*"There is no power for change greater than a community discovering what it cares about"*
*Margaret J. Wheatley*

# CONVERSATIONS WORTH HAVING

## *MANAGING COMPLEX CHANGE IN THE SPACE BETWEEN ROUTINE AND INNOVATION*

Sheli O'Connor
Dr. Marc Langlois

Sheli O'Connor has spent the last three years as an Advance Care Planning (ACP) champion with Hospice of Waterloo Region's ACP project. With three dedicated staff and funding from the Ontario Ministry of Health and Long-Term Care, the project team reached out to community and health care settings as critical sites for engagement and education. The team first established a steering committee of community leaders that represented health care providers, community professionals and the general public. The team then engaged individuals and groups across the community and health care sectors to raise awareness, build understanding and encourage ACP conversations.

With the focus on collaborative partnerships and stakeholder engagement the team then identified individuals to champion the project. These individuals included lawyers, financial planners, human resource professionals, the general public as well as providers in acute care, primary care, community and long-term care. The project was a leading edge effort in Canada. There are many other such projects across the country advancing ACP but the approach by Hospice Waterloo was unique. In addition to a distinct Developmental Evaluation and Action Research component and an attitude of trial and error, the team adopted a public health approach to reach the public, community groups, and health care professionals across multiple settings.Currently, there is a provincial discourse amongst ACP stakeholders on how to reach people where they live, work and pray as critical sites for engagement and education. The team prototyped some new ways to do this. The ACP Waterloo Story serves to share some of what the team learned.

## Choosing an ACP convener that is ready for the complexity of an engagement strategy

It's critical to think carefully when selecting organizations to convene an ACP project. Whether the role is defined as one of a backbone organization,[1] to lead a change within a single organization, and/or to help community members organize, the convener must be ready to manage the complexity that lies between routine and innovation. Ideally conveners for a complex change agenda share certain traits and experience. These include the ability to empower and engage, and to support complex change initiatives in their own organizations and often with their clients in the community.

[1] Backbone organization - a separate organization to provide some infrastructure support to projects working collectively to achieve a shared impact objective. The role is to help "plan, manage and support projects through ongoing facilitation, technology and communications support, data collection and reporting, and handling the myriad logistical and administrative details needed for the project to function smoothly (Kania & Kramer, 2011).

Not only is the hospice brand known broadly as an important and trustworthy community support, Hospice of Waterloo Region was ideally situated to house and support this community project. For the past 25 years the organization has been a community outreach focused hospice with a community-based support structure and trained volunteers with representation across all community sectors. With strong community relationships, partners and stakeholders it is respected as a community leader within the palliative care system. In the backbone role, this facilitated flexibility in how, when and what kind of engagement fit a wide variety of healthcare and community settings. In addition, access to Hospice volunteers with personal ACP experience provided information to understand ways in which volunteers can be part of a sustainable ACP strategy.

## Responsive Evaluation Is Useful Evaluation

The journey to substantive and lasting change is often circuitous. The process to innovate for impact requires ongoing learning, planning and adaptation. At every turn whether roadblocks, finding new champions, or experiencing unexpected twist the Hospice Team was called upon for new ideas and solutions. A method of evaluation and community research was required that complemented the project's complexities, fast pace and developmental nature.

Innovation in a complex situation requires that evaluation and learning be intrinsically linked, with evaluation contributing to learning and vice versa (Chevalier & Buckles, 2008). The project was supported by a team from Twelve Canada led by Dr. Marc Langlois. Design thinking processes and tools were framed within a distinct cyclical Developmental Action Research and Evaluation (DARE) methodology, and whole systems change model (Langlois, M. 2013, p. 24; p. 216).

The Developmental Evaluation DARE component focused on the Hospice Team members and what they were learning to build their capacity. The primary focus of the Action Research component carried out by the Hospice Team was to track and guide relevant activity in the project's operational environment.[1] DARE is premised on the understanding that practitioners and service beneficiaries are legitimate agents of knowledge rather than passive recipients. DARE provided timely and actionable data on both what and how the Hospice Team was doing its work, and how it might adapt to complexities as they arose.
A central principle for those employing the DARE method is to re-frame challenges with an appreciative framing. This approach meant the ACP Team was encouraged to flip it - meaning, to first identify characteristics of any given challenge and re-imagine it appreciatively in order to uncover new innovative opportunities.

{2} project's operational environment - The environment of immediate concern to a system, in this case, the system defined by the ACP project objectives.

Sheli remembers the early challenges working with faith-based groups. These groups did see their role saying "we are the safe place that people can have these conversations.... and take home to loved ones". As a result we were trying to connect and we did find faith leaders who supported the cause. However, the team soon learned the leaders' support was limited to hosting a session or providing resources to their members and associations. Rather than viewing this situation as a problem only, the Team flipped it to focus on the opportunity the supportive faith leaders represented. The Team moved forward and leveraged its connection with the ministers who then linked the team to lay ministers, and members of their faith community, who could begin work on a faith based campaign.

## ACP is not a healthcare issue - Let the Public Lead!

The central premise of the Hospice Team is that ACP is not a health care issue. If the public is not aware of this situation such an awareness is not going to happen in a hospital at a time of crisis. One hospital staff member shared this concern: "Emergency and hospital rooms crisis is a common place to have the conversation and it's the worst spot and timing."

The Hospice Team discovered a desire by the public to know more about ACP. The Team realized that once people knew about ACP they readily shared the information with others. One of the Team members shared their excitement, "I have never worked on a topic that was so positively received before. It wasn't that we had to sell this information, it was that the public just needed to know about it. We just had to get out and start talking to people."

Despite the public's interest in ACP, the healthcare system is organized so that the system, not the public, must drive an ACP movement. Asset-based community development elder John McKnight (1995) posits that, "Care can never be produced, provided, managed, organized, administered, or commoditized. Care is the only thing a system cannot produce" (p. x). As the Hospice ACP project discovered, there is reason to be concerned that the conventional healthcare change management methods may be a significant constraint to the kind of broader public engagement healthcare is trying to encourage. Maverick social critic Ivan Illich adds, "As the power of professional and service systems ascends, the legitimacy of community descends" (1976).

Unfortunately, it is an understatement to say things moved slowly in the healthcare sector for the ACP project, particularly in light of the public interest in the project. This is not surprising when one considers that the dynamics of change in healthcare are subject to deep-rooted status quo within a layered hierarchy of decision-makers of healthcare providers, policy-makers, funders and senior leaders. To create lasting change in complex systems requires a culture of innovation that values diversity, open communication, teamwork between diverse elements, and experimentation with support rather than blame (Westley, 2007).

Regardless of the necessity of cultural readiness, the project funder advised the Hospice Team to focus its' effort in Acute Care and Long Term Care, specifically in relation to policy development. This was not where the Team thought it best to start.

In the end, the hospitals where Acute Care resides, proved to be the most challenging sector within which to make any progress. Acute Care policy in and of itself is not designed to create change. It was proven on many occasions that the misunderstandings and confusion regarding ACP and healthcare consent within Actue Care were deeply entrenched. After numerous policy discussions, revisions and expert consultation the confusion about ACP remained and was particularly evident in the policy paperwork. There was a lack of both the readiness and educational opportunities necessary before beginning policy revisions.

## The challenges discovered in the project's operating environment

Central to the DARE method is to constantly clarify and characterize the operating environment the change makers must know the most about to create the desired change. The ACP Team navigated the complex landscapes of their project with daily access to tactical information from multiple points in their operating environment. They learned a great deal about some of the challenges for an ACP objective. What follows is an exploration of four of these challenges.

### Musical Chairs

Initially the majority of those they reached out to in healthcare thought that championing ACP was someone else's responsibility. As an example, Acute Care blames Home and Community Care (formerly Community Care Access Centre) which blames the family doctor. However, ACP is everyone's responsibility. One Acute Care clinician shared the following:

"It is the clinician's responsibility to stay current, they have a responsibility with their college to adhere to the standards of care and having these conversations is part of ensuring the standard of care. By not having ACP conversations they are not adhering to that standard of care."

### Education not policy breads collaboration. Policy without education breads resistance.

In order to change incorrect practice and policy that is not aligned with Ontario law, the change should start with education. There is an appetite for education whereas policy change is often met with reluctance.

> Health care relied on and felt the need for policy to guide their work. However, firmly entrenched practices in both Acute Care and long-term care were not correctly aligned with Ontario law. 'Levels of care forms' or 'physician order forms' were strongly entrenched even though the staff collaborators we the Hospice Team worked with fully recognized that there was incorrect practice/understanding associated with these documents. For those that wanted correct policy direction it was clearly an exercise in frustration, one staff likening it to "trying to find way out of a locked room in the dark without a flashlight."

### Tools don't drive change, conversations do

It is necessary to first meet with interested parties and have meaningful conversations which nurture understanding and to then provide those parties with the tools they require. Comments from members of the public such as: "what do you mean my neighbour can't decide for me,

she's been my friend my whole life" underline the importance of conversations first, tools and /or resources second. ACP is something people didn't understand. Everyone wants a quick fix. The starting point however is education which begins with conversations that engage and provide the opportunity to be more informed about the meaning and value of ACP.

### ACP language is brutal

People need simple truths about health care decision making in Ontario. They need it in non- legalistic language, presented in an interactive way. The terms Substitute Decision Maker (SDM) and the Hierarchy of Decision Makers repeatedly dominated the education sessions, requiring clarification and practical/personal examples as explanation. Public feedback on the lack of current tools available highlighted the complexity of the problem. It was further complicated by a lack of consistency in the language and the use of incorrect terms like "living wills" and "advance directives."

## Eight Principles to Guide the Design of a Successful ACP project

As a result of working with collaborating healthcare providers and community professionals, the Hospice Team created a set of principles that had emerged to guide their important strategic decisions. Any project faced with navigating a complex environment will be developmental in nature, that is, emergent, unpredictable and fast-paced. In moments of uncertainty design principles established in calmer times, can be invaluable to help decision makers adapt quickly and wisely. With structured reflections as a central part of the DARE method, the Hospice Team was able to identify the following eight principles to help them and others design and lead ACP initiatives.

- Find and Recruit Leaders to Champion ACP
- Facilitate Cross Sector Collaboration
- Break it down to manageable bites
- Expand Your Reach with System Navigators
- Keep it simple 1 - 2 - 3 - 4
- Engage the End-User
- The community is not one big organization... tailor your approach!
- Art as a medium for Advance Care Planning Conversations

### Find and Recruit Leaders to Champion ACP

In the search for footholds the Hospice Team engaged slowly yet deliberately with potential ACP champions as these champions emerged. The Team learned not to waste valuable time with a direct effort to engage decision makers who repeatedly showed no interest in ACP objectives. The Hospice Team found other ways to go around these leaders or move on to others. It is leaders who build cultures that encourage experimentation and empowerment that are invaluable champions to a change project like the Hospice ACP initiative. The Team learned to focus on those leaders ready to champion ACP who encouraged their staff and associates to engage and co-create with them. Together with these leaders, the Hospice Team co-created innovative ways to support the ACP objective. The leaders that championed ACP included a:

- Human Resource professional with a passion for community service,
- Nurse Practitioner leading in the Renal Unit of a local hospital,
- Lawyer volunteering to develop and launch a pro bono legal clinic for the vulnerable,
- Nurse in a local community health centre who worked passionately with staff to develop and champion conversations with every patient about SDM,

- Local physician who worked with the team to create a tool in the electronic health record, that made it easier for physicians to ask about and document the SDM.

These champions had three things in common: i) they were considered leaders in their setting, ii) they had credibility and authority given their professional designation, and iii) they worked on the front line to pilot and champion their ACP work, moving beyond management and administration, policy development to work alongside colleagues and patients to make change.

For two years we worked with one unit, loyally attending meeting after meeting. Acute Care staff transferred in and out of the process so the lack of progress was not surprising. Early into the third year staff changes included the addition of a passionate champion and within six months this champion led staff in surveying all patients to obtain feedback and pilot a process for ACP discussion with patients. As a Nurse Practitioner this champion did not sit and create policy but asked a set of interview questions to every patient to determine next steps. This resulted in a standardized prototype approach on that unit. Within the broader Acute Care environment this is a positive sign.

## Facilitate Cross Sector Collaboration

Key to long-term ACP outcomes is facilitating spaces where individuals with diverse perspectives and varied roles within health care and in community settings come together to co-create shared responses to the ACP cause. The work is not always easy but it is critical. Researcher Jane Cooke Lauder (2005) describes these spaces as "…not a process but noisy, complex, unwieldy and unpredictable situations where the competing interests of different parties are always present, and where the resulting tensions and ambiguities need constant attention" (p. 16). The Hospice Team provided the constant attention Lauder describes for some very effective cross sector collaborations that included: organizational ambassador training; volunteer presenters, the project steering committee, a quality improvement project, and a cross sector ACP team.

*" Being part of this.... helped us to identify and begin to realize the strength and possibilities that exist when we choose to act in genuine partnership (health care and community) around issues that are of importance to all of us on a human and professional level."*
*Member, ACP Steering Commitee,*

## Break it down to manageable bites

To manage the complexity that lies between routines and innovation the Hospice Team realized it was necessary to break the work into manageable bites that fit each context.

For the Public – It was clear during an early environmental scan of the task environment that the public audience was easily overwhelmed with the material that aligned with Ontario law and lost sight of the key components of ACP. Before moving to "how to have these conversations" the public need a stronger foundation in the law governing health care decision making. The Team worked with a local professional to create a standard Powerpoint that broke down the process into simple steps and ensure an adult learning focus with multimedia and an interactive approach.

## For Primary Care

After surveying and interviewing physicians early in the project, it was evident while ACP conversations were viewed as part of their responsibilities to their patients, there was discomfort with the topic and an assumption that it would be too time consuming. The Team moved forward by encouraging primary care practitioners to narrow their focus to working with patients to educate and identify their SDM(s). This iteration provided value to both the patient and the healthcare system. Reducing the focus to this first element of ACP resulted in much greater engagement by primary care practitioners. An additional innovation emerged with a physician creating a stamp in their electronic health records which provided space to flag and document the SDM while also facilitating physician/patient conversations about the SDM. There was also a successful prototype in a local community health centre. A process was established for engaging patients about their SDM from the time they arrived for their appointment, throughout their visit and was picked up again at their next visit.

## Expand Your Reach with System Navigators

A critical component of being a successful backbone convener is to associate and engage with those that have established relationships in the project's operating environment (Langlois, 2013, p.143). The Hospice Team found valuable ambassadors to expand the ACP message that could navigate within various community systems the Team would not have otherwise reached. The established relationships of these ambassadors provided insights into the personalities, vernacular and culture of the various systems they were each associated with. This strategy significantly expanded the reach of the project. The ambassadors included groups of: Psychogeriatric Resource Consultants, Pain and Symptom Management Consultants, and Human Resource professionals.

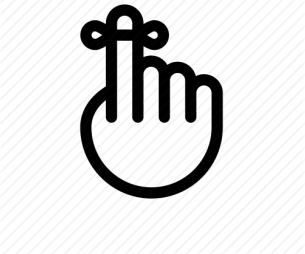
The Team also trained a group of ambassadors to work with their specific client group as part of their positions. These individuals seized opportunities within their own organizations and patient/client community to build capacity and understanding about ACP. This group included social workers with the Alzheimers society, Intensive Geriatric Service Workers, Estate Planners, Shelter staff and Housing Coordinators, Acute Care nurses and social workers to name some of the 150 + ambassadors that have been trained to date.

## Keep it simple 1-2-3-4

To grow ACP in Ontario its simply about confirming SDMs and having the correct conversations that can guide and inform SDMs and others. Amidst all the difficult language and misunderstandings of the legal process, the Hospice Team developed a simple 4 step process for the Ontario context:

1. Identify your Substitute Decision Maker
2. Clarify your wishes. What's important to you? What does the SDM need to know as a guide in the event he/she /they need to make health care decisions on your behalf
3. Have the conversations.
4. Take Action. To help the individual move from talk to ACTION the project created an SDM wallet card (aligned with Ontario law but not a legal document ) that he/she was encouraged to attach to one's health card).

**REMEMBER**



1. Identify your Substitute Decision Maker

2. Clarify your wishes

3: Have the conversations.

4: Act

## Engage the End-User

ACP is personal, it's about the individuals relationships and the need is universal. It's because it's personal that the approach needs to be community-centred. ACP resonates with everyone because everyone has a story. Every person regardless of their designated sector i.e healthcare, community or the public, has been or will be impacted by health care decision making. It would stand to reason therefore that the end user is the most expert designer for growing ACP. It's about the public - this is where the appetite, momentum and ownership must lay. These are their conversations and their choices. We need to recognize that organizations don't make change, people do.

## The community is not one big organization... tailor your approach!

Characterizing a project's operating environment as the community is not sufficiently clarified to zero in on an effective strategy. Community is made up of a large diversity of groups, organizations, associations and family units. Community is not a homogeneous unit that responds in a predictable and consistent manner. The ACP Team quickly learned to tailor their outreach and education to the unique context of each audience - groups and individuals. For instance, the language and approach necessary with the public was not necessarily the same as that used with health care.

This proved true, despite engagement and opportunities for collaboration being a constant.The individuality of each system became clear in the Team's collaborative work with community professionals. The competitive nature of the markets of lawyers, estate planners, and financial advisors made collaboration ACROSS their sectors difficult. However, these same professionals were still keen to collaborate with the Team individually. This gave the Team the added advantage of providing each collaborator a way to better serve their customers. Collaboration with the whole sector didn't work but what did was working individually or in pockets where professionals had developed trust in their working relationships.

In one instance of collaboration in a pocket within a sector, two lawyers and an estate planner (their own small mini network) partnered to create a Power of Attorney Q&A which was then distributed across their sectors. Having these champions work with us to identify any confusion and then take the initiative to design a tool, highlighted the success that is possible when you provide the education and then step aside to let the community lead in their own way. This small group created a tool that could be used by their colleagues and competitors with the ultimate goal of facilitating conversations with their clients that created clarity and correct understanding.

## Art as a medium for Advance Care Planning Conversations

Engaging the public and professionals visually and emotionally surfaced as an untapped opportunity to build understanding of ACP. By the end of the project we had distributed over 110,000 resources and provided over 420 presentations, most often employing a tailored Powerpoint presentation. At the final Hospice ACP project event the Team worked collaboratively with Hospice Wellington, and local artists to exhibit artistic interpretations of the value of ACP conversations. Using a variety of mediums, paint, sculpture, photography and videography the Team was able to reach the public differently. They would not hesitate to again explore art as a medium in a broader fashion. ACP is both personal and emotional and art reaches people on this level far more effectively than a Powerpoint. It is so important to continue look for new and alternative ways to explore ACP with each audience.

## Moving ACP from project mindset to a national campaign

The need to educate and to collaborate on ACP is ongoing. There will always be appetite in the general public for this information. As has been stated, given the law in Ontario, health care decision making requires SDMs. ACP conversations are invaluable and the public needs the education to ensure they have the right conversations. In 3 years the Hospice Waterloo Region ACP project made good strides yet barely scratched the surface educating over 11,000 people in various settings across the public, professional and health care sectors. The job is not done.

Waiting for government funding to grow ACP to the degree that it becomes second nature is a futile mindset. The ACP Team recognized that it is the public that is personally impacted by ACP and it is the public that will drive a change, not the healthcare system. The catalyst will be pressure from citizens, not healthcare providers.

In considering the next stage of ACP the team looked to successful publicly driven efforts like the seat belt campaign, Mothers Against Drunk Driving, and spouses being allowed into the delivery room. To move ACP beyond project and program mentality it will require a campaign that draws together those passionate about the cause as well as disparate provincial and sector voices as one central brain that brings forward a platform to grow ACP, not only in Ontario but across Canada. The momentum of a well executed campaign can start a movement that moves ACP organizing conversations to kitchen tables.

*"The issue is not singular, its relevant to patients, loved ones , friends and its relevant in a multidimensional way so it requires a multidimensional approach. Approaching from multiple directions leads to a more solid, sustainable change...by empowering community with information and understanding it is driving change in health care and in other parts of society"*
*(member, steering committee)*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## About the Authors

**Sheli O'Connor**

Sheli is currently developing a new role with Hospice of Waterloo Region as Director, Community Engagement and Partnerships. Prior to taking on this new role Sheli was the Program Lead for Waterloo Wellington's 3 yr Advance Care Planning Project, Conversations Worth Having. Sheli holds a Masters Degree in Social Work (Community Development) form Wilfrid Laurier University and has 30 years of experience developing programs and services for older adults. Sheli has worked with community partners across Ontario to develop programs and services and played a key in the development of the Wellington Seniors At Risk Program and the Vulnerable Seniors portfolio of Specialized Geriatric Services. Listening to the voice of the individual, engagement and collaboration across all sectors and innovation to build capacity are fundamental to her approach. Sheli brings a passion for community development and a comprehensive knowledge of the system of health and community care for older adults.

**Dr. Marc Langlois**

Dr. Marc Langlois is a leading thinker and practitioner in community development, developmental evaluation, action research, and systems change. He is widely regarded for his innovative community project designs for sustainable impact, youth and adult partnerships, experiential education, and useful evaluations. He holds a Masters of Management from McGill University and a PhD from Concordia University where he studied open systems theory, social innovation and whole system design. His extensive research focused on project design for comprehensive urban and rural community development.

## ACP Team

One of our greatest achievements was creating a strong, passionate team of partners in this project.
Our ACP team included:

**Jessica Hutchision,** BSc MA, PhD Candidate/

**Dale Gellatly**
Community Engagement Lead

**Ashley Tyrrell**, MA BPHE BSc
Health Care Engagement Lead

**Christine Bigelow**, RN, BScN, CHPCN(C)
Palliative Pain and Symptom Management Consultant and Director, NPC Consultation Services Waterloo Wellington

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