

Health matters: Staying well and feeling good in middle age

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Australians with Down syndrome are living longer than at any other time in history. Ageing tends to occur more quickly in people with Down syndrome, and health conditions can impair function and enjoyment. Thoughtful healthcare is essential to optimise quality of life and participation. This article is a guide to health considerations for people with Down syndrome in middle age.

The health issues experienced by people with Down syndrome include those important to everyone, and those with specific relevance to people with Down syndrome.



Health promotion and disease prevention

Consider:

- Regular exercise – 30 minutes of exercise a day
- Healthy well balanced diet
- Maintenance of a healthy weight
- Monitor blood pressure and blood lipids (including cholesterol) annually
- For people using a wheelchair, weight bearing activity is important to bone and muscle growth and strength. A physiotherapist can provide guidance

Oral health is crucial to general health and dignity

Consider:

- Preventive oral hygiene routines
- Regular dental review (every 6 months for people with Down syndrome)

Routine immunisation

Consider:

- Tetanus, pertussis and diphtheria vaccination
- Annual influenza vaccination
- Pneumococcal vaccination for people at risk, including those with Down syndrome

Screening tests

Consider:

- Pap tests (for those who have ever been sexually active)
- Mammography for women over 50 (earlier if family history)
- Prostate screening
- Bowel cancer screening

Mental health is fundamental to a good life

Belonging, feeling valued, knowing whom to turn to when help is needed are important factors in building resilience to adverse life experiences.

Consider:

- Encouraging healthy respectful relationships with peers
- Facilitating trusting relationships with those who can provide help and guidance
- Supporting opportunities to belong to communities
- Adults with Down syndrome are vulnerable to anxiety, and/or depression and may find it difficult to describe their symptoms.
- People with mild intellectual disabilities may find counseling helpful. Those with more severe degrees of disability usually respond well to anti-anxiety and anti-depression medication.

Implications of congenital abnormalities and previous surgery in people with Down syndrome

Consider:

- Antibiotics prior to surgical & dental procedures for those who have had cardiac surgery and/or have congenital heart defects.
- Heart valve defects may occur in adulthood. Echocardiography required in early adult life and if cardiac murmurs are detected.

Gastrointestinal issues

- Gastro-oesophageal reflux may cause pain (especially after meals and when lying down) or anaemia.
- Coeliac disease should be considered if there is recurrent abdominal pain, excessive gas, weight loss, diarrhoea, anaemia, unexplained fatigue.
- Constipation can lead to pain, discomfort and incontinence and needs energetic management.

Hearing and vision in people with Down syndrome

- Increased risk of hearing and vision impairments throughout life.
- Sensory impairments profoundly undermine ability to engage and participate.
- Vision should be tested every 2 years or if there is any suspicion of deterioration.
- Hearing should be tested every 2 years or if there is any suspicion of deterioration.

Thyroid dysfunction is more common in people with Down syndrome

Consider:

- Impaired thyroid function may be present at birth or be acquired at any time.
- Annual thyroid function tests AND if there are signs of thyroid underactivity ('slowing down', slow pulse, fatigue, depression, weight gain, hair loss, constipation) or overactivity ('speeding up', fast pulse, irritability, anxiety, sleep disturbance, fatigue).

Diabetes is more common in people with Down syndrome

- Test annually or if symptoms occur
- Type 1 diabetes is related to immune function, usually develops in children, is characterised by severe thirst, excessive urination, weight loss and weakness. Early detection is essential to avoid serious illness and death.
- Type 2 diabetes is associated with increasing age and weight, progresses slowly.
- Both are associated with risk of cardiovascular, renal and eye disease and must be energetically treated.

Obstructive sleep apnoea relates to low muscle tone and being overweight

- Investigate if excessive tiredness, snoring, brief cessation of breathing during sleep.

Immune system of people with Down syndrome is often somewhat impaired

- Associated with higher incidence of respiratory infection and some immune disorders (eg thyroid dysfunction, coeliac disease, Type 1 diabetes).
- Leukemia is rare in adulthood, but is more common in people with Down syndrome.

Atlanto-axial instability

- Some people with Down syndrome have an abnormality in the bones at the top of the spinal column that can result in atlanto-axial joint instability (AAI). Most never develop symptoms, but in some (~1%) the spinal nerve damage causes neck pain/stiffness, motor or sensory changes in the limbs, and/or changes in bladder/bowel function. If untreated this may lead to permanent paralysis. Symptoms must be investigated urgently. Surgery may be required.
- Investigate if there is weakness or tingling/numbness in limbs, neck pain/stiffness, or changes in bladder/bowel function.

Medication

Consider:

- Multiple medical issues may require multiple medications, increasing the risk of drug side effects.
- People with Down syndrome may find it difficult to identify or describe side effects.
- Health professionals and carers must remain vigilant for changes in behaviour that may indicate side-effects (eg not wanting to eat may relate to nausea).

Behaviour

Consider:

- Behaviour is a communication.
- Behaviour change may relate to physical/mental ill-health, a reaction to the environment and/or an attempt to obtain or avoid something.

Unusual behaviours may reflect:

- A lack of understanding about the behaviour expected in certain situations.
- Emotion (excitement, fear, frustration) or experience (loneliness, powerlessness, lack of control) or physical discomfort (pain, hunger, thirst, heat, cold, toothache, nausea, constipation or reflex) or mental distress (depression, anxiety, hallucinations, confusion).
- Attempts to obtain something (food, a favorite object, social engagement, control) or escape something (social demands, noise, an activity, boredom).
- Note: Consider psychological or physical abuse if there is a sudden change in behaviour.
- Behaviours may be further complicated by frustration or despair at not being understood.

The key to addressing the behaviour is to understand what it is communicating. Once understood the underlying issue can be attended to and/or the person can be supported to find more appropriate ways of obtaining the outcome they are seeking.

Skill decline

There are a number of reasons why someone with Down syndrome may lose skills in middle age – these are outlined in the article on pp 16 – 18.

Alzheimer's disease is one possible cause, but is unusual before the age of 40. Regardless of age, treatable causes of skill loss must be considered before a diagnosis of dementia is made.

Social changes

Although not strictly health related, changes in life circumstances of people with Down syndrome can have profound effects on physical and mental health.

Consider potential impact of changes relating to:

- Important people and relationships – family, friends & paid carers
- Opportunities for choice, decision-making and autonomy
- Interests and ability to share these
- Changes in routines and plans
- Developmental life stages and needs and opportunities at each

Key message

Ongoing vigilance in health monitoring is essential to optimise physical, mental and social health and provide the person with Down syndrome with the best foundation to develop, to build and enjoy relationships, and participate and contribute throughout their life.

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Further information:

Medical care for people with Down syndrome
www.cddh.monash.org

Australians with Down syndrome: Health matters
www.racgp.org.au/afp/201104/201104tracy2.pdf

Understanding intellectual disability and health
www.intellectualdisability.info/search?SearchableText=down+syndrome

Dental advice for people with disabilities
www.dhsv.org.au/dental-advice/general-dental-advice/people-with-disabilities/