

June 11th, 2015

Mimi Lowi-Young
Chief Executive Officer
Alzheimer Society of Canada
20 Eglinton Avenue West,
16th Floor
Toronto, Ontario
M4R 1K8

Dear Ms. Mimi Lowi-Young,

We are an advocacy group led by people with dementia called the Ontario Dementia Advisory Group (ODAG). This group is focused on the development of an Ontario Dementia Strategy and actively advocates for the engagement of people with dementia in public policy decision-making that will affect our lives.

We are very pleased that Alzheimer Society of Canada (ASC) has made public awareness as one of its main objectives as detailed in the "2015 Pre-Budget Submission to the Standing Committee on Finance" proposal. In particular, to do so by the creation of a multi-platform awareness campaign based on the highly successful UK Dementia Friends model. This model does an excellent job in transforming the way the nation thinks, talks and acts about dementia.

The Pre-Budget report states "Dementia Friends will: Give Canadians a better understanding of dementia." Therefore, upon watching the Dementia Friends video released on June 5th 2015, we were shocked and disappointed to see that it does the opposite of its objectives. This video only serves to highlight stigma and dramatize, in a frightening manner, myths about dementia.

On its release ODAG was contacted by dementia advocates in the international community asking if we had participated in the making of it. Its reaction was swift. Some blog comments include:

"But really, whoever made and approved that video needs to think about the possible damage they are doing to the rights and advocacy of people with dementia vs the possible value of awareness at any cost."

"How humiliating....To see dementia only as symptoms and labels, not as people with possibilities dealing with issues."

"A bit of a shock. I'm sure it has been done with the best of intentions – but way, way off the mark. Did they consult with any one from the Dementia Friends? If so, they have missed the message. If not... why not! Either way, it's emotional, theatrical – and disappointing."

"Found the DVD quite negative in its portrayal of people with dementia, would be interested in how they facilitate their DF sessions and what materials they use."

In addition to this, members from ODAG found the video to promote the very myths identified on the Dementia Friends site.

ODAG's motto is "Nothing about us without us." It is extremely disappointing that this video does not feature persons with dementia who are living well. There are so many alternate scenarios that could have been featured instead of one that portrays people with dementia as violent and aggressive and that people need to be careful how we are approached.

Dementia Friends is a wonderful inspiring international movement. We are pleased that Alzheimer Society of Canada and the Federal Government have taken the initiative to adopt it. However, we are very concerned and do not agree with how people with dementia are represented in the video. Taking this view, we are unable to endorse it.

We understand there will likely be future material developed to support Dementia Friends. ODAG will be pleased to act as advisers to promote a message that supports the notion of people living well with dementia; we have many talents which we can still utilize; and finally, nothing about us without us.

Sincerely,

Ontario Dementia Advisory Group (ODAG)

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