Re-Thinking Palliative Care in the Community

A CHANGE GUIDE
WORKBOOK

The Change Guide Workbook

This workbook contains activities and worksheets for brainstorming and putting into action the tools presented in the Change Guide for re-thinking palliative care in the community. Suggested activities are provided for using the worksheets to create an action plan.

The worksheets included apply to these 5 tools:

1. Achieving the 7 Commitments of Palliative Care
2. Community Assets Assessment
3. Reflection on PEP (people, entrepreneurialism, and purpose)
4. Evolution Process of Team Milestones and Measures
5. Learning from Others

Using these tools will help you to:

- Formulate strategies to achieve the quality commitments for improved patient care.
- Determine the existing strengths and limitations of the local community to build an effective team.
- Reflect on the presence or absence of key ingredients required to build a strong team.
- Identify the key opportunities, challenges, and appropriate outcomes measures according to your team's evolution stage.
- Draw from the experiences of others who have implemented successful palliative care teams.

PALLIATIVE CARE INNOVATION
www.palliativecareinnovation.com

Tool 1: 7 Quality Commitments to Patients and Families

Description:

After conducting over one-hundred interviews with core members of fifteen different palliative care teams across Ontario, we discovered that providing patient focused, high-quality proactive care was made possible by some key actions that were taken by the palliative care providers. In our change guide, we summarized these key actions into a short list of commitments entitled '7 quality commitments to patients and families'. Although addressing each of these commitments is essential to creating a successful palliative care team, it is important to realize that there are many possible ways each could be addressed.

In the following activity…

In the following activity, you will have the chance to focus on one of the seven commitments and share your ideas and insights about how your community could fulfill the commitment and help improve the quality of palliative care in your community. In addition to improving palliative care for the patient and their family, addressing the seven commitments will also benefit the health service providers involved. If you want to learn more about this, please refer back to the change guide.

7 Commitments Activity Instructions:

1. Select the Commitment your team struggles with the most from the Quality Commitment tool.
2. Reflect upon the selected Commitment in terms of what you or your team is doing now to meet that commitment, what the barriers are to meeting it better, and how these barriers might be overcome.
3. Record you ideas on the 7 Commitments Worksheet and discuss how to address the Commitment.
4. Create/decide on an action plan to directly impact that commitment.

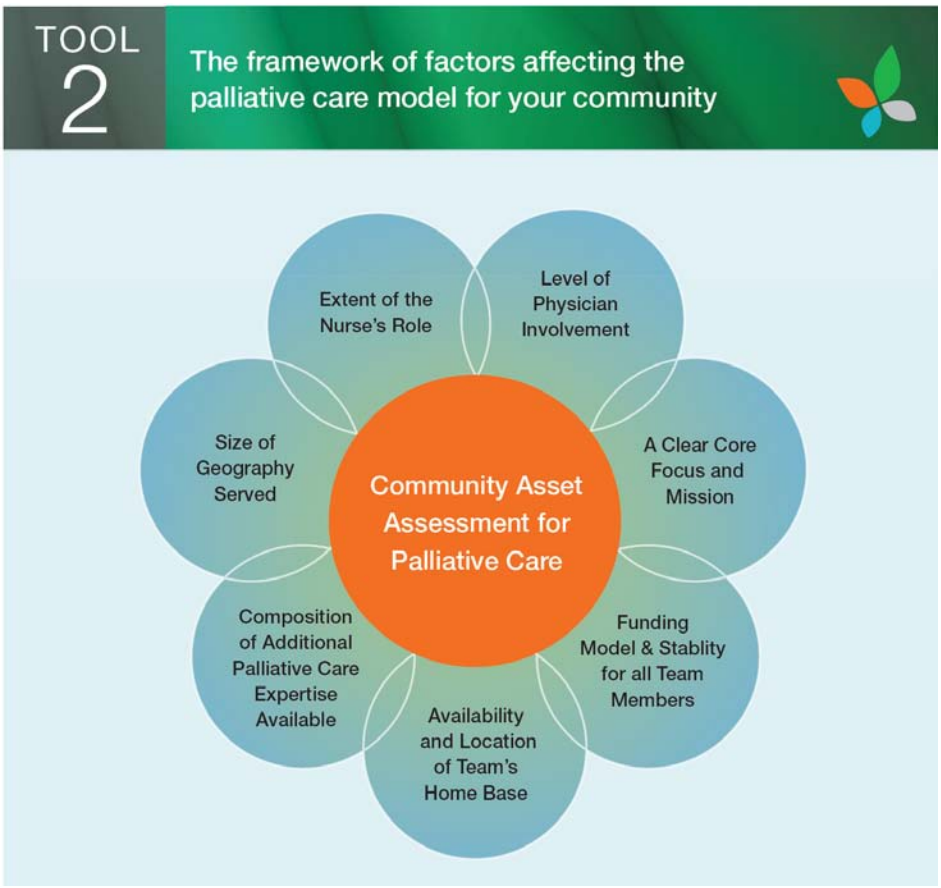
Tool 1: 7 Commitments Worksheet

Commitments	What are we doing now?	What are the challenges?	What else can we do?
1. We will provide dedicated expertise 24/7 so you never feel alone			
2. We will communicate and connect as providers so you don't have to repeat your story numerous times			
3. We will respond in a timely and effective manner so you experience minimal discomfort and distress			
4. We will attend, proactively, to the wellness of your mind, body and soul so all forms of suffering can be alleviated			
5. We will provide education and guidance so you can prepare for what lies ahead			
6. We will support you to resolve personal affairs and realize goals so you can feel fulfilled, and at peace			
7. We will serve as advocates so you can achieve the type of care, and death desired			

Tool 2: The Framework of Factors Affecting the Palliative Care Model for your Community

Description:

In our examination of palliative care teams, it became clear that different models of care and physician involvement worked better in different regions depending on the location, the size of the palliative care team, and the different roles the team was comprised of. This demonstrates that the standardization of quality care throughout different regions is possible without a cookie cutter approach. Since no two communities are the same, no two palliative care teams should be the same either. When thinking of how to build a successful team in your region, it is important to remember to build on the existing strengths in your community and over time, your team will evolve to build new capabilities and relationships to address previous weaknesses.



In the following activity…

In the following activity, you will have the chance to assess the strengths and weaknesses of your palliative care team. This can then be used to help you develop a model of care that will work best in your region.

Models of Care Activity Instructions:

1. Complete the Models of Care Worksheet for your team.
2. Circle strengths and use squares for weaknesses.
3. Use the Community Assets Assessment Tool to discuss how to build on strengths to overcome weaknesses.

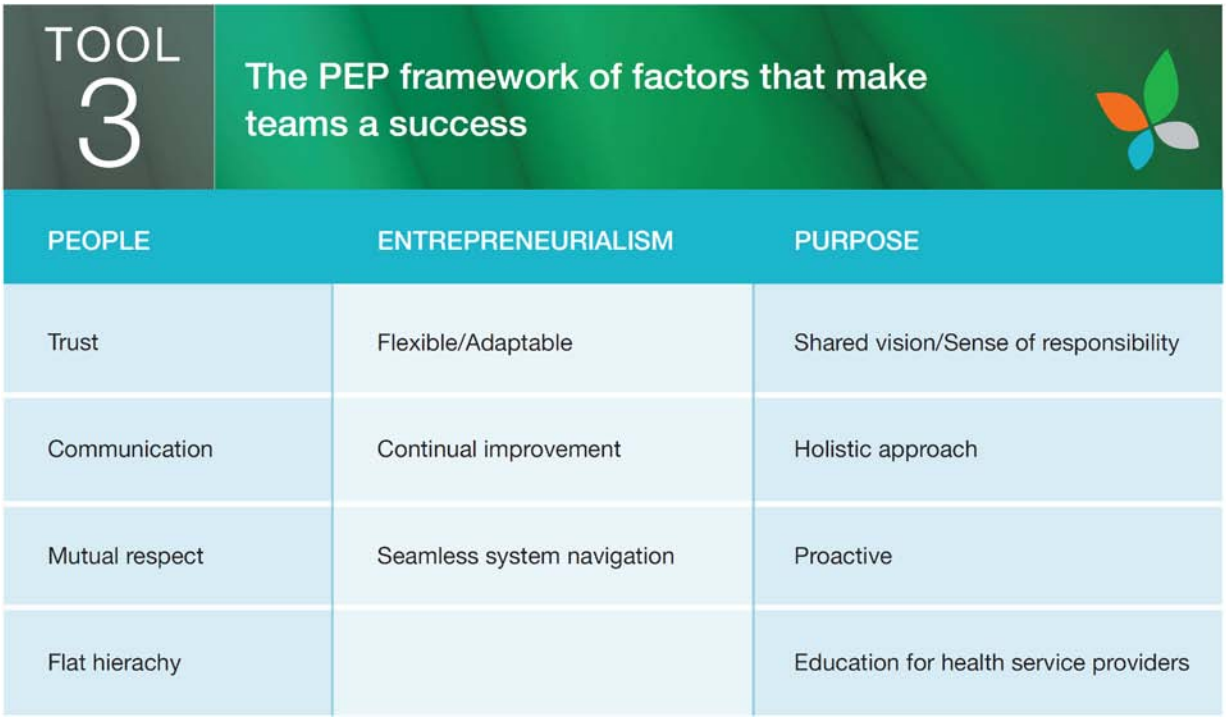
Tool 2: Models of Care Worksheet

Asset	Circle the word/phrase that most accurately describes each of the identified assets in your community				
Physician Involvement	Consult		Shared		Substitution
24/7 Physician Availability	Not available	Rarely available	Available every once in a while	Somewhat available	Available 24/7
Clear Focus	Not at all clear	Not very clear	Neutral	Somewhat clear	Very clear
Funding	Directly from LHIN	Community fundraising	Hospital	CCAC	Hospice
Teams 'Home Base'	Hospice	Hospital	CCAC	Virtual	
Additional PC Expertise	Bereavement services		Psycho-social/spiritual services		Visiting/ hospice volunteers
Geography	Rural community	Small community	Medium community	Large community	Urban community
Nurse Role	Palliative care NPs	Specialist homecare nurse	Generalist homecare nurse	Advance practice nurse	Clinical nurse consultant
24/7 Nursing Availability	Not available	Rarely available	Available every once in a while	Somewhat available	Available 24/7

Tool 3: The PEP Framework of Factors that Make Teams a Success

Description:

Although replicating everything a successful team does may often make sense, through our study we realized that some tools and processes that were essential to certain teams were unsuccessful to others. However, despite this fact, each team was able to function well and provide high quality care to their patients. This was because their model of care was relationship based, and much of the success was a result of less tangible factors relating to culture, attitude, communication, and commitment. In the end, the secret to successful teams was not due to certain tools and processes, but instead was due to the teams' passion to improve palliative care which led them to share certain behaviors, practices, and characteristics. In addition, they all had a special quality, a certain PEP (people, entrepreneurialism, purpose) that differentiated them from the less successful teams that were struggling.



PEOPLE	ENTREPRENEURIALISM	PURPOSE
Trust	Flexible/Adaptable	Shared vision/Sense of responsibility
Communication	Continual improvement	Holistic approach
Mutual respect	Seamless system navigation	Proactive
Flat hierachy		Education for health service providers

In the following activity…

In the following activity, you will have the opportunity to assess yourself and the role you play in one component of PEP. After this, it is important to share your thoughts and insights with the rest of your group so you can learn from each other and work together to improve the quality of palliative care in your region. If you want to learn more about the different components of PEP, please refer back to the change guide which will go into more detail about each.

PEP Framework Activity Instructions:

1. Choose one topic from either People, Entrepreneurialism, or Purpose, your team struggles with.
2. Complete the PEP Worksheet independently for that topic it terms of how you contribute to this issue, your role in improving this issue, and something that you can do in the next 10 days to improve this issue further.
3. Discuss your thoughts.
4. Use the PEP tool to guide your discussion.
5. Create an action plan for individuals and the team to build PEP.

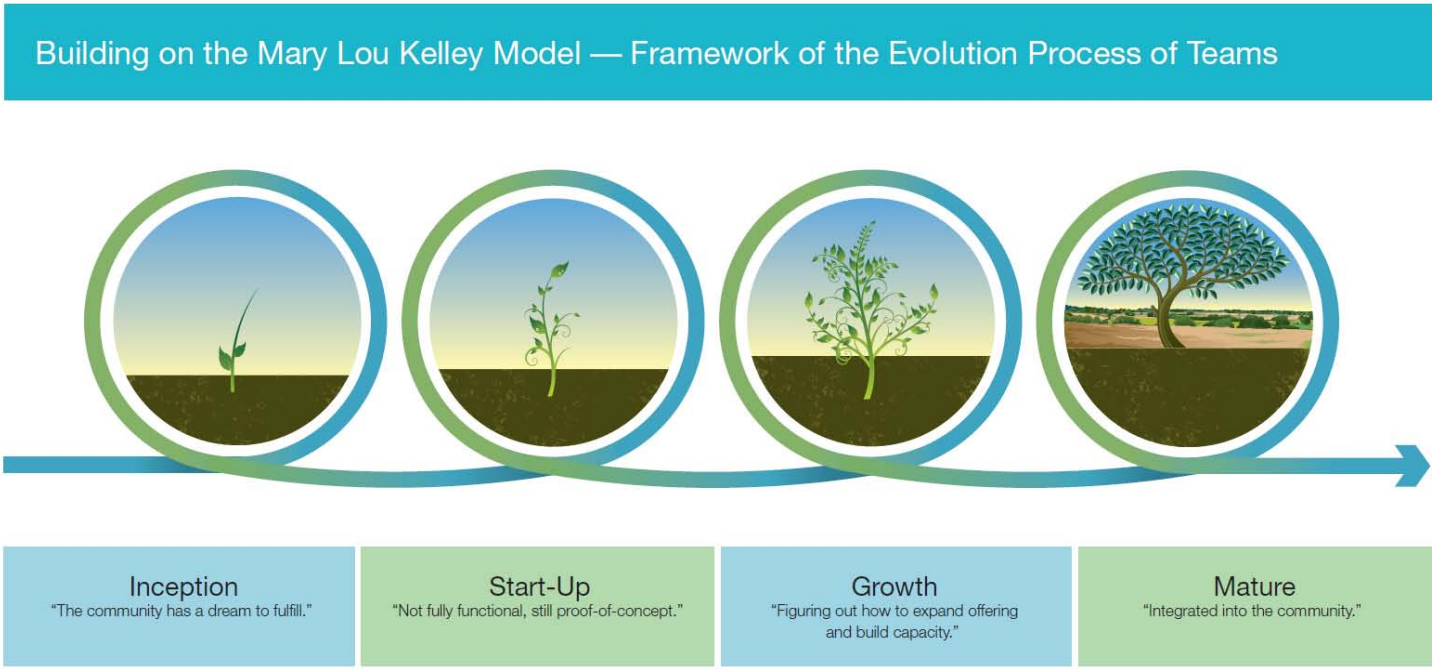
Tool 3: PEP Framework Worksheet

	What if any _____ issues do we have in our community?	What is my role in contributing to this issue?	What is my role in improving this issue?	Within 10 days from now I will do the following to improve this issue.
PEOPLE	Trust			
	Communication			
	Mutual respect			
	Flat hierarchy			
ENTREPRENEURIALISM	Flexible/adaptable			
	Continual improvement			
	Seamless system navigation			
PURPOSE	Shared vision/Sense of responsibility			
	Holistic approach			
	Proactive			
	Education for health service providers			

Tool 4: Framework of the Evolution Process of Teams and Appropriate Outcomes

Description:

As a palliative care team goes through different phases of evolution, they will encounter different opportunities and challenges that they need to overcome. This is why it is important to identify relevant goals and appropriate objectives based on where the team, and the community, is in their journey of development. This will help them to better anticipate and set expectations for how their team may evolve in the coming years. The diagram below shows a framework that was created to help teams navigate progress and identify potential milestones to aim for from team inception to maturity. However, it is important to remember that this is not a definite standard, but instead represents the framework of a growth chart to which each team can add their own trajectory and unique points.



In the following activity…

In the following activity, you will have the chance to assess the your palliative care team and determine which phase best suits you, which will allow you to learn what to expect in the future and set some realistic goals your team.

Evolution Process of Teams Activity Instructions:

1. Go through the Framework of Evolution Process tool and determine which phase most of your team is in.
2. Discuss potential milestones and measures for that phase and record them on the Evolution Process of Teams Worksheet
3. Refer to the Change Guide if you need some suggestions appropriate to your phase.
4. For each of the milestones and measures think about a timeline for action, who will be responsible for making each of these happen, and what data will be collected.

TOOL 4

Framework of the evolution process of teams and appropriate outcomes

	Inception	Start-Up
Summary Statement	"The community has a dream to fulfill."	"Not fully functional, still proof-of-concept"
What's Happening	Local champion has a vision for improving palliative care. Begins building necessary infrastructure, resources and relationships through grassroots efforts.	Founding members begin to build team and ways of collaborating. They define and market services offered to patients and providers
Key Opportunities	• Build on existing palliative care relationships/network in community • Build local intelligence for a better understanding of needs, gaps, assets and what will succeed/fail • Create foundational relationships for a strong core team	• Develop effective ways of sharing info amongst team and broader ecosystem that is not dependent on common electronic medical record • Build rapport with community providers • Build an understanding in community of the team's role and how they can support providers • Outreach to upstream partners in the community, to encourage timely referrals and collaboration
Key Challenges	• Building team and buy-in cannot be top down. Team foundation must be built on grassroots relationships, before resources can be applied • It takes time and patience to build relationships • Obtain funding or find creative ways to maximize existing funding	• Maintain flexibility as team develops and fills local gaps. • Avoid turf wars with local homecare nurses and HSPs • Manage patient caseload with limited teams members • Lack of PC-trained local home care nurses and/or physicians • Work towards providing 24/7 care • Get referrals from physicians and hospitals • Secure enough funding to sustain team through start-up
Milestones	• Complete a needs assessment: Identify existing PC infrastructure, untapped capacity, what unmet needs can be served, and how to more effectively use resources • Articulate a shared vision of team and how to connect to community • Start to build buy-in from key stakeholders and providers in the ecosystem • Determine the offering to complement what exists — not compete	• Assemble core team of essential roles, including nurses and physicians • Practice the culture of a patient-centred mission and vision during decision making and problem solving • Establish team processes such as communication tools and methods • Create open ongoing dialogue of pain points and successes
Potential Measures	**Environmental Scan** **Perceived gaps in care:** service inaccessibility, service bottlenecks and inefficiencies, communication gaps **Taking inventory:** existing infrastructure, potential alliances, and resources including expertise and funding opportunities	**Team and Program Formation** **Formative (administrative) data:** caseload, patients seen, ED visits, urgent calls, home visits, doctor visits, bereavement contacts, professional consults, triage statistics, referral sources and destinations, place of death **Tracking process progress:** Identify most responsible physician, orphaned patients connected with a doctor, patients' end- of-life preferences (including place of death) documented, advanced care planning, ongoing patient monitoring, physicians providing 24/7 care **Tracking relationship formation:** perceptions of "team" collaboration, conflict resolution, power equity, role clarity, communication

Growth	Mature
"Figuring out how to expand offering and build capacity."	"Integrated into the community."
Stable core team with established relationships works to expand reach.	Team is trusted and valued. Seen as hub for knowledge-sharing and expertise.
• Make all core and extended members feel part of the team • Build palliative care capacity among health service providers • Gain providers' trust by working side by side to support and educate them • Form partnerships with community institutions and leverage opportunities to share resources (i.e. hospice)	• Deliver seamless continuity of care between settings • Continue to build capacity of community providers • Advocate for growth of palliative care network, ecosystem, and resources in community
• Find/hire compatible team members to work in dynamic environment • Build a critical mass of providers who feel comfortable addressing palliative care needs with minimal help from the team • Do the most with a mix of full-time and part-time team members • Manage travel and serving large regions with limited headcount • Get more referrals, earlier in patient trajectory • Find additional funding and resources to support growth	• Prevent team member burnout • Manage team turnover • Maintain role clarity and integration with CCAC and other partners • Manage changes in health service provider contracts and policy changes • Maintain continual sources of funding and resources
• Team has established local role and dependable partnerships • Able to offer 24/7 care • Work towards a full suite of compatible roles (nurse, spiritual care, PC specialist, CCAC) • Serve more patients	• Successfully building community's health service provider palliative care capacity • Health service providers understand when/how to best utilize and involve team • Effective feedback loop with patients and families • Team helps strengthen entire palliative network in community
Spreading Quality to more Patients **Formal capture of patient experience:** Start to collect and assess patient and family experiences: care need being met, preferences (including place of death) recorded and met, caregiver burden, provider continuity **Adverse incidences:** urgent calls not responded to in a timely manner	**Health System Measures** **System outcomes:** Acute care use, acute care death, end-of-life emergency department use and re-admission rates, palliative care admissions to hospital deemed inappropriate (alternate level of care beds) **Remaining gaps in care:** Palliative care at patient diagnosis, length of time in team's care before death

Tool 4: Evolution Process of Teams Worksheet

Phase: _____

	What are they?	Timeline	Who's responsible?	Data collection
Milestones				
Potential measures				

Tool 5: Learning from Others

Description:

There are champions out there who can, and will, help you succeed in the quest for a high-quality palliative care system in your community. The best way to support both new and existing teams is to connect with these leaders who have lived through most of this already, and are willing to share the lessons they learned along the way. By connecting teams on the ground with established teams the best mentoring and advice can be provided in real time. And you can get off to a better start, more quickly and efficiently, without re-inventing the wheel. As a starting place, we compiled a list of frequently asked questions in building quality palliative care and collected answers from 14 leaders from established teams.

Learning from Others Activity Instructions:

1. Go through the FAQ tool and determine which issues your group is struggling with.
2. Go to the FAQ page on palliativecareinnovation.com and read through the champions' solutions to the issue(s).
3. Determine which solutions are most appropriate for your community and think about how it can be applied.
4. If you are still struggling, reach out to a champion you know or to one featured on our website.

Tool 5: Frequently Asked Questions and Solutions Worksheet

FAQ	Relevant Solutions Offered
1. How do you get a team started?	
2. How do you start without boiling the ocean?	
3. Please describe the philosophy of your team.	
4. Can you give examples of how you used existing resources differently, instead of relying on new money?	
5. How do you sustain the program in the face of shifting priorities at the LHIN and provincial level?	
6. Although the system may be broken, can you give examples about how your team makes it “work” despite system barriers?	
7. How do you promote the team in the community?	
8. How do you achieve role clarification and avoid turf wars among all organizations in hospice palliative care?	
9. When there was an elephant in the room, how did you start talking about it and resolve it?	
10. We all know that relationships, trust, and mutual respect are critical to interdisciplinary care. How do you foster these qualities?	
11. What have you learned about in terms of how to get buy-in from family physicians?	
12. When trying to improve care delivery how do you move beyond naming, blaming, and shaming?	
13. How do you know that your team is doing a good job?	
14. What things did your team do to improve care over time?	
15. What piece of advice would you give to developing teams?	

A Final Word

You have the power to implement meaningful change in palliative care. This is not easy work but the tools and worksheets we have provided will help you on this journey.

This workbook is intended as a companion to the Change Guide which explains each of the tools in further detail and how we arrived at these key lessons for developing community-based palliative care.

The Change Guide and links to Dr. Hsien Seow (seowh@mcmaster.ca) and the research team can be found at:

www.palliativecareinnovation.com

Remember… DON'T WAIT FOR:

1. For system-level indicators. The driver of change should be patient needs and quality commitments. While it will take time before the broader system as a whole is affected, you *can* start with improving care for the patients you see today
2. For the perfect model. All regions need to develop a unique team, based on their own community's resources and assets
3. For the perfect tools to deliver palliative care. Communication and relationships will always be more important than tools
4. For new resources. Use what you have, differently
5. For the perfect plan, or to know it all before getting started. You will fail before you succeed, which provides the greatest lessons of all. Teams and the broader ecosystem are constantly evolving, changing and in a state of flux. You should strive to continually improve
6. For the perfect standardized pathway. Standardization *without* recognizing individual needs would be bad quality. Instead strive for customized standardization.
7. For electronic medical records (EMRs) to be the solution for communication gaps. Technology will never replace old fashioned, face-to-face or telephone conversations
8. For the palliative care expert to arrive. We are all responsible for basic palliative care knowledge
9. For the champion to emerge. You can become a champion. Many champions are needed
10. For someone else, such as policymakers, to eliminate the barriers and make the task easy. Working through bureaucracy in order to deliver a personalized care plan is not easy. Adapting to constantly-changing circumstances is not easy. Providing good patient care is hard work — it always has been and so it will always be