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Legal issues on dementia journey cause concern

Alzheimer Society of B.C. working to preserve legal rights of people with dementia

Vancouver, B.C. – For families caring for a person with dementia, reliance on the health care system escalates and needs of the person becomes more complex. Preferably, legal decisions are made well in advance; however, the legal health care decision-making is currently fraught with significant issues, ranging from the neglect of person-centred principles of care to a complete loss of legal rights. The Alzheimer Society is leading a one-year legal education project to help remedy this situation.

With amendments to the adult guardianship legislation coming into force on Sept. 1, 2011 an understanding of how the legal decision-making process works is both timely and critical.

By the end of the one-year project, and through a collaborative consultation process, the public will have access to a plain-language and accessible legal and ethical framework for use by people with dementia, their families and caregivers, as well as, the interdisciplinary team of health care providers.

“Part of our mission at the Alzheimer Society of B.C. is to help alleviate the personal consequences of Alzheimer’s disease and related dementias, and to promote public awareness. The realities of the progression of the disease, the care that is needed, and the impact on families necessitates the need for this project so that families can better understand and be equipped with resources for important legal planning,” said Jean Blake, CEO, Alzheimer Society of B.C.

Barbara Lindsay, Senior Manager, Advocacy & Public Policy at the Society adds that the collaborative approach is what will help to ensure the relevance and accessibility of the information delivered through the project.

“By bringing together people with dementia, caregivers and health care providers, we are integrating legal, ethical, and real-life perspectives of health care decision-making into a functional tool for people with dementia, their families and caregivers, as well as, health care providers who deliver care.”

Health care providers are in a situation where they need to preserve the legal rights of individuals with dementia in their care, even in times of an urgent issue, and to do so they need to understand the legal framework for decision-making and how to incorporate the legal planning documents. This is a challenge when families have not arranged their legal health care plans with the person living with dementia.

Families are often confused, distressed, and unprepared, and particularly during times of immense stress, there is a risk that the legal rights of people with dementia in care can be misunderstood and the role of families undervalued.

“There is often a lot of confusion, or at least legal ambiguity, among families impacted by dementia about making legal health care plans, and for legally appointed decision-makers, about how to make health care decisions on behalf of a person with dementia when called upon to do so,” added Lindsay.

“Our aim is to help families and health care providers better understand what legal plans need to be in place as well as the impact of the new amendments to the legislation so that the legal rights of people with dementia are preserved and upheld.”

This project is being funded by the Law Foundation of British Columbia and is expected to be completed by August 2012. The toolkit is anticipated to be available in March 2012 followed by public educational workshops.

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