



INFORMATION FOR HEALTH WORKERS IN EMERGENCY DEPARTMENTS

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

This fact sheet is for health workers in emergency departments (EDs) providing 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 and of serious illness due to COVID-19
- be more likely to present late or with atypical symptoms, and their condition may deteriorate rapidly.

Listen to and involve the person and their family, carers and disability workers in assessments and decision-making as much as possible. The person may need a family member or carer present throughout their time in the ED.

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 and often have complex comorbidities and pre-existing health conditions. These groups experience very high mortality

rates and reduced life expectancy. Many deaths are due to potentially avoidable causes

- can experience difficulties accessing appropriate health care, and 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
- people with intellectual or developmental disability have high rates of mental health and behavioural issues. COVID-19 may exacerbate these due to 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 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 EDs?

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

- present to ED with a family member and/or disability worker
- be at risk of infection with COVID-19 due to difficulty understanding health advice and instructions about risk reduction measures, including social distancing
- present with advanced or rapidly progressive disease due to late presentations and pre-existing comorbidities
- have atypical or late presentations due to communication and cognitive difficulties
- have difficulty with communication. This may impact their health care if they:
 - are unable to explain pain. This may mean its presence and causes may not be diagnosed and treated

- present with behavioural change from an underlying physical health condition. This may mean critical physical health issues are not identified
- are unable to perform tasks such as self-administering medications, initiating calls for assistance or complying with required dietary modifications (e.g. thickened fluids)
- are unable to explain fear and distress. This may present in the form of behavioural change
- present with behavioural change due to an underlying physical health condition.

People with intellectual or developmental disability may be 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. They may not be able to communicate worsening symptoms due to communication issues.

How can I adjust how I communicate information?

- You may need to simplify your language or adjust your communication, such as when asking the patient questions about their symptoms.
- Communicate information and instructions about social distancing and other risk mitigation strategies in an accessible manner, using simple language and signs.
- Make communication adjustments to show that you know and respect the person's communication preferences.
- Ask family members and/or disability workers to assist you to understand how to communicate effectively with the person.
- **Note:** wearing PPE could compound communication issues. You may need to repeat explanations using Easy Read resources.

What should you consider when assessing people with intellectual or developmental disability?

When assessing a person with intellectual or developmental disability in an ED, clinicians should:

- 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
- be aware of late and/or atypical presentations. Some symptoms may be reported or present differently. For example, symptoms may present as changes in behaviour. The disability or treatment might impact some symptoms. For example, there may be no fever present due to medication or an altered inflammatory response. A thorough assessment will reduce the risk that important health issues are missed or misdiagnosed
- involve family members and/or disability workers as much as possible. These people are likely to have knowledge of the symptoms that indicate illness or that the person is deteriorating. They can also assist in managing any anxiety, confusion or stress
- identify and involve as appropriate the health practitioners involved in the person's ongoing health care
- allow extra time for the clinical interaction and observation due to the complexity of health, disability and communication needs
- be aware of the potential impact of the unfamiliar physical and sensory environment of the ED on the person. Use a low stimulus room if possible
- monitor the person's mental wellbeing and behaviour for impacts of the pandemic
- flag in the electronic medical record that the person has an intellectual or developmental disability. Record the contact details of the Medical Treatment Decision Maker.

What to consider when making treatment decisions

When making treatment decisions for a person with intellectual or developmental disability in an ED, clinicians should consider:

- the [ACEM Ethical Framework](#)
- relevant national, state and local guidelines relating to COVID-19
- supporting adults to make their own medical decisions to the greatest extent possible. If the person is unable to consent, follow substitute consent laws
- the potential for the patient's health to deteriorate rapidly due to pre-existing complex comorbidities and/or potential late or atypical presentation
- difficulties they may have in accessing appropriate health care. Take these into account when considering alternative pathways to assess or manage the person's condition. This includes decisions to divert from ED or refer on to other services
- the risk to staff and others, including from behaviours of concern and lack of adherence to protective measures
- implementing additional appropriate infection control measures. Consider family and disability workers and disability related equipment such as wheelchairs, communication devices and aids, indwelling catheters, etc
- the potential impact of illness on the role and needs of a family member or disability worker
- whether you 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>.

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