People with dementia face discrimination and social rejection
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“People with dementia face discrimination and social rejection,” says Professor Pia Kontos, who spent most of her career challenging perceptions of dementia through her research. Credit: Bigstock image

January is Alzheimer's Awareness Month and Professor Pia Kontos wants Canadians to be better informed about both the disease and its broader implications.

"People with dementia face discrimination and social rejection," said Kontos, an associate professor in the social and behavioural health sciences division of the Dalla Lana School of Public Health and the Rehabilitation Sciences Institute at the University of Toronto. "Often they are ignored.

"Others will address a caregiver even when the person with dementia is standing right there. They may lose friends because of misconceptions about abilities."

As spokesperson for the Alzheimer Society of Canada's #StillHere campaign – the social-media awareness initiative aiming to dispel myths and encourage all of us to see the person beyond the condition – Kontos is working to reduce the stigma associated with dementia.

"Our cognitive abilities alone do not define us," she says. "People with dementia can continue to engage with the world in many other meaningful ways. And supporting their dignity and worth improves their well-being and quality of life."

Kontos is also a senior scientist at Toronto Rehabilitation Institute of the University Health Network and the Rotman Research Institute at Baycrest Health Sciences. Her research is gaining attention through both the #StillHere campaign and her innovative awareness-raising activities.

Kontos is co-producer of Cracked: New Light on Dementia, a theatrical production that blends science and drama to address stigma around dementia. The play is a collaboration based on research by Kontos and colleagues from the Ontario Institute for Studies in Education, the University of Waterloo and York University.

"Theatre is a very powerful medium," Kontos told U of T Magazine. "It can challenge assumptions and practices that are taken for granted and open audiences to new possibilities for supporting the humanity of people living with dementia."

Kontos has spent most of her career challenging perceptions of dementia through her research.

"Pia's hugely successful theatre productions have been received with great interest and enthusiasm by the health-care community and by the general public," says Joan Eakin, professor emerita in the Dalla Lana School of Public Health and past director of the Centre for Critical Qualitative Health Research, where Kontos is an academic fellow.

"This is public health prevention, applied intervention and knowledge transfer at their very best."