

Down syndrome and mental health



Good mental health is important for everybody. It allows us to deal with a certain amount of stress and get through difficult times in healthy ways. The World Health Organisation describes mental health as ‘a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community’.

Mental health is often described as existing on a spectrum. Good mental health means you feel good and function well and can cope with stress more effectively. Poor mental health or mental illness is at the other end of the spectrum with symptoms that can affect a person’s thoughts, feelings and/or behaviour in negative ways. Mental illness can also disrupt a person’s ability to function day to day, their sleep patterns and have an impact on their physical health.

It is important to take steps to maintain good mental health as much as we can and seek advice and professional treatment if experiencing poor mental health.

This resource talks about what people with Down syndrome and their families can do to support good mental health, as well as help identify when professional support might be required.

Acknowledgments

This resource has been developed based on the lived experiences of people with Down syndrome and their families. In addition key information has been sourced from research articles as well as the following resources:

- *Mental Wellness in Adults with Down Syndrome*, a book published in 2006 by Dennis McGuire, Ph.D. & Brian Chicoine, M.D.
- *Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals*, a resource published by the NSW Ministry of Health in 2017

Both these resources are highly recommended for further reading.



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Does having Down syndrome affect mental health?

People with intellectual disability, including Down syndrome, are two to three times more likely to experience mental illness than people without disability.¹

The reasons behind this are unclear but some suggest that social barriers, rather than the disability itself, mean that people with Down syndrome are more likely to experience some of the risk factors for mental illness. These include:

- poor community inclusion
- bullying
- low expectations
- limited access to meaningful work and social activities.

People with Down syndrome may also find it harder to access support due to barriers within the health system such as:

- difficulty finding appropriate doctors or therapists
- doctors attributing symptoms to Down syndrome, rather than mental health
- difficulty understanding effective ways of maintaining good mental health or understanding treatment for mental illness
- difficulty in communicating and expressing feelings, making it harder to talk about issues affecting mental health.

People with Down syndrome can also have specific behaviours and habits that are useful to them but misunderstood by others. This misunderstanding can lead to misdiagnosis or difficulty getting access to the supports that are needed.

Mental health strategies used by people with Down syndrome

When any of us find ourselves under pressure and facing stress, we look for ways to manage this stress. People with Down syndrome are no different and often use the same strategies as other people such as trying to relax with a favourite activity or hobby, talking to friends or taking part in exercise. Sometimes, however, the strategies that work best for a person with Down syndrome can look a bit different to the ways most people manage stress. The two common strategies are: using audible self-talk and familiar routines.

¹ Schroyen Lantman-de Valk, H.v., et al., *Prevalence and incidence of health problems in people with intellectual disability*. Journal of Intellectual Disability Research, 1997. 41(1): p. 42-51.



Self-talk

What is self-talk?

Self-talk is when people talk to themselves. We all talk to ourselves sometimes. People do this to help themselves focus or to respond to strong emotions. The main difference for people with Down syndrome is that this self-talk often happens out loud.

The importance of self-talk for people with Down syndrome

Self-talk is important for people with Down syndrome for many reasons including to:

- help with problem solving
- vent feelings
- help order thoughts
- process events and feelings
- express imagination and fantasy.

Self-talk also has the benefit of helping parents and carers understand what the person with Down syndrome is experiencing.

Self-talk and imaginary friends are common in adolescents and adults with Down syndrome. This should be understood as part of their coping strategy. Families should only be concerned if the self-talk is getting in the way of the person doing other things they want to do or if they seem distressed and/or having symptoms of mental illness. Changes in self-talk can be a reflection of changes that are happening in a person's life and might mean there is a need for some additional support. (e.g. if self-talk becomes dominated by negativity, self-disparagement or self-devaluation).

Routine

Many people with Down syndrome use routines and repetition to help them complete daily tasks. To support good mental health, it is useful for people with Down syndrome and their families to recognise routines and understand why they are useful.

Common routines include:

- doing daily tasks at the same time or the same way every time
- careful organisation and presentation of their home and possessions, as well as themselves
- defined interests in a favourite musician, sports team or celebrity
- repetitive activities such as compulsive writing.

The importance of routine

Routines can be helpful for people with Down syndrome and can support independence. They can help in a number of different ways including:

- making life more predictable
- helping people to relax at the end of the day
- supporting people to communicate when they are having a hard time expressing themselves with words.

When routines can be problematic

While many routines can be useful for people with Down syndrome, there are times when routines can have a negative impact on a person's mental health (e.g. if a routine becomes too rigid and stops a person doing other activities they like or is inappropriate.) When a person is under a lot of stress, they may use routines more rigidly to cope or avoid the cause of the stress.

It's important to notice when a person's routine changes from helpful to problematic as it could mean there is a major stress in the person's life that they might not be able to explain in other ways, especially if they don't use spoken or written language. Look for the cause of this stress and address that too.



Flexibility and resilience

Flexibility is essential to mental wellness. It is important for everyone to be able to adapt and be resilient to stressful events. For a person with Down syndrome, developing flexibility and resilience can take time due to the need for routines which can sometimes be rigid and inflexible. When changing a routine that isn't productive for a person with Down syndrome:

- be patient and allow time for change
- explain why change might be necessary
- break down the issue into smaller tasks
- encourage the person to change an unhelpful routine at a manageable pace
- look for ways to reintroduce a healthier routine that helps the person manage stress.

Pushing or rushing a person to change a routine may cause more stress and be counterproductive, so be patient.

Maintaining good mental health

Many of the strategies recommended for maintaining good mental health in people with Down syndrome are the same strategies that work for the general population – such as eating well, being physically active, having good social relationships, being occupied in meaningful activities, and getting enough sleep.

Now that we understand the ways people with Down syndrome commonly respond to and cope with stressors, let's take a look at ways to encourage and support a person with Down syndrome to maintain their mental wellness in ways that are meaningful to them.



Tips to support a person with Down syndrome

- Encourage the person to be actively involved in making their own decisions.
- Respect the benefit of healthy routines and model ways to maintain them.
- Find a good General Practitioner (GP) who focuses on the person and not just the medical aspects of Down syndrome.
- Be mindful of important transition periods such as transitioning from school into adult options such as further education, employment, volunteering or day services.
- Ensure friendships are made and maintained.
- Encourage the person to pursue all opportunities they are interested in.
- Encourage the person with Down syndrome to join a peer support group where they will have opportunities to develop and strengthen friendships and support networks.
- Don't assume that changes to a person's behaviour and temperament are just a part of having Down syndrome. It could be an indicator of something else such as a reaction to pain or stress, a medication side effect, or poor mental health.
- Create a formal support network for the person with Down syndrome by developing a circle of support or a microboard. <https://downsyndromevoice.org.au/april-2019/2019/3/17/circles-of-support-and-microboards>

Being active in life and the community

Everyone needs the opportunity to do the things they love and that are important to them. This helps to give us a sense of accomplishment and purpose, boosts confidence and helps us connect with others.

In young adulthood, there are many changes that occur including transitions from school to further education, getting a job, becoming more independent, changes to routines, changes within social circles and opportunities to make new circles of friends.

These life events can make it hard for all young adults to manage their mental health, but people with Down syndrome may face additional social barriers to achieving these milestones. As their peers leave school and transition to further study and/or employment, young people with Down syndrome can quickly become isolated, especially when they compare their social life to that of their siblings or friends.

People with Down syndrome often have a higher level of scrutiny of their intimate relationships from family or social networks which can also contribute to increased levels of stress and poor mental health, so it is important for parents and families to be respectful when discussing a person's relationship choices.

Spending time with family (including pets), friends and people in the community can help strengthen mental health and wellbeing. Trying things like volunteering, working, hobbies, joining clubs or committees and new sports are all ways for people with Down syndrome to find safe communities where they can meet new people and feel connected.

Talk about feelings

Talking about your feelings is one strategy that can help with mental wellbeing. Some people with Down syndrome may be very comfortable talking about their feelings and others may need more support.



Some practical suggestions include:

- Help people to name and describe their feelings.
- Brainstorm the things that make them feel better.
- Using books or movies such as *Inside Out* can be a helpful way to start talking about feelings.
- For people with limited verbal communication, look for other ways to communicate about their feelings. This may mean being mindful to changes in behaviour or providing alternative ways to communicate this idea, e.g. visual aids.



Taking time to think about how someone handles tough times is really important. Helping people with Down syndrome develop skills for handling tough times will come in handy now and in the future. Some options to explore include:

- using creative activities like art, music or journaling to express feelings
- spending time in nature
- setting some small goals, and get help seeing them through
- talking kindly to yourself
- physical activity
- practising mindfulness, meditation and/or yoga.

Self-esteem

Having good self-esteem can help contribute to a person's mental wellbeing.



Some practical tips to develop good self-esteem include:

- Talk about what the person is good at and what they enjoy doing.
- Set goals for things that they want to change, achieve or be proud of.
- Get involved in community activities where contributions are valued.
- Be physically active (going to the gym, walking).
- Get involved in self-advocacy. Self-advocacy training can be a great way to help people with intellectual disability feel proud of who they are. Advocacy organisations run this training in each state and territory. For more information, please visit:

<https://www.inclusionaustralia.org.au/contact-us/state-agencies/>

Building independence builds mental health

Sometimes, families can unintentionally limit opportunities for a person with Down syndrome in an attempt to keep them safe. This happens when a person is prevented from trying new things out of fear of them failing or getting hurt. However, it is through failure where people develop skills and reach new milestones.

Importantly, supporting the independence of people with Down syndrome ensures they are staying with their peers through different life stages.

A lack of independence can contribute to poor mental health. It is very important to give people with Down syndrome the opportunity to gradually make their own decisions and take measured risks. People can only learn to make good, well-thought-out decisions when they have had the opportunity to try and learn from any failures. This is called dignity of risk. Down Syndrome Australia have developed a resource about supported decision making and Down syndrome, which is available [here](#).

Mental health treatment for people with Down syndrome

Notice behavioural changes

Changes in behaviour is one of the most common symptoms of mental illness for people with an intellectual disability. Mental health issues can be missed or not treated effectively if behaviours are incorrectly attributed to the person's intellectual disability. Therefore, concerning changes in behaviour should be investigated rather than dismissed as 'disruptive'.

If family, friends or carers have concerns about changes in a person's behaviour, a mental health assessment should be sought to ensure there is not an underlying mental health condition.

Seek advice

If a person with Down syndrome is struggling with their mental health, the same process applies as for people without Down syndrome: seek advice from health professionals and seek out the recommended health interventions available (e.g. counselling, medication, support groups, etc).

One of the most important things you can do to support the mental health of a person with Down syndrome is to develop a good relationship with a General Practitioner (GP). A good GP, especially one you have been seeing for a long period of time, can provide you with regular advice and link you to other services that may be appropriate. Most mental health assessment tools generally ask how the behaviour has been for the past two or four weeks, but a good GP will be able to notice behaviour changes over a longer period if they know the person well. For example, instead of asking how the individual's sleep is currently, a good GP should ask how their patient's sleep has been for the past two years (for example), how it has changed in that time, and how it is now in comparison to that period.

Finding a quality mental health service

If the person with Down syndrome needs additional support, your GP should be able to direct you to an appropriate mental health service (by writing a referral) and may be able to answer any initial questions and concerns you have about what's next.

People with Down syndrome (and their families, if appropriate) must be comfortable with their chosen mental health practitioner such as therapist, counsellor, psychologist, psychiatrist, etc. A good practitioner should make information easy to understand so that the person with Down syndrome is well informed, understands all potential treatments and options, and is able to give appropriate consent.

To deliver quality care, mental health practitioners should:

- be proactive
- focus on strengths
- be flexible
- be multidisciplinary (work with others)
- be empowering and inclusive.

If you find that a mental health practitioner isn't a good fit, you can exercise your right to choose a different practitioner or make a formal complaint.

It is generally encouraged for people (with or without disability) to try a few different psychologists before they find someone that they're comfortable with.



Diagnosing mental health conditions

Identifying a mental health condition in a person with Down syndrome can be challenging. Sometimes a person has a mental health condition that an assessment does not detect because the symptoms are wrongly assumed to be a part of the person's disability. Other times, a person doesn't have a mental health condition but the mental health assessment incorrectly concludes they do. For example, the person may have habits or preferences, or use coping strategies (e.g. self-talk and routines) that seem unusual or bizarre to the treating health professional who incorrectly interprets them.

Before diagnosing a mental health condition, practitioners should also take into account that some behaviours and cognitions that are thought to be due to mental illness may in fact be caused by pain, physical illness, medication side effects or stress. Specific physical checks should be undertaken to make sure there is not another reason for behaviour changes (for example, a case where a tooth abscess caused behaviour that was deemed 'psychotic').

It can be helpful to keep a record or journal of a person's usual routines and habits to create a baseline that can be compared to if things change. This can be useful for clinicians to refer to when diagnosing patients who have Down syndrome but also useful for a person's support network to check back on periodically. This kind of record keeping is also useful for detecting early-onset dementia. Resources about dementia and Down syndrome are available at:

<https://www.downsyndrome.org.au/resources/dementia.html>

Mental health treatment uses the 'recovery model'. This is where people aim to recover from their mental illness, instead of treating the symptoms.

Just because somebody has Down syndrome, it doesn't mean they cannot recover from mental health conditions.

By understanding and identifying the usual and unusual behaviours for a person with Down syndrome and seeking out the right assessments and treatments, people with Down syndrome can manage their mental health and live happier lives.



Handy links

<https://www.sane.org/>

<https://www.headspace.org.au>

<https://www.blackdoginstitute.org.au/>

<https://mhaustralia.org>

<https://www.beyondblue.org.au/>

<https://cmha.org.au>