Dementia Care Innovation in the Region of Peel

The Compassion Revolution Series: Article 1

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The first article in this series focuses on the Region of Peel’s bold decision to pilot and implement a groundbreaking approach for dealing with people living with dementia. This model of care has proven effective at dramatically enhancing residents’ quality of life and wellbeing, their family’s satisfaction and involvement, as well as employee engagement, fulfillment and retention, all while reducing the number of incidents, and creating more positive relationships all around.

Key information for this piece comes from an interview with Mary Connell, Project Manager for the Butterfly Initiative Implementation at the Region of Peel, pictured here.

In the series, we will look at the methodology used by these innovative organizations leveraging the 4D Process – Define, Discover, Design and Do, created by IRC’s Brenda Barker Scott. But first, a look at why today’s organizations are transforming service delivery, and the increasing role that Emotional Intelligence (EQ) and Spiritual Intelligence (SQ) play in design and implementation.

**Context and Impact**

Nowadays, many public and not for profit organizations are radically transforming their service delivery models to better support vulnerable and at risk populations such as: injured workers, autistic children, people with disabilities, refugees, victims of violence, homeless people, the physically or mentally ill, those recovering from trauma, grief, war experience, etc.

Maclean’s Magazine July 2019 edition, entitled ‘Join the Compassion Revolution (or we are all doomed)’ strongly articulates the argument stating: “The urgent call for compassion is the last gap remedy for systems on the brink: politics, health care, civil society, the planet itself.”

New Zealand Prime Minister Jacinda Arden graces the cover, hugging a victim of the recent Mosque attacks in Christchurch. “She took swift action following the tragedy, not only offering

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support and assistance, but passing legislation to ban most semi-automatic weapons from the country, echoing her call for ‘kindness over fear’ from her UN address last fall.”

Meanwhile, private sector organizations are enthusiastically embracing Corporate Social Responsibility (CSR) defined as: “Voluntary activities undertaken by a company to operate in an economic, social and environmentally sustainable manner. Typically, involvement falls into 3 main categories: philanthropy, ethical labour practices, and sustainable environmental practices.”4 In other words, corporations seek to positively contribute to the communities they serve, not only financially, but in kind.

For instance, WestJet encourages its employees to suggest worthwhile community projects which, if selected, are funded by the organization and led by employees. As a result, WestJet maximizes community presence in a locally relevant manner, enhancing employee engagement, providing leadership opportunities, and multiplying partnerships with various stakeholders. A good example is the 2015 12,000 Holiday miracles initiative, where employees chose and executed community specific projects in 24 hrs. Watch the heartwarming video: it says it all!5

This rapidly growing trend is based on 3 core pillars:

1. **Stewardship:** Acting for the greater good of those under one’s care. It’s about ‘choosing service over self-interest’ as Peter Block affirms in his famous book6 entitled *Stewardship.?*

2. **Client Focus:** Optimizing the client experience for maximum value through practices like: fast tracking service access and multiplying service delivery methods. For instance, Alberta Health Services (AHS) developed an Emergency Wait Time App that enables patients to select a hospital, register online, and map the best route to get there.

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3 Ibid
Here’s a video featuring early days inception: a true game changer!8

3. **Systems Thinking & Action**: Encompassing the whole system including configuration, dynamics and components, in order to enhance its synergy, connectivity, performance and sustainability. For instance in 2017, the UK launched a [National Campaign to end Loneliness](https://www.campaigntoendloneliness.org/about-the-campaign/) based on the following:

Principle: “People of all ages need connections that matter.

Data: There are 9 million lonely citizens in the UK, and 4 million of them are older people who find constant loneliness hardest to overcome...

Goals: The campaign is designed to produce the following outcomes:

- People most at risk of loneliness are reached and supported
- Services and activities are more effective at addressing loneliness
- A wider range of loneliness services and activities are developed”.9 Here’s a touching video involving surprising ‘experts’.10

These fundamental shifts stem from the realization that more than organizational efficiency & effectiveness is required to deliver positive client experiences, in order to mobilize the level of engagement and motivation required for sustainable transformation. When dealing with vulnerable and at risk populations, caring must come first. As the adage goes: ‘People don’t care how much you know, until they know how much you care.’

**The Rise of EQ & SQ**

This has resulted in increased emphasis on service delivery models driven by EQ/SQ. To clarify context, here’s a brief summary of the various forms of intelligence:11

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• *Intellectual Intelligence (IQ)*, identified in 1912, deals with the ability to: reason, analyze, think abstractly, comprehend, visualize, use language. It speaks to the MIND.

• *Emotional Intelligence (EQ)*, discovered in 1964, deals with: self-awareness, empathy, social sensitivity, relating to others and forming productive and positive relationships. It speaks to the HEART.

• *Spiritual Intelligence (SQ)*, isolated in 1997, deals with: the drive for meaning & purpose and our connection to the infinite, as well as the moral compass: ethics, values, principles which guide and inform decision making. It speaks to SPIRIT.¹²

Basically, vulnerable and at risk clients must feel that service providers are, not only connected to a meaningful purpose (SQ), but “truly care about them as individuals (EQ): acting for their greater good, and ensuring their well-being.”¹³

In the face of challenges, being treated like a number and an inconvenience, or patronized and belittled, will only add to an already heavy burden…When people are suffering, feeling comes first, then thinking, and finally taking action to deal with the issue at hand as pictured in the summary graphic here.¹⁴

**Dementia Care Innovation in the Region of Peel**

**Organizational Overview**

The Region of Peel serves 1.4 million residents and approximately 173,000 businesses in Brampton, Caledon and Mississauga. Since 1974, the Region has been delivering a wide range of programs and services to enhance our community. This includes paramedic services, health programs, long-term care & senior services, child care support, garbage collection & recycling, water & its treatment, road maintenance, financial help, housing and shelter.¹⁵

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CAO, David Szwarc, leader of the strategic plan design and implementation, sought to anchor this blueprint for the future to a sound, inclusive, compassionate vision and mission:

- The 20-year vision for the region is *Community for Life*: ‘creating a place where everyone enjoys a sense of belonging and has access to the services and opportunities needed to thrive in each stage of their lives.’
- The mission: ‘working together to create a healthy, safe and connected community’ is achieved by focusing on three key areas:
  1. **LIVING**: People’s lives are improved in their time of need
  2. **THRIVING**: Communities are integrated, safe and complete
  3. **LEADING**: Government is future-oriented and accountable.

**Process Overview: The 4D**

The 4D\(^{18}\) is an action learning process invented by my Queen’s IRC colleague Brenda Barker Scott. Simple, sound and powerful, it provides a methodology for systems transformation and will be used throughout the series:

![4D Process Diagram](image)

**DEFINE: Scoping the issue**

Dementia is fast becoming the epidemic of our time. Here are some facts & stats:

- **Cure**: “At this point in time, there is no cure and no treatment that will slow down its progression. But there are drug treatments that may temporarily improve symptoms.”\(^{19}\)

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\(^{17}\) Ibid.

\(^{18}\) Barker Scott, B. (2011). Designing organizations from the inside out. Queen’s IRC. Retrieved June 14, 2019 from [https://irc.queensu.ca/articles/designing-organizations-inside-out](https://irc.queensu.ca/articles/designing-organizations-inside-out)

- **Worldwide:** “Approximately 47.5 million people worldwide are living with the condition, a number that set to triple by 2050”\(^{20}\)
- **In Canada:** “The number of Canadians with dementia is rising sharply. As of today, there are over half a million Canadians living with dementia - plus about 25,000 new cases diagnosed every year. By 2031, that number is expected to rise to 937,000, an increase of 66%. Canada needs a National Dementia Strategy…now.”\(^{21}\)

The Peel Region LIVING Focus Area is about improving people’s lives in time of need. There is no greater time of need than when people are losing their memories and are struggling to express their needs.

**DISCOVER: Exploring the issue and Stakeholder Needs**

In 2015, Nancy Polsinelli, Commissioner of Health Services, took stock of the situation, sensing that the approach used was overly clinical and institutional. Inspection results were satisfactory, but she thought patients were being emotionally let down. The model of care was too passive, (lacking patient engagement and involvement), too rigid (focused on routine tasks), too limited (lacking variety and choice), and uninspiring (lacking life force and joy).

Keeping in mind the Peel Region’s desired outcome: *Residents in our Long Term Care homes receive care to enhance their quality of life*, Nancy hired a researcher to investigate advanced and innovative strategies, better adapted to dementia patients’ needs.

This led to the identification of a successful UK model: *The Butterfly Project*, brainchild of Dr. David Sheard,\(^{22}\) (pictured here with a resident.) Nancy heard him speak at a conference in 2016, and became convinced the Butterfly Project approach was the way to go.

She retained him to conduct an audit about the current state and the results confirmed her assessment of the

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situation. “Dr. Sheard declared the facility empty of kindness, laughter or any semblance of hominess.”

In 2017, the Region contracted his organization to develop an implementation strategy for the Peel Region. The philosophy was: “Let people live, before they die. It had the potential to be so transformative that Peel’s long-term care leaders spoke about the possibilities with tears in their eyes.” Mary Connell became the project manager in March 2017.

Watch this video featuring Toronto Star Reporter Moira Welsh, contrasting differences between a traditional approach and the Butterfly project.

**DESIGN: crafting or adapting a solution that will meet stakeholders’ needs**

Believing that “creating a family atmosphere and sharing closeness matters in dementia care,” Dr. Sheard designed a radically different dementia care system, based on the following shifts:

<table>
<thead>
<tr>
<th>FROM</th>
<th>TO</th>
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<tbody>
<tr>
<td>Over emphasizing physical care…</td>
<td>Prioritizing emotional care</td>
</tr>
<tr>
<td>Providing sterile, clinical, hotel environments called units…</td>
<td>Creating busy, filled up, engaging places that feel like home</td>
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<tr>
<td>Running a home for people…</td>
<td>Involving people in the running of their own home</td>
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<tr>
<td>Emphasizing separateness in how a building and employees look …</td>
<td>Appearing more informal, best friends, and family like</td>
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<tr>
<td>Focusing on task orientation…</td>
<td>Being comfortable with a relaxed, freed up atmosphere</td>
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<tr>
<td>Purchasing training on dementia care awareness about ‘others’…</td>
<td>Developing learning about being person centred in ourselves</td>
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<tr>
<td>Doing detached management to…</td>
<td>Being an attached leader</td>
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24 Ibid.


“These shifts are significant and whilst the concepts of family, closeness and mattering may be simple, the achievement of these shifts in a care home culture and environment are complex.”

This meant a profoundly different type of relationship between staff and patients. Employees were in favour of this approach, believing that they could do much more to raise the bar...Here’s a poignant video that summarizes the approach.

**DO: Piloting solution, learning from pilot, implementing across the system**

Once the Peel Regional Council approved the Butterfly program in late March 2017, the pilot began:

1. **Intensive Employee Training**: focused on emotional intelligence (EQ): the ability to understand another person’s feelings and respond with empathy and compassion. An experiential approach featuring various scenarios was used, asking employees to put themselves in the residents’ shoes. This helped staff relate to their anxiety and fears. The process also included coaching, leadership development and role modeling.

2. **Massive Décor Makeover**: designed to transform the institutional look into a home like one. This included bright colour painting, as people living with dementia have trouble discerning soft colours. Bright colours also help residents with spatial orientation, facilitating room differentiation, while an *all beige approach* adds to confusion. Murals were added to bring the outside in, as well as homey props added like clothes lines, flowers, etc.

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29 Photos in this section are from the Butterfly Project Pilot Project - courtesy of the Region of Peel.
Décor was adapted to what was popular in the 50s & 60s when residents were young. Whenever possible, employees get a photo of the front door of residents’ last home. It is then turned into wallpaper, affixed to the resident’s room door. This enables recognition and a sense of home. “If you live in a sterile environment, it will kill your soul,” says Dr. Sheard.30

3. **Resident Engagement Strategy:** aimed doing things with residents instead of to them. This means involvement in activities like: meal preparation, laundry, games, puzzles, music, crafts, gardening… It is also about creating a comforting environment through interacting with pets. A home dog comes every day, and through a connection with pet therapy programs, other dogs visit regularly. In addition, there are also teddy bears and dolls to hug… Moreover, tactile activities such as hand massages, hand holding, hugging etc. ensure that residents are not deprived of human contact.

4. **Family Atmosphere:** Four months into the experiment, family style eating was introduced. Instead of residents being served set meals, large platters are placed on the table containing vegetables, meat, salads, desserts etc. and residents can select what they want. There’s also a mini-fridge in the dining room, stocked with milk for tea, bread, butter and marmalade. It’s self-serve, any time of day.

This approach has many benefits: increase choice, reduce food waste, and curb unintended weight loss. It’s about emotional connections through conversation laughing, jokes, games, special moments.

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With time, things are trending up:
  - Aggressive behaviour is down
  - Residents seem calmer, happier and less anxious
  - Residents’ relatives and friends are making more frequent visits to their loved ones and interact with each other
  - There is less staff turnover and a greater sense of fulfillment and freedom. “Kenroy, [a care worker] never wants to go back to the old, detached ways. ‘Now, we get to talk to people,’ he says, ‘we get to know them and understand who they are. They’re not just here in a chair, getting medicine and sleeping.’”

Results

There’s only a year of data so far, but Peel Region says staff sick days are down, fewer residents are falling, antipsychotic drug use is lower and social engagement is higher, all of which create cost savings for homes and the health care system...

Peel Council voted unanimously to keep funding the Butterfly project. Councillors voted to add the program to one dementia unit in Peel’s four other nursing homes. And they approved a motion that requires Peel staff take the unusual step of becoming advocates for change, leading the charge to get emotion-centred care picked up in nursing homes across Ontario.

The counsellors’ vote of confidence is an invitation to lead and implement social innovation to make society work better… for more people, enhancing society’s ability to act positively and constructively.

Conclusion

The Butterfly project has been an experiment in hope, and a courageous initiative that brought about real system transformation: a win/win for people living with dementia & their families, employees & managers, elected officials & the entire organization. It’s not only about institutional efficiency and effectiveness, and ‘running a tight ship’, but about helping other human beings with a caring heart, and making them feel more alive.

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31 Ibid.
32 Ibid.
Dr Maya Angelou, one of the great voices of American contemporary literature, states: “I’ve learnt that people will forget what you said, people will forget what you did, but people will never forget how you make them feel”.

The *Feelings Matter Most* model of dementia care and its Butterfly Approach are all about returning care homes back to the real *essence of care*.33

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References


