

The History of the By Us For Us Guides

The By Us For Us guides were founded by Brenda Hounam, who was diagnosed with dementia at the age of 53. After her diagnosis, it took her some time until she was ready to seek out information about dementia and what it would mean to her life.

Unfortunately, the information that she was able to find was geared towards family care partners. Very little, if anything, was developed for people living with dementia. Brenda realized there was a clear gap in support for people living with dementia. This realization, along with her son's suggestion that she should write a book, made her think about what could be done to address this gap.

In 2004, at a public speaking event in St. Thomas, Ontario, Brenda met another individual living with dementia. This individual reached out and asked if there was a project they could work on together. This simple question changed Brenda's life, and inspired her to share her idea of putting together guides for people living with dementia. These guides would focus on their experiences and share their voices.

Brenda knew they needed to get more people's experience and knowledge. She gathered individuals she knew would be interested, including people she provided peer support to or had met through the first 'A Changing Melody' conference in 2004. The early By Us For Us project team members also approached Brenda's local Alzheimer's Society to see if they could speak at the peer support group and see if any group members would like to help with the project, either by sharing their experiences or by providing input into the guide's development.

From there, a small group of friends with lived experience formed, meeting primarily at each other's houses, with many others contributing where they could - whether by attending a few meetings, providing indirect input to Brenda through mutual friends, or working endlessly in their free time with Brenda. The complexity of this process to compile the information and write the guide spoke to the dedication of all those involved.

The individuals that helped develop the original By Us For Us guides recognized that people living with dementia not only understood the experience of living with dementia, but also had other life experiences and skills that they brought to the group. In other words, their "lived

experience” included all aspects of their life, not just their dementia. This meant that everyone involved had important contributions they could make to all aspects of the guides, including the content, the layout, and the graphics. Based on their expertise, they chose the topic of the first guide to focus on memory exercises, as memory loss is typically the first topic discussed when individuals are diagnosed with dementia. The combination of dementia and life expertise, along with everyone’s willingness to contribute their knowledge, was vital to developing the guides.

From the beginning, they discussed the importance of being inclusive. All individuals who wished to contribute were listened to. Although several individuals who participated in the development of the guides have wished to remain anonymous, it is important to note the individuals who participated represented a variety of backgrounds. Including diverse voices was important to the people living with dementia who developed the guides.

Near the end of the development of the first guide in 2006, “Memory Workout”, Brenda approached the Murray Alzheimer Research and Education Program (MAREP) for an endorsement of the guide. Beyond Brenda’s expectations, MAREP immediately offered to help with printing and marketing the guide and a partnership was formed. What stood out to Brenda was MAREP’s former Director, Sherry Dupuis, and her willingness to partner on a project brought forth by someone else and how quickly she understood the value of the guides. MAREP’s former Associate Director, Lisa Loiselle, also quickly became involved, becoming a key person supporting the development of several guides in the series since 2006.

Both Sherry and Lisa supported an authentic partnership process between guide contributors and MAREP. The first five guides were launched at the annual ‘A Changing Melody’ forums from 2006 to 2008:

- Memory Workout, 2006
- Enhancing Communication, 2007
- Managing Triggers, 2007
- Enhancing Wellness, 2008
- Tips and Strategies, 2008

The authentic partnership with MAREP has continued since that time, allowing the guides to reach their current international recognition. There are now three series of By Us For Us guides:

1. A series for people living with dementia;
2. A series for people living with dementia and family and friend care partners;
3. A series for family and friend care partners.

From the beginning, the way the guides were created was unique, highlighting the voices of people living with dementia and acknowledging the important contributions they could make in supporting others. People living with dementia and/or their care partners were actively

included in all aspects of the development of the guides, including identifying the topics, planning how to gather needed information, gathering information from other people living with dementia and/or care partners, deciding on how the information should be included in the guides, and so forth. This work was far ahead of its time.

As new By Us For Us guides are developed, it is important to celebrate and honour the foundational work by the many people living with dementia who contributed to the original guides and established the framework for their development.