



INFORMATION FOR HEALTH WORKERS IN HOSPITALS

21 May 2020

SUPPORTING PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITY DURING THE COVID-19 PANDEMIC

This fact sheet is for health workers in hospitals providing health care to people with intellectual or developmental disability during the COVID-19 pandemic.

Key points:

Some people with intellectual or developmental disability may be:

- at higher risk of acquiring COVID-19
- at higher risk of serious illness due to COVID-19
- more likely to exhibit atypical symptoms and/or have difficulty communicating symptoms. Their condition may deteriorate rapidly.

Listen to and involve the person and their family and/or disability workers in assessments and decision making as much as possible.

You may need to adjust your communication to meet the needs and preferences of the person.

Are people with intellectual or developmental disability at greater risk of COVID-19?

People with intellectual or developmental disability:

- are highly vulnerable groups. They often have complex comorbidities and pre-existing health conditions
- experience very high mortality rates and reduced life expectancy. Many deaths are due to potentially avoidable causes
- can experience difficulties accessing appropriate health care. Some conditions may be undiagnosed or undermanaged

- and those around them may have an increased risk of infection and transmission due to comprehension, communication and behavioural issues
- have high rates of mental health and behavioural issues. The COVID-19 pandemic may exacerbate these because of extra stress around changes in routine, supports and community access.

Respiratory disease and infections are among the most common causes of death in people with intellectual disability.

This means that some people with intellectual or developmental disability with certain risk factors may be at higher risk of:

- **acquiring** COVID-19
- **serious illness** due to COVID-19.

It is important to:

- consider these vulnerabilities
- consult relevant specialists
- make any reasonable adjustments to enhance health outcomes for these groups
- uphold the human rights of people with disability to equitable, accessible and tailored health care.

What can be different about treating people with intellectual or developmental disability in hospital?

People with intellectual or developmental disability may be more likely to:

- be at risk of infection with COVID-19 due to difficulty understanding health advice and instructions about risk reduction measures including social distancing
- experience rapid deterioration and rapidly progressive disease due to late presentations and pre-existing comorbidities
- require additional assistance or rely on others for essential support for their daily needs
- have difficulty with communication. This may impact their health care. For example, they may:
 - be unable to explain pain. This may mean its presence and causes may remain undiagnosed and untreated
 - present with behavioural change from an underlying physical health condition, risking critical physical health issues being overlooked

- be unable to perform tasks such as self-administering medications, initiating calls for assistance or complying with required dietary modifications (e.g. thickened fluids)
- be unable to explain fear and distress, which may present in the form of behavioural change.

People with intellectual or developmental disability are less likely to:

- be able to immediately comply with social distancing and risk mitigation strategies and instructions (e.g. cough etiquette, use of PPE, isolation) due to difficulty understanding and applying information
- present with typical symptoms such as a fever and cough or be able to communicate worsening symptoms.

How to minimise the risks to people with intellectual or developmental disability in hospitals

- Ensure the person has access to their usual disability supports during hospitalisation. Involve parents, other family members and/or disability workers as much as possible. These people are likely to be familiar with the symptoms that indicate illness or that the person's condition is deteriorating. They can also assist to manage any anxiety, confusion or stress.
- Conduct a detailed review of the health and disability information that came with the person. This may contain important information about:
 - what is normal for the person
 - how to provide support to access health care
 - their communication preferences
 - their medical history, allergies and current medications.
- Identify and involve where appropriate medical specialists involved in the person's ongoing health care.
- Conduct regular and detailed clinical reviews including repeat examinations to re-check clinical status and detect deterioration.
- Allow extra time for clinical interaction and observation due to the complexity of health and communication needs.
- Adjust your communication to provide information in an accessible way that the person can understand and that respects the person's communication preferences. **Note:** wearing PPE may cause fear or anxiety and could compound communication issues. You may need to repeat explanations using Easy Read resources.
- Understand the usual strategies the person uses to manage high stress situations or investigations, such as the use of PRN anxiolytic medication in procedures.

What to consider during hospitalisation

When a person with intellectual or development disability is hospitalised, hospital staff should consider:

- the need for a multidisciplinary team approach to health care. Include relevant specialists involved in the person's ongoing health care
- the potential impact of the person's environment and the need to support stress reduction
- flagging in the electronic medical record that the person has an intellectual disability and record the contact details of the Medical Treatment Decision Maker
- supporting adults to make their own medical decisions as much as possible. If the person is unable to consent, follow substitute consent laws
- the risk to staff, family members, disability workers and others from behaviours of concern and lack of adherence to protective measures. Factor these into management decisions.

What to consider in hospital discharge planning

When planning to discharge a person with intellectual or developmental disability from hospital, hospital staff should:

- consult with the person's support network, the hospital allied health team and regular health care providers about how to arrange post-discharge health care and support in the community, to be in the person's best interests and of their family. Note that staff in group homes are usually not health professionals
- consider the difficulties the person may experience when accessing appropriate primary health care and out of hospital specialist care. Take these into account if you develop an alternative pathway to manage the person's condition, such as support in the home
- the potential impact of illness on the role and needs of a family member or disability worker. There may be a potential need to trigger urgent social-welfare assessment and mobilise additional health and disability supports, including through the NDIS.

Where can I get more information?

For the latest health advice, information and resources on the COVID-19 pandemic, go to www.health.gov.au. For additional information specific to people with disability during the COVID-19 pandemic, go to <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability>.

General guidance about responding to the needs of people with disability during hospitalisation is available. For example, see the NSW Health guideline on [Responding to the Needs of People with Disability during Hospitalisation](#).

An Intellectual and Developmental Disability Health Working Group convened by 3DN, UNSW Sydney prepared this fact sheet.