

COMMUNITY DEMENTIA CARE

A Guide to Viewing: *Advocating for Hilda*

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- The short film, *Advocating for Hilda*, reflects the emotional and complex nature of home-based dementia care.
- Talking about dementia care relationships can be emotional and complex but is well worth the challenge. Relationships do matter for people living with dementia as well as for their family/friend caregivers (herein called care partners), and working together as advocates for those who we care about is vital to their and to our health and wellness.
- By watching, reflecting on, and talking about this short film, it is hoped that all viewers will develop healthy relationships with and among their groups thereby promoting optimal home-based dementia care.
- This guide* provides important information and viewing tips designed to both enrich the viewing experience and the post viewing discussions regarding advocacy for people living with dementia.

How was *Advocating for Hilda* developed?

Based on a Canadian Institute of Health Research (CIHR, Grant no. R2474A12) funded qualitative research study led by Dr. Catherine Ward-Griffin and her research team from Western University in London, Canada, this 22 minute film examines relationships in home-based dementia care. As part of the study on which the film is based, investigators spoke to people living with dementia, their families and their home care providers. The stories the people provided about how they make dementia care decisions, manage dementia care resources, and evaluate dementia care practices were incorporated into the film's script. The characters in the film do not depict specific real-life persons or real-life situations; rather, the story plotlines were scripted to reflect the complex interplay of decision-making and care management that all of the persons in the research study experienced.

What is the *Advocating for Hilda* about?

Advocating for Hilda has two main plotlines. The first plotline deals with Hilda, a widow in her 80s, who has been diagnosed with an Alzheimer's-related dementia. Hilda is able to live alone at home with some home care assistance and with the support of her two children, Mike and Laura. The film begins with a personal support worker named Stephanie who visits with and cares for Hilda. Soon, Hilda's children come by for a visit, and viewers begin to get a sense of how different characters advocate for home-based dementia care. In the second plotline, Hilda's son and daughter meet with Betty, a friend, who shares with them her own story of advocating for her parents.

The complexity of advocating for oneself and for a family member living with dementia becomes evident by the end of the film. Unanswered questions and difficult choices create a sense of uncertainty. While the film is not 'educational' in the sense that it provides one-size-fits-all solutions/answers to home-based dementia care, it conveys the complexities of dementia care relationships among care partners and between care partners and the community-based dementia care system.

The learning objectives for viewers of *Advocating for Hilda* are to:

1. Reflect on and exchange with other's personal knowledge and experience of caring for someone living with dementia;
2. Consider what advocacy for home-based dementia care might look like in one's own context.

Who should watch *Advocating for Hilda*?

The film was developed with three target audiences in mind:

- Dementia care partners
- Dementia healthcare providers
- Healthcare educators

Notably absent from the list of target audiences are people living with dementia. We support inclusion, dignity and respect of persons living with dementia. However, some of the complex issues discussed in the film and the language used may be beyond the cognitive skills and understanding of those living with dementia. The challenges related to

understanding are particularly pronounced for those who are in the moderate to advanced clinical stages of their journey with dementia. In addition, we suggest that the film is best suited for family members and care partners who are more experienced in their caregiving journey.

It is our intention that small groups of people from one or more of the previously suggested target audiences watch and then together discuss issues presented in *Advocating for Hilda*. We recognize that the film is densely packed and includes many issues and concerns associated with home-based dementia care. We also recognize that some issues will resonate more with some viewers than others. It is possible that some of the issues presented in the film will not match the experiences of some viewers, who, in turn, may feel frustrated and/or have additional questions.

It is our belief that open and honest dialogue about what did and what did not resonate for viewers will help to build relationships among care providers as well as foster care provider knowledge exchange. People viewing *Advocating for Hilda* should understand that this material may create more questions than answers. Moreover, some viewers may see that, in some instances, significant caregiving issues are not resolved and/or do not fade away.

What should be kept in mind while watching *Advocating for Hilda*?

Prior to any post-viewing discussions, it is important to take the time to create a space for safe discussions. In such a 'safe' space, people are made to feel comfortable expressing their experiences and perspectives without judgment.

Respect and honesty are crucial components of productive dialogue. Viewers are encouraged to openly share their feelings, to raise and to discuss ideas, and to maintain an environment of support and reconciliation.

Some key principles to keep in mind when facilitating appropriate and safe conditions are:

- Inclusion
- Turn-taking
- Active listening
- Patience
- Compassion

Our belief is that critical reflection and dialogue will help viewers generate insights into their own dementia care relationships.

As noted in the preamble to the film, viewers are invited to watch the film, keeping in mind the following three questions:

1. What parts of the film resonate the most with you? Why?
2. What parts of the film are different than your experience? How so?
3. What conversations should you have about dementia care, and with whom?

At the end of the film, viewers are asked to consider sharing their responses to these questions with others. During these discussions other questions may be generated that warrant further discussion with family, friends, colleagues and care providers.

RESEARCH TEAM

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PROJECT COLLABORATORS

Aging Brain and Memory Clinic, Alzheimer's Outreach Services, Alzheimer Society of Canada, Alzheimer Society London and Middlesex, Alzheimer Society of Ontario, Canadian Association on Gerontology, Canadian Coalition for Senior's Mental Health, Canadian Dementia Knowledge Translation Network, Canadian Mental Health Association Fort Frances Branch District Mental Services for Older Adults, The Centre for Family Medicine Memory Clinic, Employment and Social Development Canada, Health Canada, McCormick Home, National Institute for the Care of the Elderly, Ontario Association of Non-Profit Homes & Services for Seniors, Resource Research Network, Ontario Long Term Care Association, Public Health Agency of Canada, South West Community Care Access Centre, St. Joseph Care Group, Victorian Order of Nurses – Middlesex Elgin, Victorian Order of Nurses Canada, Waterloo-Wellington Local Health Integration Network

CREDITS

The film *Advocating for Hilda* (<http://youtu.be/V6i4KDbARck>), a product of the Canadian Dementia Knowledge Translation Network and Alzheimer Society of Canada funded study entitled "Research-Based Theatre as a Vehicle to Promote Knowledge Exchange in Primary Care" (Principal Investigators: Drs. Gutmanis, Speechley, and Ward-Griffin; Co-Investigators: Drs. DeForge and Van Bussel), was produced by Dr. Iris Gutmanis with screenplay by Dr. Mark Speechley (Production: Evoke Media Solutions; Production Facilities: Producers Post Inc.).

*On May 20, 2014 a group of care partners, care providers, educators, administrators, policy makers, and other professionals from the community, social service, and private sectors participated in a one day, Canadian Institutes of Health Research (CIHR, Grant No. DGE 129655) funded workshop titled: Knowledge Translation in Dementia Care: It Takes a Community, in Toronto, Ontario. This guide was developed in response to a commitment made by the workshop participants to disseminate *Advocating for Hilda* to a wider audience.

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For more information:

<http://uwo.ca/nursing/cwg/dementia/knowledge.html>