



# LESSONS FROM **CHANGING CARE**

Co-Design Events



JANUARY 2019

CHANGING  
**CARE**

## ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think-tank that works to inform positive change in Ontario's healthcare system. With a firm commitment to engaging the voices of patients, family caregivers, and health and community care providers, the Foundation explores contemporary healthcare issues through different projects and partnerships to evolve our healthcare system in Ontario and beyond. The Change Foundation was created in 1995 through an endowment from the Ontario Hospital Association and is dedicated to enhancing patient and caregiver experiences and the quality of Ontario's health care.

## ACKNOWLEDGEMENTS

The Change Foundation would like to acknowledge the four Changing CARE project teams for their hard work and dedication to improving the experiences of family caregivers in their respective communities:

- **Connecting the Dots for Caregivers:** Huron Perth Healthcare Alliance, Alzheimer's Society of Perth County, the North Perth Family Health Team, One Care Home and Community Support Services, the South West Local Health Integration Network and the STAR Family Health Team.
- **Cultivating Change:** Sinai Health System and WoodGreen Community Services.
- **Embrace:** Cornwall and District Family Support Group and the Cornwall Hospital Community Addiction and Mental Health Centre.
- **Improving CARE Together:** all sites of St. Joseph's Health Care London.

We thank the project teams for sharing what they learned when they engaged with caregivers and providers to co-design new processes of care and innovative solutions to long standing challenges.

The Foundation would also like to acknowledge the hard work and creativity offered by the many caregivers and providers who participated in the co-design events sponsored by the Changing CARE projects. As a result of those efforts, the experiences of caregivers and providers will be improved in their communities.

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## MESSAGE FROM THE PRESIDENT

**Family caregivers are the backbone of our healthcare system. Without them, in many ways, the system would crumble. So when we talk about system change, the conversation must include the caregiver voice, and the caregiver perspective.**



But what does it look like to truly include the caregiver voice, and to truly embed the caregiver voice in the healthcare system? Not to check a box. But to affect real change? While there isn't a one-size-fits-all answer to that question, The Change Foundation wants to start filling in the knowledge gap with some of the lessons our four [Changing CARE](#) teams have learned on their journeys so far.

In 2015, The Change Foundation launched its strategic plan – *Out of the Shadows and Into the Circle* – which focused on improving the caregiver experience in Ontario. But we knew we couldn't do that without listening – and I mean really listening – to caregivers, so that the system could be designed to meet their needs. And so, in 2015-16, we engaged with family caregivers, and health and community care providers, across the province through [The Caring Experience](#) initiative.

And as a “think-tank that does” we soon moved into action. In 2017, the Foundation identified four key partnerships from across Ontario to receive funding and support over the next three years to improve the caregiver experience for their individual populations. All four [Changing CARE](#) partnerships were designed with caregivers in key design and decision-making roles. The partnerships are now leaders in caregiver recognition, support and integration in the Ontario healthcare system and are changing the way healthcare organizations, providers, patients and clients, and caregivers, work together.



The Changing CARE teams are including caregivers every step of the way, making adaptations for the setting and remaining flexible and open to the spirit of co-design. For these teams, caregiver engagement isn't a checklist exercise, it's core to their being and crucial to their success.

This is the second in a series of reports that focus on learnings from the Changing CARE projects. The first report, *Lessons from Changing CARE: The Discovery Phase of Experience Based Co-Design*, presents practical, how-to tips to help guide organizations in their caregiver and provider engagement efforts. This second report will focus on what the Changing CARE projects are learning from their initial co-design events to address priority areas for improvement.

We hope that you will use and adapt what we've learned about co-design so that you can co-design solutions in your own setting. After all, our intention with Changing CARE isn't to limit better caregiver experience solely to those sites. We want to see improved caregiver and provider experience all across Ontario, and beyond. These learning reports are intended to help on that journey.

Sincerely,

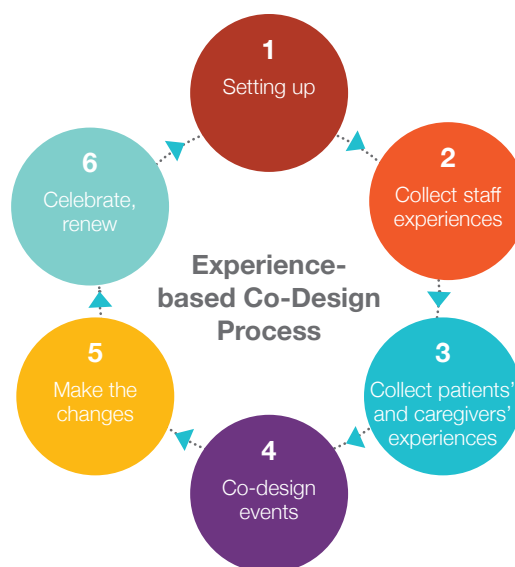
**Cathy Fooks**  
President & CEO

## INTRODUCTION

### What do we mean by “co-design”?

Co-design is a fundamental feature of the Changing CARE projects. Experience Based Co-design (EBCD) is an approach that enables staff, patients and clients, and family caregivers, to co-design services and care pathways together in partnership – “we listen to our users and then go off with them to do the designing.”<sup>1</sup> The Change Foundation brought 135 people together in March 2017 for a one-and-a-half day training session focused on giving the Changing CARE teams a common solid foundation in experience based co-design and quality improvement methods. The training also provided an opportunity to build cohesion both within and among the Changing CARE projects.

The Changing CARE projects sponsored various engagement opportunities with family caregivers and providers during the “discovery” phase of EBCD to gain a deeper understanding about their respective experiences. What they learned from caregivers and providers during the discovery phase influenced their improvement and innovation efforts moving forward. The first report in the Lessons from Changing CARE series, *The Discovery Phase of Experience Based Co-design*, presents 40 practical tips from the Changing CARE projects on planning and recruitment for engagement, engagement events and follow-up after the engagement.



This second report in the series focuses on what the Changing CARE projects are learning from their initial co-design events. Co-design events can take a variety of forms – they can be large and involve many participants talking about general themes, they can be small with a limited number of participants focusing on a specific change initiative, they can be time limited or continuous and embedded in daily project activities. The

<sup>1</sup> See [The Point of Care Foundation](http://www.healthcodesign.org.nz/index.html) for a description of the EBCD methodology. Another useful resource is a Co-Design Toolkit from New Zealand Health Service: <http://www.healthcodesign.org.nz/index.html>

Changing CARE project teams have a range of experience with co-design and will continue to co-design with caregivers and providers as they address additional improvement projects. However, it makes sense, at this point, to pause and reflect on what we have learned so far.

### Who are the Changing CARE projects and how did they approach co-design?

The following is a brief description of each of the four Changing CARE projects and a description of their co-design to date. Although each project's aim is to improve the experience of caregivers with the care system, each of the Changing CARE projects had a unique approach to co-design.



**Connecting the Dots for Caregivers** brings together six local healthcare organizations and family caregivers to create tools and resources that will help caregivers feel more supported, valued, respected and engaged in their essential role.

Project partners include the *Huron Perth Healthcare Alliance, Alzheimer's Society of Perth County, the North Perth Family Health Team, One Care Home and Community Support Services, the South West Local Health Integration Network and the STAR Family Health Team.*

Following engagement throughout Huron and Perth Counties in the summer of 2017, a group of caregivers and healthcare and community care service providers from across partner organizations came together in a co-design event to review local findings and highlight priority areas. Three streams of work were then determined: (i) awareness and recognition; (ii) communication and information; and (iii)



education, training and supports. Phased co-design teams develop change ideas within each stream of work, featuring equal participation of caregivers and providers. Each team holds a series of scheduled meetings to create and plan implementation of change ideas. For example, the Awareness and Recognition team hosted by the STAR Family Health Team (FHT) was comprised of 10 caregivers and 10 providers (five providers from the host site and five sector representatives from project partners). The team met for four hours every other week, for a series of six meetings. In conjunction with these larger teams, smaller focused co-design groups meet to work on specific change ideas that span multiple project themes – a website, for example.

This phased co-design approach was designed to identify and plan a pilot for the improvements, and also assist with the implementation, evaluation and spread of change ideas to partner organizations. Through the first stream of work, the caregiver awareness and recognition toolkit that was piloted by the host STAR FHT is now being spread across the other five partner organizations within the primary care, hospital and community care sectors.



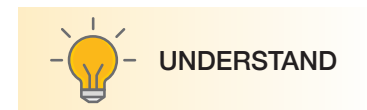
**Cultivating Change** aims to co-design, with family caregivers and providers, a caregiver-friendly hospital and community.

The project partners in Toronto – *Sinai Health System and WoodGreen Community Services* – will build a culture of care in which caregivers are partners, and where caregivers are formally identified, valued for their deep knowledge and actively listened to. The Cultivating Change team is undertaking work in four streams: Neonatal Intensive Care Unit (NICU), Stroke care, Community services, and Palliative care.

Cultivating Change’s approach to co-design is a four-step process which begins with capturing the caregiver experience,



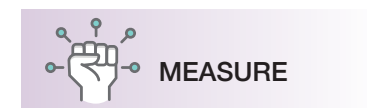
**CAPTURE**



**UNDERSTAND**



**IMPROVE**



**MEASURE**



understanding the gaps, identifying opportunities for improvement, and measuring the change. While the process varies for each stream of work, the core components of the process include brainstorming events with providers, caregivers and community partners to generate collaborative ideas for change, and prioritizing change ideas through various voting mechanisms. The brainstorming sessions comprise exercises and activities such as journey mapping, empathy mapping, caregiver speakers and videos illustrating caregiver experience. For example, for the Neonatal Intensive Care Unit (NICU) stream, the NICU Parent Advisory Group and the clinical team selected two priority projects: (i) E-Rounds to enable parent caregivers to teleconference into medical rounds, shifting their role from interested observer to primary caregiver and advocate for their child; and (ii) E-Talk to develop a series of videos to provide support and education to parent caregivers in the NICU, with topics for the videos being identified through a survey to over 400 parents on the Facebook NICU parent caregiver alumni group. Another example of co-design, a Community Caregiver Summit was sponsored by the Community Services stream with a goal to describe the ideal caregiver experience and co-create change ideas. Priority projects from the Summit include: improving access to respite care; improving accessibility, flexibility and cultural sensitivity at WoodGreen's Seniors Day Program; developing opportunities for caregivers to prioritize self-care; and developing a caregiver commitment statement that articulates the organization's commitment to caregivers.



**Embrace** aims to improve interactions between family caregivers and doctors, nurses, therapists and other providers, with a focus on caregivers of those with mental health and addiction challenges. The project partners are the *Cornwall and District Family Support Group* and the *Cornwall Hospital Community Addiction and Mental Health Centre*.

The Embrace Project spent time early on to embed caregivers in the foundation of the project. Caregivers were integral to the writing of the project proposal; they are on the project Steering Committee and the Advisory Council; a caregiver was hired as an employee to co-lead the overall project; there are caregiver co-leads on every project stream; and each project working group is comprised of caregivers and providers working together. The Embrace Project frequently brings together French

and English-speaking caregivers, rural and urban caregivers, and younger and older caregivers. Caregivers' time is recognized through nominal financial compensation to show appreciation for the time and effort to participate.

Embrace's five streams of work are: (i) family inclusion; (ii) caregiver support and training; (iii) provider support and training; (iv) young carers; and (v) sharing our story. These streams culminate to create a sixth stream – (vi) a resource hub – which is a physical and virtual space for caregivers and providers to find local information and support.



Source: The World Café/Avril Orloff

Embrace engaged local caregivers to help plan and host a co-design World Café event attended by over 100 participants – with nearly an equal number of family caregivers and health providers, including physicians. Embrace reported the summary results of its discovery phase at the World Café and introduced the streams that came out of the discovery phase. There were facilitated discussions about each theme at tables which all of the participants rotated through. This consultative process allowed caregivers and providers to express their interests, exchange ideas and identify specific needs that they felt could be addressed by Embrace. Following this initial co-design event, project stream teams were created, each co-led by a project specialist and a family caregiver. Project stream teams are comprised of caregivers and providers, all sharing in the project work. Co-design events with additional caregivers and providers are held as needed.



**Improving CARE Together** aims to improve family caregiver engagement and acknowledgement in program planning and direct clinical care at all sites of *St. Joseph's Health Care London – St. Joseph's Hospital, Parkwood Institute, Mount Hope Centre for Long Term Care, and the Southwest Centre for Forensic Mental Health Centre*. The initial

focus in the first year of the project was on rehabilitation and geriatric care. Patients, family caregivers, healthcare providers and twelve community agencies have been engaged in all phases of the project.



**DISCOVERY**

The Improving CARE Together team engaged the project partners during a half-day co-design event that included 71 participants – staff and physicians, patients and family caregivers, community partners and senior leaders. At the event, feedback from the discovery phase was themed and presented as the “top eight themes we heard.” Participants viewed a video that profiled the perspectives of four family caregivers and illustrated the eight themes. Participants then had an opportunity to discuss the themes and vote on the top three themes that they felt were the biggest priorities for changing care. Consequently, three project streams emerged: (i) caregiver involvement; (ii) caregiver education; and (iii) care transitions. Each table was facilitated by a project team member and participants at each table discussed strategies and solutions to improve the three project streams. Participants were asked to evaluate the overall event. Following the co-design event smaller working groups were formed with patients, family members and staff where the change ideas were developed collaboratively. Multiple smaller working groups were held over a four-week period to further collaborate on solution design.



**CO-DESIGN**



**IMPLEMENT**



**EVALUATE**

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The four Changing CARE projects are addressing similar themes to improve the caregiver experience. All four teams are using experience based co-design to co-create change initiatives and quality improvement innovations to address their priority streams of work. Each of the Changing CARE projects have a common approach of bringing caregivers and providers together to co-design new approaches and innovative initiatives. However, there are also differences in their co-design approach – differences in the scale of co-design teams, the composition of co-design participants, and differences in the frequency of co-design events.



# PLANNING FOR CO-DESIGN

## PLANNING FOR CO-DESIGN

The Changing CARE teams learned that there is important work to do up-front to prepare people – caregivers and providers – to work together to co-design change initiatives. It is important to establish a tone and an environment where people feel that they are an integral part of the process.

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“On this project we spend more time just talking to staff and caregivers about the things we are thinking of changing before any work begins.”

—PROJECT TEAM  
MEMBER (STAFF)

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### 1. Ensure that people within your own organization, your partners and the caregivers are well-informed about the goals of the project, well-versed on co-design and prepared to work together:

- Host a lunch and learn or other information event on-site or at partner organizations to provide information about the project, and the role of caregivers and partners. These events can generate enthusiasm and beneficial feedback for co-design planning.
- Meet with caregivers prior to group meetings so they have an opportunity to meet other caregivers, ask questions, review material, and have the tools to participate.
- Work with caregivers to help them see themselves as “experts” who bring an important perspective to the table – they are the only ones who can speak about their experience.

#### Be careful about:

- Information overload: people need information about project goals and the co-design approach; monitor the pace and mix of information sharing and discussion. The first meeting with caregivers may be to get to know each other and build trust with the project team.
- Changes in attendance: it can be hard for caregivers and providers to participate consistently given schedules and obligations. Establish some follow-up mechanisms if caregivers are not able to attend.

### 2. Think carefully about the pros and cons of hosting joint or separate orientation and planning events for caregivers and providers/staff.

- One project held separate orientation sessions for providers and caregivers, but upon reflection felt that they should have held smaller groups of providers and caregivers together for orientation and team building.
- Another project held separate orientation events for caregivers and providers and felt that it worked well – it provided a safe environment for participants to ask questions, share concerns and build a

camaraderie amongst themselves (i.e., they may not have initially felt comfortable speaking up in a forum with both caregivers and providers).

- Whether hosting joint or separate orientation and planning events for caregivers and providers, develop ‘team norms’ together so that everyone knows the rules of working together.

#### **Make sure you:**

- Clearly outline for participants the expectations, responsibilities and commitment.
- Provide a consistent meeting schedule and structure – e.g., Thursdays, bi-weekly, noon to 4 p.m. for 10 weeks.
- Circulate agendas in advance.
- Offer virtual attendance options.
- Start and end meetings on time.

### **3. Identify caregiver and provider/staff co-leads for co-design projects. Involve a broader group of caregivers and providers in co-design activities.**

- Ensure project streams/working groups include both staff with project leadership skills and caregivers. Having a caregiver and project team member co-lead the work is ideal.
- Ask interested caregivers about their preference for joining a particular project stream or working group. Also, have caregivers complete a “Skills and Interests” inventory to help match them to appropriate teams as the project evolves. This will help ensure a good match for both the caregiver and the project.
- Include a caregiver on the interview panel to identify caregiver co-design team members – this can establish early connections.
- Engage caregivers in the planning of the co-design event, including development of the agenda.
- Invite provider and caregiver co-leads to facilitate co-design meetings – this can inject an intrinsic sense of motivation to see the project through to success.

#### Practical tips:

- Develop a formal recruitment and orientation process and tools early in the process.
- Be mindful that there may be a caregiver who is motivated to participate as an avenue to advocate for other concerns or complaints about their personal experience. The caregiver could also be using the project to help them heal at a time in their journey when professional help might be more suitable.
- Give caregivers enough background information, including information that providers are well-versed on.
- Give caregivers plenty of advanced notice to support their participation in co-design events.
- Offer participants the option of writing down their thoughts if they are not comfortable speaking about them in a group setting.

#### 4. In planning the co-design, be mindful and strategic about the membership of the co-design teams – make sure there is a good mix of patients/clients, family caregivers, and providers/staff.

- Everyone should have experience and knowledge of the program or service where the change idea is being implemented.
- It is preferable that the number of participants who are patients/clients and caregivers be equal to the number of participants who are providers/staff, including senior leadership and physicians. The participation of senior leadership and physicians can be meaningful and impactful for caregivers.
- Ensure you involve caregivers that are reflective of the project geography, language, and population who have experience related to the project mandate.

#### Practical example:

At a World Café co-design event, think through whether you want the same people together as they rotate to different café tables, or whether it will be beneficial to re-configure the groups at each rotation – list the pros and cons of the two options and then decide.

**5. Take the time to train providers and caregivers so they understand key project concepts and can manage any technology being used.**

- Be prepared to explain the principles and challenges of change management. Giving concrete examples of successful and unsuccessful change initiatives in a similar context will help everyone have realistic expectations about timelines and required effort (see opposite page).
- Review the principles of quality improvement methodology such as experience based co-design (EBCD) and the Plan-Do-Study-Act (PDSA) model and invest in in-depth training with those who will be co-designing together over the course of the initiative.
- Invest the time to demonstrate and test project communication technology and software (e.g., technology and software used to send meeting requests, open attachments, etc.). People not associated with the lead organization may have different communication preferences, devices, software versions and user knowledge.

**6. Ensure the co-design event leaders and facilitators are well prepared for their role prior to the co-design event (see page 18).**

- Facilitators need to feel comfortable reminding participants of the scope of the project. Discussions can extend beyond the scope to include concerns about system challenges – it is important to acknowledge these concerns and bring the discussion back within scope.
- Facilitators need to be well prepared to facilitate the discussion and ask probing questions. Prepared facilitator notes to help guide conversations can be a useful tool, as well as a separate note-taker to document key discussion points on a template.
- Facilitators need to be prepared that some participants may monopolize the conversation with their personal story jeopardizing the opportunity to hear from others and sharing ideas on potential solutions.



Embrace uses a behavioural change framework to develop comprehensive project plans for their major change initiatives. The Cornwall Community Hospital had invested in training many of their staff in this model and extended the training to the Embrace project team. All project stream teams, which include both caregivers and providers, received the two-day training in this licensed behavioural change model. Working through the model, the project stream teams produce a strategy and action list with defined next steps. Team leads, caregivers and providers are assigned to specific tasks and meet regularly as the change initiative progresses.



Prior to hosting the co-design events, Cultivating Change held facilitator training with the purpose of educating the facilitators on the following:

- 1. Objective of the co-design event and their role as facilitators.
- 2. Objectives of each design-based thinking activity.
- 3. Intended deliverable/output for each activity.
- 4. Tips for facilitation.

Opportunities to ask questions, give feedback and practice elements of the activities were helpful for individuals. Overall, facilitator training helped the co-design events run smoothly, highlighted issues to be resolved before the events and helped build commitment and collegiality among the facilitators.



## 7. Establish realistic timelines. Co-design takes time.

- Don't assume that caregivers know and understand how complex organizations operate.
- Build in time to educate providers and caregivers on co-design methods.
- Dedicate resources to support co-design – make sure providers and caregivers have the time to participate; plan for contingencies where caregiver responsibilities may change and they are unable to participate as planned.
- Be respectful of caregivers' timelines, information needs and access to resources. For example, make sure caregivers have time to review materials well in advance of meetings to respect their timelines; make sure caregivers are kept up to date on changes and decisions taken between meetings; provide supports for caregivers who lack access to internet, printers and computers.
- Make sure your organization's leadership truly understands that good co-design takes time and staffing resources, and that they support the project by *walking the talk*.

### Practical co-design planning tips:

- Align co-design efforts to other initiatives within your organization and with your partners. This will help to optimize buy-in at all levels within your organization and to establish support from your partners.
- Encourage and help set up co-design as the methodology for other initiatives in your organization.

# CO-DESIGN EVENT



## CO-DESIGN EVENT

Co-design is a method for engagement. Co-design occurs when people are “*designed with* instead of *designed for*. Those most affected by change, have the greatest interest in designing improvements that are most meaningful to and workable for them.”<sup>2</sup> For the Changing CARE projects, the co-design event engaged with caregivers and providers to design change initiatives to address identified priorities.

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“I really appreciated the caregiver point of view. I was sad to hear about their experiences but it motivates me to do better.”

—PROVIDER

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### Practical Tips:

- Think carefully about the scheduling of the co-design event – an event in January in Ontario can be a risky call.
- Choose an accessible location and keep in mind that some people may not be accustomed to out of town travel, especially if they have been caregiving for years.
- Provide a welcoming and comfortable space. Book additional rooms for break-out sessions so participants can have more focused discussions without being distracted.
- Make sure you have access to private space where support can be provided should a participant – caregiver or provider – be emotionally triggered through participation in the event. As well, there should be private space where participants can make phone calls if necessary.
- Provide food – people appreciate receiving a meal or snacks and hot drinks.
- Make efforts to reduce power hierarchies at the event and in working groups – for example, use nametags with first name only; identify participants as a provider rather than as a manager.
- Think carefully about the length of the event and the agenda – plan for enough time for discussion but not too much time that people can’t commit to attending; consider when breaks will be necessary; think about the timing of break-out discussions and the number of participants in break-out groups.
- Remove barriers to participation – pay for organizations to backfill their staff so providers/staff can participate; establish reimbursement policies to support caregiver participation – make sure caregivers are compensated for transportation, respite or other costs (see The Change Foundation’s [Compensation Tool](#)).
- Encourage caregivers to lead activities.
- Ask participants to commit to staying for the entire event. This is important when activities build on each other throughout the event. It also demonstrates staff and leadership commitment.
- Be prepared for last minute cancellations – unexpected situations will come up for busy caregivers and providers compromising their ability to participate.

<sup>2</sup> Hilton K, Anderson A. *Institute for Healthcare Improvement Psychology of Change Framework to Advance and Sustain Improvement*. Boston: Massachusetts: IHI; 2018. (Available at [ihi.org](http://ihi.org))

**8. Provide clear information to all participants – patients and clients, caregivers, providers and other staff – about the project goals and the purpose of the co-design event.**

- Be explicit at the introduction that the co-design event is about moving forward and talking about potential solutions.
- Outline project goals at the start of each meeting to help both the facilitators and participants to stay on track and within scope.
- Prepare all participants to listen to each other, be open to others' views, and not take offence.

**9. Share caregiver stories.** Caregivers are willing to participate and share their stories – stories that can help set the tone for the co-design session and motivate everyone to make change. However, be prepared – caregiver stories may make providers feel uncomfortable, defensive, embarrassed or sad. Stories can be shared in-person or through a video presentation (see opposite page).

- Event hosts or facilitators need to be explicit in setting the stage for the sharing of stories. It is important to recognize that some of the stories may be difficult to hear, and that providers do care and are trying their best. Providers and other staff may have an emotional reaction to caregiver stories as they may see their role in the caregiver's experience – they will need support and opportunities to process the stories or it could be a potential barrier to participation in co-design.
- Allow time on the agenda for reflection and discussion about the stories shared – this is important for both caregivers and providers. However, remind everyone that this is not the time or the setting for giving advice or attempting to solve problems.

**Practical tips:**

- Coach caregivers on how to share their stories effectively.
- Coach caregivers to not identify the department or staff member when sharing their stories but rather use general terms – providers will be more open to learning from stories if they do not feel singled out or targeted.

Caregivers and their stories are the most effective ambassadors for change.

“With shock and disbelief, I have heard from caregivers, details of their journeys, each one individual, yet with similar threads of loneliness, exhaustion, grieving, feeling unheard and unrecognized, woven together in the blanket of their lives. Perhaps it is even a new life for them – one they did not ask for, nor did they see it coming. Perhaps it has been many years, and this is the first time they have spoken of these feelings. I can honestly say that what has changed in my practice is how I see caregivers. They may not see it, but I see capes and shields and swords. These people are warriors! Perhaps their hearts are bursting with love or aching with grief, or both. They may be scared or frustrated. Likely both. Caregivers deserve to be recognized and included with respect and dignity.”

– Pauline Linton, RN & Seaforth Community Hospital Team Leader,  
Huron Perth Healthcare Alliance



## 10. Create a safe and confidential environment for open sharing.

- Provide clear messaging at the start of meetings that people may feel emotional and that support is available.
- Providers and other staff may have an emotional reaction to caregiver stories as they may see their role in the caregiver's experience – they may need support and opportunities to process the stories or it could be a potential barrier to participation in co-design.
- Make sure there are strategies in place to provide support to caregivers and providers who may be emotional or experience stress during the co-design event(s).
- Plan carefully if you will be taking pictures or video of the event – not all caregivers want to be public about their role. Consider giving participants the option of identifying that they are comfortable with having their picture taken and shared, perhaps by placing a sticker on their name badge.

### Practical tips:

- Review rules of engagement at the beginning of co-design events.
- Provide on-site supports at the co-design event – consider a social worker, spiritual care worker, or peer support worker.
- Compile a list of support resources and share these with participants.
- Conduct post-meeting follow-up calls to see how people are doing.
- Provide “mindfulness” tips to counter stress that caregivers and providers may be feeling.
- Remember that many of the providers are also caregivers themselves, and their participation will fluctuate between the provider viewpoint and the caregiver viewpoint. Take the time to allow them to tell their story too.

## 11. Engage provider champions in each co-design stream/working group. Change champions must be relentless and perseverant in their belief that change is possible.

- Staff change champions who are influential with their peers are key to creating the change environment and generating enthusiasm for the change initiative.
- Co-design team leaders can be important role models for other staff.
- A close working relationship between the manager of the unit that



SOME MOMENTS  
COME WITH TRUE  
SATISFACTION



THANK  
YOU



PRESENTED BY TALENT  
A WORLD OF

# Content

## Fill In the Gaps

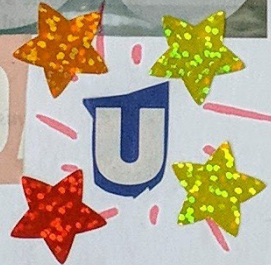
*is where the only  
thing holding you back  
is nothing at all.*

# YOU



The Broadview Hotel's rooftop bar, p. 102

# NEED YOU



### The Royal Treatment



# HEALTHY WORKPLA

## Love, Learn and Celebrate

*The Tre  
Care*

is the focus of re-design with project team members can make a big difference in successfully implementing change.

- Consistent and frequent messaging from senior organizational leaders establishes the change initiative as important to the organization.

### **12. Use innovative methods for people to express their opinions and share their experience.**

- Offer participants the option of writing down their thoughts if they are not comfortable speaking about them in a group setting.
- Consider the use of a voting technology to get input from participants (see opposite page).

### **13. At the end of the event, provide clear information about next steps, and get feedback from participants on the co-design event.**

- Leaders or facilitators should summarize follow-up action on ideas discussed.
- Provide written summaries between meetings if the co-design event is a series of meetings – be consistent across breakout groups so that those unable to attend are able to review and provide feedback and input.
- Conduct evaluations at the end of each co-design event to ensure that concerns are addressed in a timely manner and use the input to improve future events.
- Let participants know how they can stay involved in the project, or in other opportunities for engagement.
- Plan a celebration at the final co-design meeting. A celebration provides an opportunity to stop and reflect on the co-design experience. Small tokens of recognition are appreciated (e.g., gift certificates, project “swag”). Make sure the project leaders and leaders from the host site participate.

#### **Evaluations can include open-ended questions:**

- What went well?
- What didn't go so well?
- If I could change one thing for the next time, it would be...

Or, evaluations can include questions with ranked responses:

- Rate your satisfaction with how comfortable you felt to express your ideas.
- After this event, I understand the value of caregivers and providers working together.
- Rate your satisfaction with the overall format of today's event.

During the co-design session with 71 participants, the Improving Care Together team used an electronic voting system which allowed each participant to share their feedback confidentially (voting is anonymous). A series of practice questions were asked to ensure each participant was comfortable using the technology. The technology was then used to vote on priorities. Participants first looked at all eight themes and voted on the top six. These six themes were discussed in more detail at the tables. Participants used the voting technology a second time to identify the top three themes from the list of six. These three themes became the project streams and the focus of work moving forward. Participants stated that they enjoyed the voting technology as it allowed them to share their opinions anonymously. They also liked the real-time feedback – the results instantly appeared on the slide after one minute. Feedback also indicated that the technology was easy to use. Participants urged us to use this process again in the future.



## CO-DESIGN FOLLOW-UP

There are some important steps and best practice standards that should be undertaken after the co-design event or the series of co-design events.

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“Once an organization has co-designed one project, this knowledge and experience is transferable to other projects, as long as it is an expectation from the top that a true co-design approach is to be used.”

—PROJECT TEAM  
MANAGER

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### 14. Report back to all co-design participants on what will happen next. As with community engagement, this is a best practice.

- Be clear on next steps and timelines.
- Be transparent on decision-making process moving forward if the co-design event generated multiple options or diverse perspectives on project streams and change ideas.

### 15. Improve subsequent co-design events based on feedback from participants and reflections from co-design leaders and facilitators.

- Consider engaging with a mix of experienced and new participants – caregivers and providers – to help facilitate the conversation and idea generation.
- Share a concise overview of co-design work to date at the first meeting of future teams to provide a clear overview of the project and its goals.

### 16. Engage with leadership – including senior leadership of the involved organizations, as well as leadership at the unit or program where the change initiative will take place.

- Support of senior leadership can be a key contributor to successful implementation of change ideas.
- Meet with the senior leadership, including the Board of Directors if possible, to explain the value of co-design, linking this engagement methodology to the corporate strategic plan, values and operating goals.
- Engagement with the unit manager is critical to the success of change initiatives.

#### Practical tips:

- Ensure that the project lead is given enough time and resources to manage the project properly and is able to revise the plan according to the needs of the change.
- Prepare targeted communication with teams involved in the project – for specific units, for the Board, etc.
- Work with partner organizations to establish a timeline for post-pilot measurement – i.e., consider staff workload, other surveys currently in the field, etc.
- When working with caregivers, let them know that it is acceptable to take time away from project work when their caregiving duties are too much or the work is overwhelming.

special relationship hinges on personality and mutual interests

With compassion



Carers  
Community Services Providers  
Family  
Friends  
Favorite Moment



ONE STOP SERVICE

the possibilities of transforming hardship into hope and discovering the rewards and unexpected gifts of caregiving.

Make Advocating Easier



Resource

NAVIGATOR COORDINATOR

COLLABORATIVE

UNDERSTOOD

CONNECT WITH YOUR FAMILY

Plan for Their Future

- ✓ Saves time
- ✓ Helps with logistics of caregiving
- ✓ Increases your feelings of being effective
- ✓ Reduces stress

"Have patience. All things are difficult before they become easy."

— SAADI, PERSIAN POET



Get Respite Care

Connect to Key Resources and Services

— OMAR HAYAM

Flexibility

LISTEN

YOU CAN EVEN GET HELP FOR SIBLINGS OF SPECIAL-NEEDS KIDS SO THEY DON'T FEEL LEFT IN THE SHADOWS.

SUPPORT

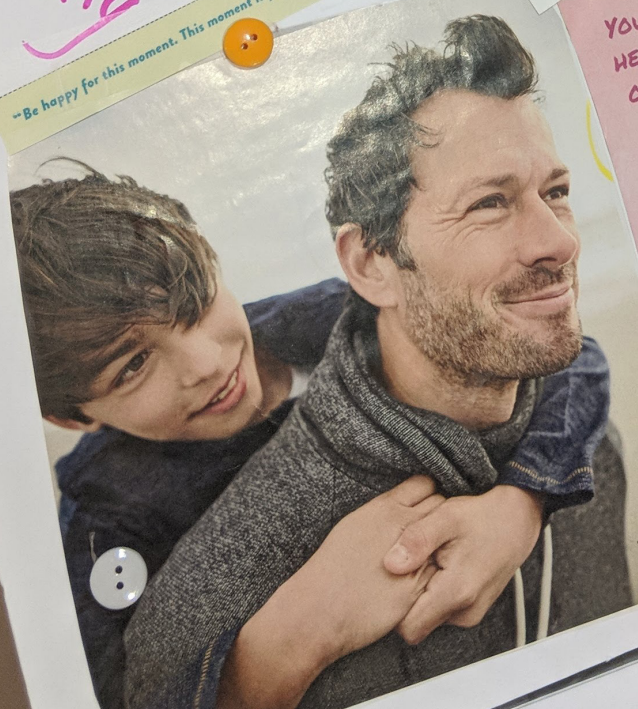
Recognition COMMUNICATION

transparency

EDUCATION

AS FRUSTRATING, CHALLENGING, EVEN UNFORGIVING AS CAREGIVING SOMETIMES IS, IT CAN BE JUST AS JOYOUS, INSIGHT-PRODUCING AND REWARDING.

hope & change



GUESS WHAT? YOU ARE DOING ENOUGH

Family

CARGO P  
GUARANTEED TO HOLD MA  
A FINGER, A SPIDER, A TO  
THE FORMULA THAT

## NOTABLE SURPRISES

The Changing CARE teams noted that there were a number of surprises – unintended consequences or unexpected opportunities – that emerged from their co-design planning and implementation.



### Cultivating Change:

- Caregiver partners from the palliative care project stream stated that their participation has contributed to their own healing related to grief and bereavement.
- Caregivers in all project streams have been incredibly motivated to participate and contribute to the Cultivating Change projects.
- The widespread attention that the project has received has led to other groups in the organization approaching the Cultivating Change team to collaborate and consult on lessons learned.
- Staff participation in the brainstorming sessions encouraged staff leading other projects to adopt co-design methods.
- Providers have stepped up as change champions in their own teams.

“As a younger caregiver, this journey was a difficult process as none of my friends had ever experienced anything similar. Being involved with this project has helped with my healing process, knowing that so many people are working towards improving the caregiver experience.” – CAREGIVER



### Connecting the Dots:

- Caregivers have started to connect with each other and provide support outside of co-design meetings.
- The co-design approach has fostered leadership among providers and caregivers, many of whom have stepped forward as ambassadors for the project.
- The co-design approach has led to innovative solutions and change ideas.
- Co-design activities have led to more awareness of the number of caregivers within the community, and the significant number of providers who are caregivers in their personal life.
- Relationships and active support are more evident in meetings between providers and caregivers.

“Connecting the Dots has been very therapeutic for me. It has allowed me to share my story and to listen to the stories of others. It did not take long for me to realize that I am not alone in my caregiving journey. There were so many common threads in the stories I heard... confirming for me the need for more support for caregivers, the true value of good listening skills and the power of human interaction.” – CAREGIVER



### Embrace:

- Project members were pleasantly surprised by how involved some of the caregivers want to be, and the high level of provider engagement.
- It became clear that there are huge opportunities for other organizational projects to be co-designed. For example, efforts to improve patient discharge across the organization could benefit from co-design with patients and their families.
- Team members were surprised how the challenge of resistance to change brought them down one day but motivated them the next day.
- Their experience with co-design on this project helped them in writing proposals for funding for other projects and was a factor in their success with these proposals. They can leverage their experience with co-design and now set up and start co-design projects quickly.

“We have all learned the beauty and magic of creativity and that all of us have it in different ways and all those ways are necessary to the team.” – UNIT TEAM LEAD



### Improving Care Together:

- Unexpected opportunities emerged from the co-design event – caregivers who attended have become more engaged as a result and have continued to be involved in the project.
- The co-design event really brought everyone together and fostered a sense of community.
- Staff members who participated in the co-design session are now stepping forward as key site champions to help facilitate the changes at the frontline.
- Following the co-design event, staff members are now reaching out to the project team to learn more about engaging family members in their work and also asking the team to assist with participant recruitment for future quality improvement initiatives.

“The co-design event was wonderful. We had the ability to have a great dialogue between staff, patients and caregivers. This was so meaningful.” – PROVIDER

“I felt very comfortable sharing my story and being a part of this group. I enjoyed the day immensely.” – CAREGIVER

## TOP TEN TAKE-AWAYS

Co-design can take many forms. The Changing CARE teams – Connecting the Dots, Cultivating Change, Embrace, and Improving Care Together – offer the following “top take-away” learnings about their experience with co-design to date:

1



Never underestimate the skills, knowledge and capacity of **caregivers to be effective ambassadors for positive change** and to be leaders in organizational initiatives.

2



**Start the discussion about change and co-design as early as possible.** Prepare those that will be the focus of the change idea as far ahead as possible and keep the conversation going during and after implementation.

3



Ensure **senior leadership support** throughout the co-design process. Engage senior leadership early on then regularly throughout the co-design process; invite senior leadership to participate in project events; and identify one specific senior leader who can be a high-level champion.

4



Develop a **shared understanding of project outcomes.** Help caregivers to understand how complex change in health care can be and the importance of clearly defining a realistic project outcome. Help providers understand that spending time up front to define project outcomes will lead to better project outcomes.

5



**Partner with a caregiver co-lead** – their leadership role sends a strong message to the rest of the project participants and to organizational leadership.

6



**Build trust with caregivers and providers** by:

- considering individual experiences when building co-design teams;
- providing a safe environment for sharing;
- paying attention to effective team building;
- acting on ideas in a timely way;
- recognizing the team for their work; and
- fostering personal connections.



7



**Profile multiple voices and perspectives** at your co-design event – a range of caregivers and providers. For example, a thoughtful video can be impactful for all participants and will foster collaboration.

8



**Tailor supports to meet the unique needs of individual caregivers who want to participate in co-design.** Caregivers will have different skills and experience, fluctuating availability (in response to their caregiving demands), varying access to resources (e.g., internet, printers, computers, electronic calendars, etc.), and a range of health literacy, English proficiency and digital literacy. Be responsive to these differences.

9



**Experience with co-design can be transferable** from one initiative or project to other initiatives, especially if there is an expectation from the top that an authentic co-design approach is to be used. Build on and improve the co-design process as you gain experience.

10



**Co-designing with caregivers and providers is not necessarily easy but it is rewarding and meaningful.** Don't be intimidated. Be flexible, creative and open to listening to others.



THE **CHANGE**  
FOUNDATION  
ENGAGE, EXPLORE, EVOLVE

#### **CONTACT US**

The Change Foundation  
200 Front Street West  
Suite 2501  
Toronto, ON M5V 3M1

Phone: 416-205-1579

[www.changefoundation.ca](http://www.changefoundation.ca)