Understanding behaviour change for people with intellectual disability or autism spectrum disorders

This information is designed to assist health professionals care for their patients who have intellectual disabilities or autism spectrum disorders.

Monash Health is located within a large and diverse community. Health professionals work across this community with many different patient groups, including people with intellectual disabilities or autism spectrum disorders. Some patients with an intellectual disability or autism spectrum disorder may have difficulty using words or language because of their disability. Their behaviour may be their main or only method of communication.

Understanding the challenges the patient may face in healthcare settings

- Previous experiences in healthcare settings may lead to the patient feeling fearful and distressed.
- Cognitive difficulties may mean the patient has trouble understanding the unfamiliar setting, what is happening around them and what will happen to them.
- Communication difficulties may make it difficult for them to either understand what others are saying or to make themselves understood.
- Sensory impairments may mean the patient may not be able to clearly hear, see or feel what is happening around them.
- Sensory sensitivities may mean the patient finds particular sounds, light, smell or touch highly distressing, painful or intolerably unpleasant.
- Motor difficulties may mean the patient has less control of their movements, including speech, particularly when they are feeling anxious.
- A lack of support, change in environment or a change in circumstances may lead to a sense of social isolation and disconnectedness.
- Social difficulties may lead to them not fully understanding the social ‘rules’ of communication and behaviour.

A person with an intellectual disability or autism spectrum disorder will have particular patterns of behaviour that are normal for them. Those who know the person well (family, carer or direct support staff) will be able to tell you how the person usually behaves, how they appear when they are calm, and how they show discomfort or fear.

Determining causes for behavioural change

Physical illness, pain or discomfort

- What conditions would you consider in any patient of this age and gender?
- What conditions are known to be more common in people with intellectual disability (for example: oral or dental disease, GORD, constipation)?
- What conditions are known to be more common in people with this particular disability (for example: hypothyroidism in people with Down syndrome)?
- Could medications be causing side effects?
Mental illness or distress

- Disorders of mental health are more common in people with intellectual disability. Biopsycho-social factors all increase the risk for mental ill health.

- Look for the ‘behavioural equivalents’ of depression, anxiety, mania, bipolar disorder, or psychosis (for example social withdrawal, not attending or enjoying previously favourite activities, crying, irritability, sleep and appetite changes could suggest depression).

- Consider emotional, physical or sexual abuse.

Sensory sensitivity or loss.

- Ask about sensory sensitivities. Try to find a quiet place for them to wait and in which you can assess them.

- Has there been a deterioration in their vision or hearing?

Changes in life circumstances or environment:

- Where do they live and with whom? What support do they need and who provides it?

- What do they do during the day?

- Who are their family and friends?

- Have there been any recent changes in people, places or activities that are significant for them?

Key points:

A change in behaviour is a symptom and may indicate a change in:

- Physical health
- Mental health
- Sensory sensitivity or loss
- Life circumstances or environment.

For information

Centre for Developmental Disability Health: www.cddh.monash.org
03 9792 7888

Useful resources