



**Non-State Actor
Dementia / Criminal Justice Initiatives:
A Review**

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Earlier this year, the Dementia Justice Society of Canada contacted over 200 dementia organizations from around the world to gather information about any non-state actor criminal justice initiatives that are underway or being developed in their respective jurisdictions. We were interested in learning about activities that focus on people with dementia who come into conflict with the criminal justice system (e.g., as accused persons, offenders, inmates). We committed to summarizing and sharing the results on our website.

Previously, we had completed a [review of 23 national dementia strategies](#), and found that only two (Cuba and England) make explicit reference to criminal justice. We had also completed a similar [review of 65 sub-national strategies](#) within various jurisdictions in Australia, Canada, Germany, and the United States, and found a few promising initiatives, such as training of law enforcement and prison staff on dementia and its responsive behaviours.

Based on this information and other anecdotal evidence, we expected to uncover only a handful of non-state actor criminal justice initiatives that focus on criminal defendants with dementia. The responses we received supported that expectation: among the 18 responses, only six indicated that their organization is involved in criminal justice activities.

What We Asked

We invited non-state actor dementia organizations to answer the following questions:

- Name of your organization
- Location of your organization (City/Town; State/Province/Territory; Country)
- What level does your organization work at? (e.g., the national level, the state level, the city/local community level)
- Is your organization involved in any criminal justice initiatives? (Yes/No)
- If Yes, please describe. Include any relevant website links and/or attach any relevant files.
- If you wish, please provide any further thoughts, observations or other comments about the challenges people with dementia may face when they come into conflict with the criminal justice system.

Who We Heard From

We heard from 18 non-state actor dementia organizations who operate at either the national, regional (e.g., state/provincial/territorial), or local level. Some work across multiple levels.

The organizations were based in the following jurisdictions: Australia; Belgium; Canada; Czech Republic; Ireland; Jamaica; Lebanon; Puerto Rico; Trinidad and Tobago; and the United States.

What We Heard

Of the 18 organizations who responded, six indicated that they are involved in criminal justice initiatives that are related to persons with dementia. In summary, these activities include:

1. Participating in a multi-sectoral advisory committee on resident-to-resident aggression.
2. Participating in an inquest following a fatal resident-to-resident conflict.
3. Advocating for families whose loved one with dementia has come into conflict with the criminal justice system.
4. Educating staff and inmates at correctional facilities.
5. Participating in health fairs at local penitentiaries to provide information to inmates.
6. Advising and educating police on topics such as wandering and strategies for communicating with people with dementia.
7. Partnering with the bar association to train lawyers and judges about how lawyers and judges themselves may have and be impacted by dementia.

Among all 18 responses, five themes emerged. These are summarized below, and we have included some illustrative quotes from various respondents:

1. There is a lack of awareness and knowledge about the intersection of dementia and the criminal justice system.

“There may be persons who have the disease and are in conflict with the law but due to lack of knowledge about the disease front line workers in the criminal justice system may not treat these persons with care. We are mindful of this and intend to begin the conversation so that the government gives this some attention.”

“A big issue within the criminal justice system is that most who work within the system do not have awareness of dementia nor have the skills to interact with an individual impacted by a dementia-related disease. Most assume it is a mental disorder, will place someone in a facility and then move on from there.”

“Dementia is not readily understood by legal and justice professionals resulting in both appropriate and inappropriate assumptions about the person’s capacity.”

“When a person who has dementia encounters the justice system the system is challenged to know how best to work with them or support them.”

2. The criminal justice system is ill-equipped to manage persons with dementia, particularly those with frontotemporal dementia (FTD).

“Frontotemporal degeneration primarily affects the parts of the brain involved with social comportment, engaging in interpersonal relationships, rationality and sound judgement. Because of these impairments people with the disease are at a high risk of coming into conflict with the criminal justice system as both a perpetrator and a victim.”

“A justice system based on enforcing laws with potential punishments just doesn’t work on individuals whose ability to follow rules and regulate behavior is biologically impaired. Especially in conjunction with a rehabilitative penal system that simply does not make sense in the context of neurodegenerative disease like FTD.”

“[M]odern legal standards of competency are hard to apply to individuals with FTD who may retain some cognitive abilities yet suffer a loss of impulse control and impairment to their decision making skills.”

3. Resident-to-resident and inmate-to-inmate conflict are increasing concerns.

“Prison populations are aging and training is nonexistent for dealing with dementia-related behaviors and communication among those incarcerated. Furthermore, this vulnerable population is far more susceptible to abuse as there is no mechanism to segregate them from the general population.”

“[An inmate] living with dementia that is repeatedly ‘calling out’ and/or wandering may become targeted or victimized by other inmates.”

“Another challenge has been in regards to activities on the unit [at a correctional facility]. Staff have been advocating for an activities staff person, knowing that when someone with a cognitive issue is kept occupied there is a less chance of exhibiting behavioral issues. The hope is that we will be able to train other inmates who could provide one-on-one activities with the cognitively impaired inmates.”

4. It is difficult to find medical-legal information on dementia and the criminal justice system.

“Finding case law that documents the legal outcomes for people with [frontotemporal dementia] is also a challenge for several reasons. First it is a rare disease and there just aren’t too many people with a diagnosis to begin with. Moreover, FTD is often misdiagnosed as a mental health illness or simply seen as immoral behavior and it never enters into the legal record.”

5. **More collaboration among stakeholders is needed.** For instance, potential partners could include academic centres such as those who are interested in law, brain, and behaviour. Two examples are:

- [Harvard / Massachusetts General Hospital](#)
- [Vanderbilt University](#)

Resources

A handful of respondents also provided links to various resources that are in relation to dementia and the criminal justice system. Some of the documents that were provided are identified below. We aim to eventually add these and other materials, including the latest academic research, to our online resource library, which we hope to develop in the near future.

Canada

- [Frank Alexander Inquest: Final Report](#)
- [Frank Alexander Inquest: Recommendation Implementation Plan](#)

Ireland

- [“In Here, Time Stands Still”: The Rights, Needs and Experiences of Older People in Prison”](#) (Irish Penal Reform Trust, 2016):

“In developing [the older prisoner strategy], there should be a wider debate about the appropriateness of detaining old and seriously ill people in a prison environment, particularly those living with dementia or other terminal illnesses. This debate should consider the significant practical and ethical challenges the continued detention of these people presents for prison staff and for other prisoners.”

“All prison staff should receive dementia awareness training, allowing them to identify symptoms of Alzheimer’s and other forms of dementia, and providing them with the skills necessary to support people living with dementia.”

“Information materials about the prison regime should be dementia-friendly and approved by National Adult Literacy Agency (NALA). These materials should be disseminated and discussed with older people to ensure they are aware of their rights.”

“The Irish Prison Service should consider the implications of the Assisted Decision-Making (Capacity) Act 2015 for older people, particularly those living with dementia. A revised Strategy for the Management of Older Persons should set out how the prison service will support those whose capacity is in question to engage in decisions about their welfare.”

“The continued detention of a person with dementia raises significant issues for the Irish Prison Service and for other people in prison. If high levels of medical care are not available this may, in certain circumstances, amount to inhuman or degrading treatment in contravention of Article 3 of the European Convention on Human Rights.”

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ABOUT DEMENTIA JUSTICE

The Dementia Justice Society of Canada is a federally incorporated non-profit society dedicated to advancing the rights, needs and dignity of people with dementia who are, or are at risk of becoming, involved with the criminal justice system. We aim to achieve our objectives through public advocacy, awareness-raising, education, and interdisciplinary legal and policy research.

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