



NTG Statement on COVID-19, Intellectual Disability, and Dementia

December 11, 2020

The aim of this statement is to provide the rationale for placing adults with intellectual disability affected by Alzheimer’s disease and other causes for dementia on priority lists for receiving special consideration in mitigation strategies for managing the spread of COVID-19 and for receiving inoculation by vaccines designed to inhibit infections by the COVID-19 virus.

Adults with intellectual disability generally have a greater number of co-occurring conditions (that is, comorbidities).ⁱ The number of such comorbidities increases when adults with an intellectual disability are affected by dementia, particularly due to Alzheimer’s disease.ⁱⁱ With studies showing the adverse impact that infection by COVID-19 has upon some adults with intellectual disability (such as those with Down syndrome), those adults with concurrent dementia may be at greater risk.^{iii,iv,v} Reports have noted increased rates of delirium among adults with dementia infected by COVID-19.^{vi} Studies also have shown that some persons who tested positive for COVID-19 may have residual cognitive and neuropsychiatric effects transcending the recovery period.^{vii} These may include anxiety, cognitive impairment, depressed mood, insomnia, and post-traumatic stress disorder. Older adults with dementia experiencing COVID-19 mitigation efforts may also show greater rates of neuropsychiatric symptoms (such as agitation, anxiety, apathy, and depression) attributed to protracted social isolation and social restrictions occurring during the pandemic.^{viii,ix} The nature of care settings has also been linked to increased risk for adverse health outcomes if a person is infected with the COVID-19 virus.^{x,xii} Therefore, the NTG recommends that additional protective measures be adopted in group care settings and in-home care when there is an adult in the residence with intellectual disability who is suspected of having or has been diagnosed with dementia.

Further, as research supports that there is an elevated risk of susceptibility for infection and potential for adverse post-infection effects, the NTG recommends that service providers and care organizations promote a greater awareness of risk due to the presence of dementia among adults with intellectual disability, and institute policies and practices that assure mitigation and prevention of exposure to the COVID-19 virus. The NTG also supports the recognition of the need for vaccine inoculation programs targeting adults in this risk pool to prevent workforce spread and adverse effects among those who may get infected.

With respect to care and prevention guidance we acknowledge and support the general recommendations developed by Alistair Burns, M.D., National Clinical Director for Dementia at NHS England/Improvement^{xiii} and others^{xiii}, which are applicable to adults with intellectual disability and dementia. We recommend the following guidance and practices:

- As some adults with intellectual disability may already have difficulty understanding complex instructions about self-protection, self-isolation, and sanitation, having dementia may add to comprehension difficulties; thus, any instructive communications should be kept simple and with the person’s understanding level in mind.^{xiv}

- As adults with dementia are more prone to develop delirium (that is, mental confusion) if they develop an infection, staff and caregivers should be advised how to react if this occurs.^{xv}
- For older adults, being taken to a hospital can be stressful particularly for those with dementia. Medical staff involved in screening and treatment should be aware if a person with an intellectual disability has dementia and be prepared to take extra time assessing and treating them.^{xvi}
- Adults with intellectual disability and dementia may lack awareness of and be less able to report symptoms because of communication difficulties. Staff and family caregivers should be alert to the presence of signs and symptoms of the virus and aware of what any new or unexpected behaviors may mean.^{xvii}
- Adults with dementia may have swallowing difficulties which could put them at increased risk of developing chest infections and dehydration. Undertaking a swallowing assessment can help determine whether any problems may be present and what compensations can be used.^{xviii}
- There may be an additional burden on family caregivers, many of whom may be in a high-risk group due to their age and physical condition and may become ill and unable to provide care. Supports should be organized so that they involve friends/relatives/volunteers or paid home care aides who can keep in contact with and support the caregiver.^{xix}
- Staff and caregivers of persons with intellectual disability and dementia may need help with accessing resources for coping with caregiving, safe-proofing their residence, mitigating contact with others who may be exposed to COVID-19, and providing personal care whilst in social isolation. Brief in-house advisories prepared for this purpose can help in identifying such local and national resources. The Centers for Disease Control and Prevention (CDC) and other organizations have numerous resources that can be drawn upon for guidance in such situations.^{xx,xxi,xxii}

Lastly, the NTG supports the efforts and positions of our colleague organizations^{xxiii,xxiv,xxv} which recommend that states add adults with intellectual disability particularly at-risk (such as, adults with Down syndrome, certain comorbidities, compromised immune systems, and *diagnosed with Alzheimer's disease and other neurodegenerative conditions*), to those at-risk groups of older adults to be vaccinated within the first wave populations as identified by the Centers for Disease Control and Prevention.^{xxvi,xxvii}

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