



# Mental health for adults with Down syndrome

by Dr Jennifer Torr

Centre for Developmental Disability Health Victoria  
([www.cddh.monash.org](http://www.cddh.monash.org))

As a community we are becoming more aware of the importance of maintaining mental health. Some of the crucial factors include supportive relationships, positive community engagement, encouragement to mature as a person, personal challenges boosting self esteem, personal resilience and acceptance of disappointments. Exercise and maintaining good physical health are also vital.

## What is Mental Ill Health?

It is important to recognise when we or someone we care about has mental ill health and to seek appropriate help. First of all, what is mental ill health? Psychiatric disorder, mental disorder and mental illness are all terms used for mental ill health. Mental ill health is a change in a person's feelings, thinking, behaviour and physical well being that is serious enough to cause the person suffering, to impact on their relationships with others, and to prevent the person from living their normal life.

## What Causes Mental Ill Health?

Mental ill health is due to a complex interaction of many factors from loss, adverse and traumatic life events, poor social supports and social skills, childhood experiences, lack of control over ones circumstances, limited coping skills, drug and alcohol abuse, as well as being genetically and physically vulnerable to developing a mental illness.

## Mental Ill Health in Adults with Down Syndrome

Adults with Down syndrome are vulnerable to mental ill health. Despite improvements in choice and community life, people with intellectual disabilities continue to have less control over their personal circumstances. Intellectual disability not only impacts upon a person's ability to think and to express themselves but can also impact on how well a person understands their social environment and how well they may cope with the stresses of life. In addition, adults with Down syndrome also have genetic risks for mental ill health. Anxiety, obsessive compulsive disorders, and depression are very common. Psychotic disorders are less common.

## Recognising Mental Ill Health

Mental illness may present with challenging or problem behaviours. However challenging behaviours may indicate a range of problems from medical problems, pain, hearing and vision impair-

ment, to life issues. Mental illnesses present with clusters of characteristic symptoms and behaviours that represent a change from how the person is usually. Diagnosis of mental illness is based on a history, physical examination and investigation and a mental state examination. An interview with the person with suspected mental illness is standard practice to determine what the person is thinking, feeling and experiencing. This is difficult to do when the person has communication impairment and impairments in abstract thinking. Hence observation and description of changes in a person's behaviour and demeanour are most important in making a diagnosis.

### **Depression**

Depression is common, often associated with anxiety and is usually easily treated. Depression is characterised by depressed mood and/or lack of interest or enjoyment in usual activities, over a period of two weeks or longer. Depression may have gradually emerged over many months or even years. A person may have a depressed mood most of the time but not all of the time. Hence depression may not be recognised. Indicators of depressed mood are: appearing to be sad or downcast, less smiling, less laughing and tearfulness. Mood may also be irritable. The person may become grumpy, angry, or even verbally or physically aggressive.

### **Mood**

- Unhappy, sad, miserable
- Not smiling, not laughing
- Lost sense of humour
- Irritable

### **Thoughts**

- Negative thoughts, death, ill health
- Loss of self esteem, no one likes me, I am bad

### **Interaction/Communication**

- Interacting less
- Communicating less

- Loss of spontaneity
- Withdrawn, spending time alone

### **Activities**

- Loss of interest and pleasure in activities
- Refusal to participate in activities

### **Functioning**

- Self neglect
- Poor concentration
- Poor work performance
- Slowed up

### **Anxiety**

- Worry, complaining
- Seeking reassurance
- Increased obsessiveness
- Refusal to do feared activities
- Agitation

### **Sustenance**

- Decrease appetite
- Loss of weight
- Sometimes increased appetite and increase in weight

### **Sleep**

- Difficulties getting to sleep, staying asleep or waking up early
- Oversleeping

The Centre for Developmental Disability Health Victoria has developed a depression checklist and this will be available on the CDDHV website in the near future - [www.cddh.monash.org](http://www.cddh.monash.org).

Occasionally a person may have severe life threatening depression. They may stop communicating and no longer tend to personal needs – sometimes to the point of not eating, drinking or toileting. Suicidal thoughts and attempts are not common in people with Down syndrome but if present must be taken seriously. A person with depression of this severity needs admission to hospital.

The most effective treatment of depression is a combination of antidepressant medications, attention to life issues and improving a person's social and coping skills. When a person has a life threatening depression and is no longer eating or drinking then the doctor may suggest treatment with ECT – electroconvulsive therapy. ECT is given under a short acting general anaesthetic and muscle relaxant. There are laws governing the use of ECT which is a generally safe and effective treatment. Adults with Down syndrome and severe depression have been safely and effectively treated with ECT.

### **Anxiety Disorders**

Anxiety is a part of life. Anxiety can be alleviated by talking about problems, reassurance and also by sorting problems out ie. problem solving. People with Down syndrome are prone to excessive anxiety. They may self talk to sort through their worries. Learning breathing, relaxation and reassuring self talk can all help a person with Down syndrome manage their anxiety.

Anxiety can also become a disorder when it causes significant distress and interferes with a person's ability to live their normal life. 'Simple phobias' include fear of animals such as dogs; fear of lifts and escalators; fear of flying; needles; getting into a car. If a simple phobia becomes a problem then step wise desensitisation (best done by a clinical psychologist), in conjunction with medication (antidepressants or very cautious and targeted use of benzodiazepines, can be helpful eg. before blood tests) can help. People with Down syndrome may have extreme reactions to adverse life events or 'something' happening (you may not know what, but something has happened). This can precipitate sudden refusal to go somewhere eg day program and this refusal can last for years. Anxiety can be exacerbated and become more pronounced in depression, in which case the depression should be treated.

### **Obsessive Compulsive Disorders**

Obsessional behaviour is quite common in adults with Down syndrome. Obsessional behaviours can actually be beneficial. People with Down syndrome may be quite particular about the care of their belongings, clothes, household jobs, routines and are often enthusiastic about their interests such as football, TV shows, music, pop stars etc. However, sometimes obsessional behaviours become problematic when they are excessive, take up time, are pursued at the expense of other activities, harmful or costly, and when attempts to restrict the behaviours results in anxiety, distress, abuse and even aggression. Common examples are ordering (rearranging furniture), counting (eg must put 20 rolls of toilet paper in the bathroom), hoarding (pamphlets, paper) or strict routines. There may be certain rules that must be followed such as having meals at an exact time, eating only certain kinds or colour of food, or lights must be turned off it is still day time (even in low light conditions).

Obsessive Compulsive Disorder is common in people with Down syndrome. Obsessions are repetitive thoughts and compulsions are repetitive behaviours. Treatment is a combination of selective serotonin reuptake inhibitors (which are also used to treat depression and anxiety disorders) and cognitive-behavioural therapy or negotiation of limits to the behaviours.

### **Psychosis**

Psychotic disorders are characterised by 'psychotic' symptoms such as delusions, hallucinations and "thought disorders". It can be difficult to clearly establish the presence of such symptoms in people with communication impairments.

Technically, delusions are fixed false beliefs that have no basis within the person's cultural context. The risk of delusional thinking is when people act on the delusions.

It can also be difficult to make the distinction between fantasy and delusions. Fantasies about meeting favourite pop and soap stars are generally fantasy and not delusional.

Hallucinations are clearly seeing and hearing things as if they are actually real, and not being able to distinguish what is seen or heard from reality. Talking to oneself is not 'hearing voices'. We all self talk, replay conversations, rehearse, self coach, self reproach. It is common for adults with Down syndrome to do their self talk out loud. It is a bit like reading out loud.

Disorganised or 'bizarre' behaviour or jumbled up speech can also indicate a psychotic disorder.

### Seeking Help

This is not a complete list of psychiatric disorders but these are the disorders most commonly seen in adults with Down syndrome. If you are concerned about the mental health of someone with Down syndrome you should arrange a visit to their general practitioner. If possible book a long appointment.

Many GPs have not had any training in assessing psychiatric disorders in people with intellectual disabilities. You can assist the GP if you take a list of your observations with you. The GP may refer the person to a private psychiatrist or to your local area mental health service.

You can find out more about accessing Area Mental Health Services at

[www.cddh.monash.org/assets/documents/fact-sheet-accessing-mental.pdf](http://www.cddh.monash.org/assets/documents/fact-sheet-accessing-mental.pdf)

You may also ask for a referral to the Centre for Developmental Disability Health Victoria. CDDHV provides an assessment and management plan. However CDDHV does not have the capacity to provide urgent assessments or to provide ongoing care. There is often a 2-3 month wait for an appointment. You can download a preappointment questionnaire at [www.cddh.monash.org/paq-download.html](http://www.cddh.monash.org/paq-download.html).



## Look after yourself too!

The physical and mental health of a primary carer is extremely important, as it is difficult to deal with a family member with a disability if you feel unwell or stressed. Take time to think what assistance would make a difference and how this may be achieved. Most importantly, share any concerns with others: family, friends, neighbours, professionals, staff at Down Syndrome Victoria and family network group parents in your region.

Commonwealth Carer Respite Centres work with carers to plan sensible approaches to respite and other support needs and also arrange 24 hour emergency respite care.

Call their toll free number on 1 800 059 059.