise awareness among those with limited access to the internet and mass media, distribute hard copy material at primary care sites (e.g. clinics, access centres) and throughout the community (e.g. community organizations, places of worship, newcomer organizations, libraries, shelters, etc.).

Appendix A:
WRHA Community Areas



Appendix B:
Local Health Involvement Group Members (2020-2021)

Downtown and Point Douglas	River Heights and Fort Garry
Mohamed Behi Jodi Bond Cameron Susan Allen Mankewich Athena Monayao Gerry Pearson Randy Ranville Community Area Director - Sharon Kuropatwa	Barbara Scheuneman Carey Sinclair Ashley Volpi Adrienne Winfield James Wright Community Area Director - Natalie Imbrogno
Seven Oaks and Inkster	River East and Transcona
Gurleen Aulakh Hicham Bagui Roy Bechard Olia Katchanovski Walter Murray Victoria Ponomets Community Area Director - Luba Bereza	Laryssa Sawchuk Sukhpalvir Sidhu Diana Szymanski Kathy-Lynn Teles Rose Troia Community Area Director - Lisa Lacroix
St. Boniface and St. Vital	St. James-Assiniboia and Assiniboine South
Adekanmi Akinlade Melanie Allard Chris Ashley Helene Beauchemin Linda Campbell Noah Kennedy Judy Kidd Community Area Director - Bria Foster	Martin Landy Sarah Legoupil Pedro Egas Proano Deanna Waters Wedin Michael Wickman Sharon Community Area Director - Eve Omar
	Judy Anderson Deloris Ankrom Melanie Cardinal Heather Cardona Carol Ellerbeck Patricia Eyamba Darlene Hildebrand Community Area Director - Natalie Imbrogno
	Kathryn Dyck Merle Fletcher Joseph Geodisico Leslie Hancock Ursula Hartel Denis Lavallee Community Area Director - Lisa Lacroix
	Shirley Canty Brian Clerihew Maegan Clerihew Lawrence Klepachek Community Area Director - Eve Omar
	Ololade Iyogun David Laird Thania Martis Bob Newman Abhinav Sud Sandra Sukhan Community Area Director - Natalie Imbrogno
	January Melillo Justine Panganiban Reetul Patel Maureen Peniuk Sem Perez Simran Saggi
	Tim McIsaac Jennifer Patryluk Lynn Silver