Down Syndrome
Australia

Ageing

This document has been produced by
Down Syndrome Australia.

Down Syndrome Australia is the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

Acknowledgements

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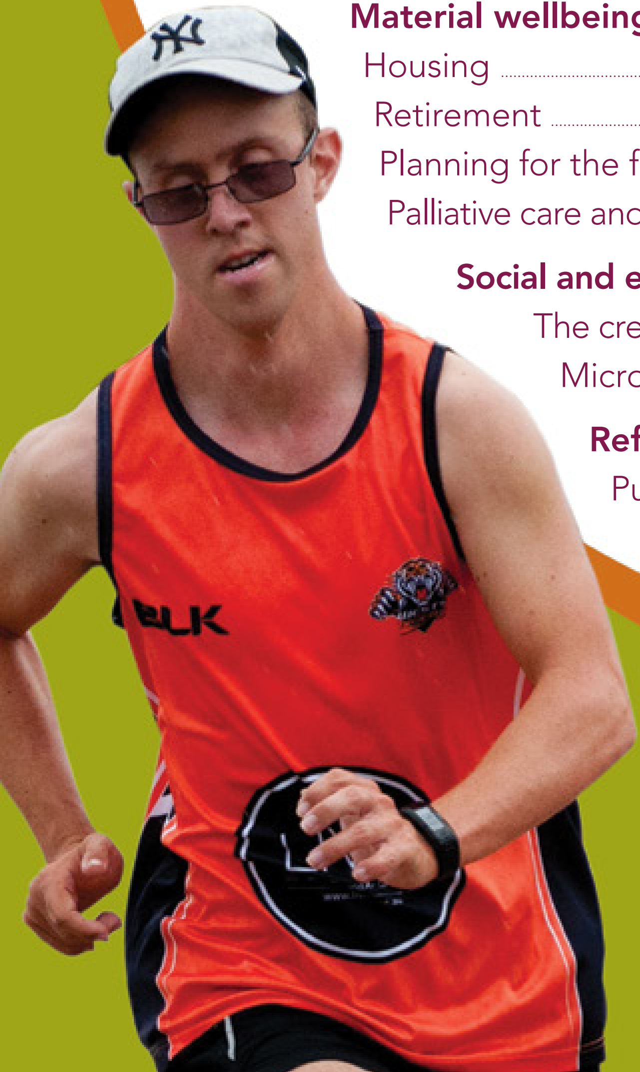
Contents



Ageing and Down syndrome

In Australia people with Down syndrome have an average life expectancy of 60 years of age, and more than one in ten adults with Down syndrome will live to 70 years. Ageing and growing older brings with it many exciting milestones and some unexpected challenges for all people, and people with Down syndrome are no different.

This booklet has been designed as a resource for adults with Down syndrome, their families, medical professionals and anyone involved in the health and wellbeing of someone with Down syndrome as they age. We have explored four key areas of wellbeing[1], and divided the resource into four main sections to help develop and maintain a coordinated approach to support and optimise the wellbeing of an ageing adult with Down syndrome.

The key areas which we will look at are:

- productive wellbeing
- physical wellbeing
- material wellbeing
- social and emotional wellbeing.

By recognising and understanding individual needs in each of the key areas, and working with the person with Down syndrome, better outcomes can be achieved. Planning for the future allows the person with Down syndrome to grow old with dignity, love and care. It also helps to reduce the many stressors ageing can bring to them and their carers, families, medical professionals, therapists, work colleagues and friends. It is also important to stay connected to local state or territory Down syndrome associations who are able to assist with accessing up to date, relevant information.

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[1] Felce and Perry (1997)

Productive wellbeing

Productive wellbeing is about a person's developmental growth, what he or she does on a daily basis, their independence, their productivity and their contribution to their own community and life. Productive wellbeing is linked to an individual's ability to exercise choice, control and contribute to what happens to them, and to use their time constructively. Productive wellbeing can be expressed in all areas of life, at home, work, leisure and in education.

As people with Down syndrome age, they will usually continue to be involved in many of the same hobbies, activities and social engagement as they have in the past. Sometimes due to ageing, things may need to be adapted to make this possible (for example, if someone has arthritis they may need to change their participation in sport). Sometimes people like to explore new hobbies or ways of participating in their community. They may stop work and want to do some volunteering. Down Syndrome Australia has a range of resources around community inclusion which may help to support ongoing community engagement. These resources can be found at: **www.downsyndrome.org.au/resources/toolkits/**

As people age, it is important that they have the opportunity to continue to be involved in their community, enjoy time with their friends and family, and to participate in meaningful activities. This resource encourages the productive wellbeing and growth of all individuals with Down syndrome, to enable them to effectively contribute to their own ageing care and plans for their future.

Physical wellbeing

Physical wellbeing is concerned with the individual's health. Sustaining a healthy lifestyle by eating well, exercising regularly and having annual checks with medical professionals are the most important steps to maintaining physical wellbeing. We will look at a range of medical conditions that may occur more commonly in adults with Down syndrome. Certainly not all of these will occur in each individual but it is good to know what *may* occur. We also discuss conditions that develop with age and can present earlier in ageing adults with Down syndrome, these may include:

- hypothyroidism
- Type 2 Diabetes (occurs more commonly in people aged over 45)
- visual impairments such as cataracts and keratoconus
- auditory impairments
- heart abnormalities
- gastrointestinal conditions
- coeliac disease
- obesity
- reflux
- constipation
- atlanto-axial instability
- obstructive sleep apnoea
- depression
- epilepsy
- dementia – Alzheimer's disease
- immunodeficiency
- arthritis.

DSA have developed a health screening tool for health professionals and carers of people with Down syndrome. This tool provides information about health screenings for people with Down syndrome across the life span. **www.downsyndrome.org.au/services-and-supports/professionals/health/health-screening-tool/**

Suggested testing or screening regimen:

Biannual

- audiology testing and otoscopy (ear exam)
- visual screening by an optometrist for vision, glaucoma, keratoconus and refractive errors
- screening for coeliac disease.

Annual

- blood test for: thyroid function (TSH), full blood count, urea and electrolytes, liver function, cholesterol screening and blood glucose level
- blood pressure testing
- cardiovascular exam which may include echocardiogram (ECG)

Biannual in women

- mammogram (50–74 year old) along with regular breast examinations

Every 5 years in women

- PAP smear (18–70 year olds who have ever been sexually active)

Annual in men

- testes examination
- prostate specific antigen (PSA) blood testing annually if over 50

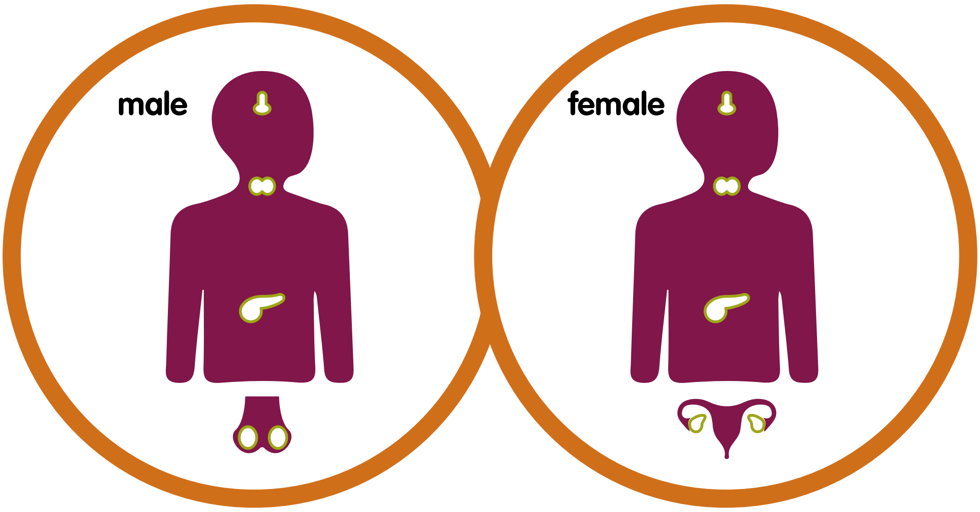
Every 5 years after the age of 50

- bowel screening for faecal occult blood. A free test is sent to everyone at age 50 and tests can be purchased from a chemist if there are concerns about blood in stools or bowel pain.
- haemorroids check

It is also recommended that a diary or journal of all doctor and allied health appointments, tests, scans and test results are kept together by the individual as well as by the GP. All medications that the person is taking and any side effects experienced by the person should also always be noted. For a person with Down syndrome, it is recommended that medications be started at a lower dose than the general population and side effects be closely monitored.

My Health Matters (MHM) is a folder for people with an intellectual disability to take to appointments. The MHM folder aims to empower people in their own health story and to improve their health outcomes. **https://cid.org.au/resource/my-health-matters-folder/**

Endocrine system



Hypothyroidism

Studies have shown that approximately 40% of adults with Down syndrome will develop hypothyroidism (underactivity of the thyroid gland), causing metabolism to slow down (Barnhart R. C. & Connolly B., 2007). The thyroid gland regulates many metabolic processes, including growth and energy use, making proteins and regulating hormones. Overactivity (hyperthyroidism) of the thyroid gland can also sometimes occur.

If untreated, hypothyroidism may present as a decline in cognitive skills and may be misdiagnosed as dementia.

Signs to look for are:

- increased levels of lethargy and fatigue
- decreased motivation
- mental sluggishness
- unusual weight gain
- constipation
- bradycardia (slow heart rate)
- dry skin and hair
- muscle cramps and aches
- intolerance of cold.

Diabetes

There are no Australian research studies to show if type 2 diabetes is more common in adults with Down syndrome, however we do know that 5–16% of Australian adults over the age of 45 have diabetes or pre-diabetes (ABS 2011–12 Australian Health Survey). It is also known that poor diet, lack of exercise and obesity are common causes of diabetes.

Treatment for type 2 diabetes usually involves dietary management, increasing exercise and sometimes tablet medication as advised by your GP.

Signs to look for:

- increased thirst and dry mouth
- sudden weight loss
- increased hunger (especially after eating)
- re-occurring infections
- frequent urination or urine infections
- fatigue (weak, tired feeling)
- mood swings
- vision problems
- numbness in fingers or toes
- headaches.

Further information on diabetes and checklists can be found at:
www.diabetesaustralia.com.au

Menopause

Menopause is said to have occurred 12 months after a woman has had her last menstrual period. Menopause is a natural biological process and occurs due to changes in female hormone levels. Studies have indicated that women with Down syndrome have an earlier age onset of menopause - approximately five to six years earlier than the general population (Esbensen A. J., 2011). This has implications on the general health of women with Down syndrome. Menopause produces an increased risk for heart disease, depression, osteoporosis, dementia and breast cancer in all women, but the incidence of breast cancer in women with Down syndrome is reportedly very low. Symptoms of menopause may occur at any of the three stages of menopause (peri-menopause, menopause and post menopause).

Signs to look for:

- irregular periods or cessation of periods
- hot flushes, night sweats, sweating
- tiredness, insomnia
- weight gain and food cravings
- depression
- mood or behavioural changes including increased anger or irritability
- reduced sex drive
- changes in skin and hair condition.

The treating GP should be consulted and treatment may be recommended to reduce the impact of these symptoms.

Sensory

Sensory changes may produce alterations in a person's mood, motivation and participation in the world around them. These conditions can often be rectified or improved with glasses, hearing aids or other treatments and should always be investigated.

Eyes

Cataracts and glaucoma can be a natural part of the ageing process.

Cataracts glaucoma

Cataracts are the most frequent eye disorder reported for adults with Down syndrome. Recent studies have shown that the occurrence of non-congenital cataracts appears to affect 42% of individuals over the average age of 48 (Zigman W. B., 2013). Surgery is often the recommended treatment. Signs to look for:

- cloudy eye lenses
- blurry vision
- unable to see in dim light
- seeing halos around lights.

Glaucoma

Glaucoma is caused by deterioration in the optic nerve and gradually affects sight without warning and often without symptoms. Treatment is a life time regime of drops prescribed by a doctor.

Age related long-sightedness is called presbyopia and like hyperopia (which can occur at any age) makes it difficult to focus on near objects. Myopia makes it difficult to focus on objects in the distance. Glasses can be prescribed by an ophthalmologist to treat many of these vision issues.

Signs to look for are:

- headache
- tired eyes
- frowning or squinting
- blurred vision when looking at close or far away objects.

Keratoconus (conical cornea) is a progressive eye disease that causes the cornea to weaken and bulge outward. Blepharitis (inflammation of the eyelid), conjunctivitis (inflammation of the eyeball and inner eyelid) and keratitis (inflammation of the cornea) are common in adults with Down syndrome. A GP can check for these conditions and provide drops or ointment. Signs to look for are:

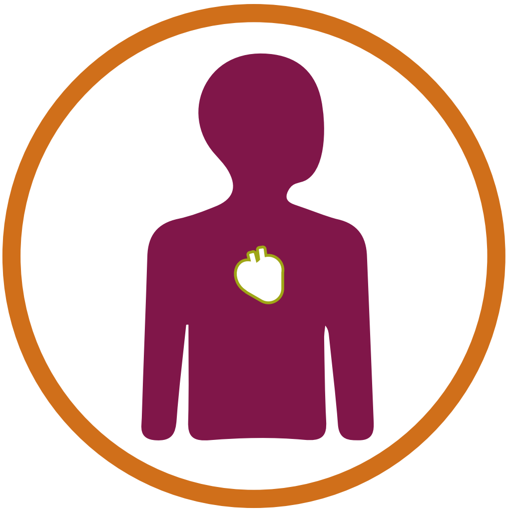
- redness
- pain, itchiness or burning feeling
- stickiness
- watering of the eyes.

Ears

Hearing loss that is age related appears to be more common in adults with Down syndrome and has an earlier onset than the general population. It is thought that medical conditions and recurrent ear infections early in life may influence the ear health of the individual later in life. Hearing aids can assist with deteriorating hearing. Signs to look for are:

- difficulty hearing
- person asking for things to be repeated or ignoring when spoken to
- ringing in the ears
- sensitivity to sound
- social isolation
- changes in speech.

Heart



Adults with Down syndrome may have a higher occurrence than the general population of cardiac valve conditions, cardiac arrhythmias or pulmonary hypertension which can occur even in those who have had no previous heart issues (Prasher V. P., 1994). An Australian study (Sobey C.G., 2015) suggests there may be a link between these issues and a higher incidence of stroke or transient ischemic attack (TIA), also known as mini stroke. Some experts recommend that all young adults with Down syndrome receive an annual cardiac assessment, regardless of cardiac symptoms.

Signs to look for:

- fatigue
- weight gain
- difficulty in breathing (dyspnoea) with activity.

Gastrointestinal

Adults with Down syndrome may be prone to a wide range of gastrointestinal problems which may include reflux, constipation, obesity and coeliac disease.

Coeliac disease (CD)

Coeliac disease (CD) is a condition where the immune system reacts abnormally to gluten (a protein found in wheat, rye, barley and oats), causing small bowel damage and preventing absorption of some nutrients. CD can present at any age and a single negative test does not rule out CD for life. Doctors will do specific blood tests for initial screening. If the results are positive, your doctor will refer you to a gastroenterologist, as a biopsy of the small bowel is required to confirm diagnosis.

Signs to look for are:

- fatigue
- vomiting
- abnormal abdominal distension
- abdominal pain
- bulky fatty and smelly bowel motions
- diarrhoea
- constipation.

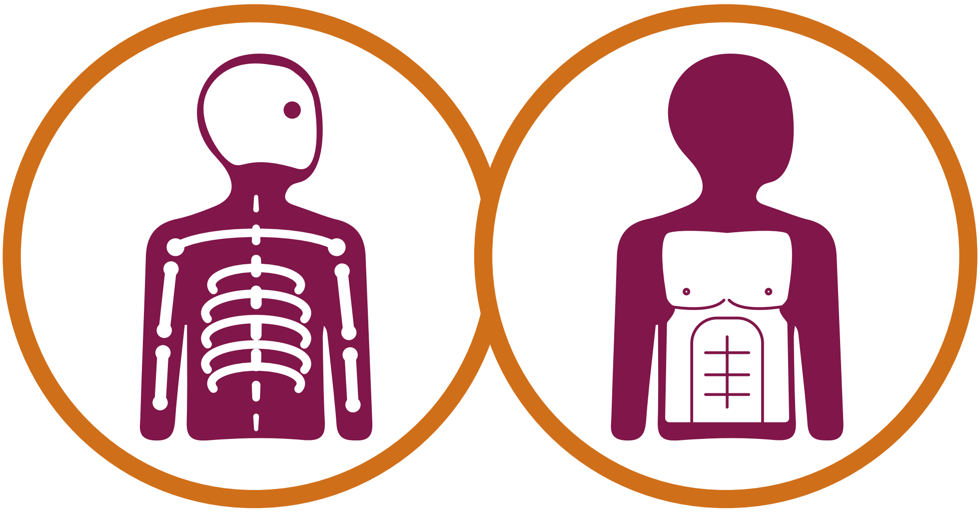
Obesity

Obesity, in all people, may be related to many medical issues such as diabetes, joint pain, cardiac disease, depression and respiratory problems such as obstructive sleep apnoea (OSA). A diet which is higher in fats and sugars than healthy food choices and a more inactive life, can also contribute to obesity. Steps to prevent obesity can be made by improving a person's lifestyle and wellbeing. The presence of hypothyroidism, coeliac disease or mitral valve issues can increase a person's tendency to gain weight and should be identified and treated by a medical practitioner.

Strategies to help prevent obesity could include:

- access to recreation that motivates and is enjoyable
- community interactions
- speak with a Dietician about a healthy, balanced diet

Musculoskeletal



Some adults with Down syndrome may show signs of osteoporosis and arthritis at an earlier age than the general population, this may be due to lower activity levels, early onset menopause or other causes.

Osteoporosis

Osteoporosis occurs when the bones become weak and brittle, making them more likely to break. Anyone can develop osteoporosis but it is more common in people who have a family history of osteoporosis, early onset menopause or long-term use of some anti-seizure medications and steroids. A healthy, calcium-rich diet, vitamin D and regular physical activity throughout life can help prevent osteoporosis. Bone density tests may be done if this condition is suspected.

Arthritis – rheumatoid and osteoarthritis

Rheumatoid arthritis is an autoimmune condition which results in inflammation in the joints, particularly the hand, wrist, ankle, and foot bones, but can affect any joint.

Osteoarthritis is a result of wear and tear on the joints and can occur as a person ages. It usually affects hips, knees, shoulder and back joints. It is painful, may restrict movement and may prevent people participating in usual activities. Treatment is usually about pain management and keeping joints moving, sometimes surgery may be required to replace worn joints. Activities which are fun and motivating but low impact such as swimming or hydrotherapy, are recommended.

Atlanto-axial instability

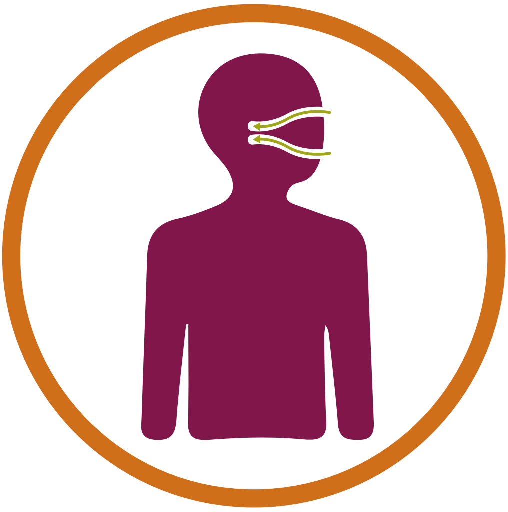
Degenerative osteoarthritic changes affecting the spine are reported to affect between 22–40% of adults with Down syndrome (Esbensen A.J., 2011). If instability of the first and second cervical spinal bones is present and degenerative changes occur there is a risk of damage to the cervical spinal cord.

Signs to look for are:

- weakness in limbs, arms or hands
- neck pain
- changes in behaviour, walking pattern
- incontinence
- clumsiness
- tingling in fingers or toes.

Respiratory

Obstructive sleep apnoea



Obstructive sleep apnoea (OSA) is present in approximately 30–55% of children with Down syndrome due to the anatomy of the face and throat and decreased muscle tone. Although there are limited studies, adults with Down syndrome still have the same anatomy and often have other associated factors, so it is suggested that OSA has a high prevalence amongst an ageing population with Down syndrome (Trois M. S et al., 2009). Hypothyroidism and obesity can also be associated with OSA. Sleep studies, which can be referred by your GP, can be performed to detect OSA. Treatment can include using a breathing machine called a CPAP machine when asleep, along with weight loss and other lifestyle modifications.

Signs to look for are:

- irritability
- inability to concentrate and pay attention
- fatigue and other behavioural changes
- snoring
- waking frequently during sleep.

Neurological

Neurological changes such as epilepsy, Alzheimer's disease and dementia are areas to be aware of in the ageing person with Down syndrome. The most common and prevalent neurological change for an adult with Down syndrome is Alzheimer's disease with up to 55% at age 40 showing some signs and symptoms of having Alzheimer's disease (Head E. et al., 2012).

Dementia

Dementia is an umbrella term that includes a range of conditions that cause symptoms associated with a decline in memory or other thinking skills. Dementia is not a normal part of ageing. Normal ageing can have an impact on memory or speed of thinking, but not to the same degree as dementia. Loss of previous skills or abilities is a sign of something more serious than normal ageing occurring. Alzheimer's disease is the most common form of dementia in the general population.

People with Down syndrome are more likely to develop dementia than other people in the population. Independent studies have revealed different rates, but research suggests that more than half of people with Down syndrome have a diagnosis of dementia by the time they reach 60. It is uncommon for someone with Down syndrome to have dementia before the age of 45.

Down Syndrome Australia has a detailed resource on Dementia available on our website: **www.downsyndrome.org.au/blog/resource/down-syndrome-and-dementia-a-guide-for-families/**

Recognising and diagnosing Alzheimer's disease

The first sign of Alzheimer's disease is usually a change in the person's level of functioning. The difference for people with Down syndrome is that there is a level of pre-existing intellectual disability, which affects thinking, remembering and performing daily skills. It is therefore helpful to consult a medical practitioner who is familiar with the person, their general health and their communication style.

It is also valuable to assess the individual's overall medical health, and medications, before assuming Alzheimer's disease. As Alzheimer's disease is diagnosed clinically and there is no single blood test or scan that can make or confirm a diagnosis, 'baseline' knowledge of the person and their medical history assists the medical practitioner enormously.

It is a good idea to collect and keep a record of the person's abilities from late teens throughout adult life. The more detailed the information, the more valuable it is for a clinician. Taking photographs or video clips of the person performing daily tasks is very helpful. It is important that the clinician performs a thorough and full assessment of the person's physical and mental health, including medical, psychiatric, environmental and social influencing factors.

It is worthwhile suggesting visual memory tests rather than auditory. Side effects of any current medications should also be looked into as a possible cause of changes in a person's ability. Your GP can perform these assessments and, if required, refer the person to a public or private assessment service.

After diagnosis

There is no cure for Alzheimer's disease, however, there are some medications that may have some benefit to cognitive function and quality of life. For the person with Down syndrome, it is commonly suggested that these are commenced in lower doses and closer attention paid to observation of side effects. These medications should only be prescribed by an accredited medical professional, such as a geriatrician, neurologist or psychiatrist.

There is also a range of strategies that can be put in place to assist the person with Down syndrome who has dementia and improve their quality of life. This can include different approaches to communication, ensuring the physical environment is set up appropriately, and ensuring that any issues with pain are treated.

Support

It is very important to ensure that the person with Down syndrome and their carers have a support network. Alzheimer's disease is a progressive disorder and the person's needs will increase over time. The network of support should include a primary medical person (GP) who can refer the individual to allied health and other home-based supports when required. It is also very important to support the person and their symptoms by creating a team around the person with individuals and environments they feel comfortable and familiar with.

Family members may want to seek support through their local **Down syndrome organisation**, or their local **Dementia Australia** office. Dementia Australia maintains a national helpline which includes a telephone service (1800 100 500) as well as an online web chat service (go to **www.dementia.org.au** for more information).

- Routine is very important. Change can be stressful for a person with Alzheimer's disease. It can increase the fear and fatigue of trying to make sense out of an increasingly confusing world.
- Avoid environmental stressors – loud sounds, loud voices, poor lighting.
- Keep the person active but simplify daily tasks to become more manageable.
- Ensure a safe living and working environment.
- Make use of visual cues and photo memory cards of familiar people, places and activities.
- A positive approach should be emphasised and non-verbal communication used, which can create a safe and calm atmosphere. Tone of voice, facial expressions and body language should all be calm and positive. Avoid negative words and actions.
- Use strategies to assist the person to understand what you are saying – make eye contact, show the person what to do, use visual aides and short concise sentences, and deliver information slowly.
- Patiently wait for responses.
- Observe for behaviours that may represent feelings of frustration, anger, pain and anxiety.

Resources and contacts

Down Syndrome Australia has produced a resource called Down Syndrome and Dementia: A Guide for Families. It is available at: **www.downsyndrome.org.au/blog/resource/down-syndrome-and-dementia-a-guide-for-families/**

For further support and services specific to your state or territory contact your local Down syndrome association via **www.downsyndrome.org.au/about-us/our-federation/**

Dementia Australia: www.dementia.org.au or **1800 100 500**

Dementia Behaviour Management and Advisory Services (DBMAS): www.dbmas.org.au or **1800 699 799**

General information on aged care: www.myagedcare.gov.au

Better Health: www.betterhealth.vic.gov.au/conditionsandtreatments/dementia

Material wellbeing

As with all stages of life for a person with Down syndrome, it is important to plan ahead. Planning for housing and living environments is no different. It is also very important to ensure that the person with Down syndrome is properly included in the planning process. Planning allows for decisions to be made when all options can be calmly and methodically weighed up without other factors influencing a decision-making process.

Housing

As the person with Down syndrome ages, it is important to periodically discuss with them whether their living arrangements are still working well for them. Things to keep in mind should include independence, health, safety, and access to transportation.

Some considerations that need to be thought about are:

- Proactively plan for possible illness, disease, incapacitation or death of the caregiver. Dependence on one individual may be unrealistic in the long term. Explore other options for future care.
- A gradual transition to alternate living arrangements may be helpful.
- Be proactive when looking for shared accommodation, discuss the ageing process and modifications that can be made as the individual ages.

- If changes to where the person lives are needed, try to minimise the impact by allowing for current activities to continue and proximity to family and friends to be maintained.
- The impact of change is decreased when there is planning, the person with Down syndrome is involved and when the change occurs one thing at a time.
- Maintain social connectedness.

Contact your local Down syndrome association for advice about local services to assist with housing and accommodation and possible funding options. Your local Down syndrome association will also be able to assist with keeping you up to date with changes in the NDIS and how it impacts on housing and accommodation.

Retirement

Retirement is a natural progression for any working person and can often bring with it different emotional responses. Some people may feel lonely or sad after leaving employment. Planning for retirement for a person with Down syndrome is a very important part of ageing. Ensure that the person with Down syndrome understands that retirement is a natural part of most people's working life, and plan for alternative interests and activities that the person can participate in instead of work.

Planning for the future

A major concern for people who support a person with disability is how the person they care for will be supported in the future when they are no longer able to provide the love, support and care themselves. The following links provide information concerning some decisions and issues that you may need to address when planning the future with a person who has Down syndrome.

The Department of Social Service (DSS) *'Planning for the Future: People with Disability Booklet'* provides:

- guidance on the things to consider when planning for the future
- options available to families when planning for the future
- information about how to set up a trust
- information about how to obtain financial and legal advice.
- useful contacts

A copy of the booklet can be found at **www.dss.gov.au/disability-and-carers-publications-articles/planning-for-the-future-people-with-disability**

Down Syndrome Australia strongly supports self-determination for adults with Down syndrome, however, many will need the support of a parent or other adult in making decisions about financial, medical or accommodation matters. Supported decision making is a model for supporting people with disabilities, often cognitive disabilities, to make significant decisions and exercise their legal capacity. Specific decisions are addressed, weighed and concluded by the person with disability, while drawing on the support of family members or other trusted advisors.

'Supported Decision Making' explains what supported decision making is, why it is important, and how to make it happen. **www.downsyndrome.org.au/blog/resource/supported-decision-making/** 'Decision making, guardianship, and people with Down syndrome' covers common questions people about decision-making and guardianship. **www.downsyndrome.org.au/blog/resource/decision-making-guardianship-and-people-with-down-syndrome/**

The Office of the Public Advocate website in each state has information on obtaining power of attorney, guardianship and administration, medical consent and other information which may be helpful.

Palliative care and end of life choice

For some individuals who may be experiencing a life-limiting illness, decisions may need to be made on their behalf, particularly in circumstances where the person's quality of life is very poor. Palliative care services are available to assist with in-home or in-hospice facilities. These discussions and decisions should be made in consultation with your medical practitioner, and the person with Down syndrome, if possible.

More information is available at: **www.palliativecare.org.au**

Social and emotional wellbeing

A person's social connectedness and emotional wellbeing affects all other areas of their life and can influence both physical and mental health, directly and indirectly. Essential in a well-balanced life is the maintenance of social and emotional wellbeing. Inclusion in the community, having friends, playing an active role in family and being valued ensure a sense of self-worth and subsequent overall wellbeing.

Social isolation and lack of social connectedness can be one reason for an individual to have feelings of depression. Depression can have similar symptoms to that of Alzheimer's disease and must not be ruled out in the individual with Down syndrome. Sometimes the person with Down syndrome could have difficulty in expressing the emotions of depression. The changes may be observed by others around them.

Signs of depression to look for are:

- change in mood
- loss of interest in previously enjoyed activities
- deterioration in ability to concentrate
- changes in sleep patterns
- changes in appetite
- lack of interaction with others.

When treating depression it is important to firstly consult the person's GP who can refer to an appropriate clinician if necessary. In addition to medical intervention, it is also very important to look at, and address, circumstances in the person's life which may cause depression such as bereavement, changes in living environment, relationship issues, retirement, menopause or any other external factors.

UNSW Department of Developmental Disability Neuropsychiatry has a free e-learning course for families on intellectual disability and mental health. This course can assist families in better understanding some of the issues, symptoms, and how to best respond. This can be accessed at: **www.3dn.unsw.edu.au/content/carers-elearning**

They have also developed a well-being record which can be used to document how the person usually behaves and feels so that any changes can be identified. This record can be used by health professionals who are doing an assessment to look at changes in wellbeing. This resource can be downloaded here: **www.3dn.unsw.edu.au/wellbeing-record**

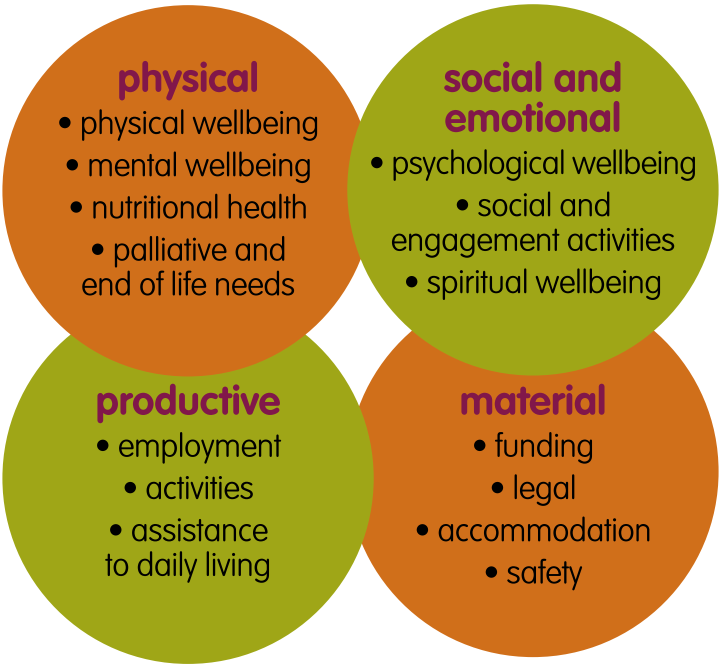
There are many different ways people can access support to assist in overall wellbeing. Circle of supports and microboards are two options which are outlined below. Some useful links have also be provided to further information about planning for the future.

The creation of a circle of support

All of us have different ways of getting support when we need it. Many people rely on some kind of support network to encourage us and help us out at different times in our life. A circle of support is one way of creating a more formal support network for a person with a disability. It involves a group of people who are invited to volunteer to come together in a deliberate way for the support of, and in the interests of, the person with Down syndrome. It should have a focus on the needs and wants of the person with Down syndrome. A circle of support can occur organically or be planned.

The group forms a community of friendship and support around the person with Down syndrome and supports the individual to have control over their life. It can work in many different ways. Often the group might meet together to work with the person on how they want to live in the future and what is important today.

Listed on the next page are some suggestions for consideration when reflecting on what to work towards with the person.



physical

- physical wellbeing
- mental wellbeing
- nutritional health
- palliative and end of life needs

social and emotional

- psychological wellbeing
- social and engagement activities
- spiritual wellbeing

productive

- employment
- activities
- assistance to daily living

material

- funding
- legal
- accommodation
- safety

Every circle of support is individual to the person at the centre. There is no right number of people who participate and the number can also change as the individual's life situation and needs change. Often an initial meeting of chosen people is arranged to give information about what the circle is and roles each person could take in the circle. Some people may provide practical support such as teaching the person a new skill, for e.g. painting, catching transport or cooking. Others may have an advisory role such as where to look for information or how to fill out forms. Others may offer an emotional support such as being the person to call in the middle of the night if they need to talk. Members of the group may come and go over time, or move from being very active, to being on the periphery. How often the group comes together, how formal the meetings are, their location and the topics discussed will also vary depending on the changing wants and needs of the person with Down syndrome.

Suggested resources and examples on how to create a circle of support can be found at these websites. Your local Down syndrome association can assist you with creating a circle of support for someone with Down syndrome:

www.civilsociety.org.au/Circles.htm

www.mychoicematters.org.au

www.adhc.nsw.gov.au

www.learningdisabilities.org.uk

Microboards

Microboards are a type of circle of support but are more formalised. They are an incorporated body and the people involved act as board members. It is set up as a not-for-profit entity and incorporation means that the board can manage or raise funds on behalf of the person they are assisting. They were originally designed in Canada to allow people with a disability to move away from traditional services and receive individualised funds. The microboard works with the person to help them plan and achieve their goals for a good life. NDIS funding may be able to be used to set up a microboard.

For more information about microboards please visit: **http://microboard.org.au**

Other helpful resources for planning for the future

Some other helpful resources that provide information on helping people with a disability to plan for the future can be accessed at:

Planning for the Future: **www.dss.gov.au/disability-and-carers-publications-articles/planning-for-the-future-people-with-disability**

Supported Decision Making: **www.downsyndrome.org.au/blog/resource/supported-decision-making/**

Decision making, guardianship, and people with Down syndrome: **www.downsyndrome.org.au/blog/resource/decision-making-guardianship-and-people-with-down-syndrome/**

Disability Gateway: **www.disabilitygateway.gov.au**

Carer Gateway: **www.carergateway.gov.au/future-planning**

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Publications

Down Syndrome - Information sheet for Adults
The material in this sheet has been adapted from the Therapeutic Guidelines book 'Management Guidelines for People with Developmental and Intellectual Disabilities' and updated from the 2005 version, Management Guidelines – Developmental Disability' which can be consulted for more detailed information.

www.cddh.monash.org

Annual Health Checks for Adults with Down's Syndrome
Ageing and its Consequences:
A guide for Parents and Carers
Supported Living Series Factsheets

Down's Syndrome Association
www.downs-syndrome.org.uk

Aging and Down Syndrome: A Health & Well-Being Guidebook.
National Down Syndrome Society ndss.

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Associations

National: 1300 881 935

New South Wales

Down Syndrome NSW
T: 1300 881 935
E: admin@dsansw.org.au
W: www.downsyndrome.org.au/nsw

Victoria

Down Syndrome Victoria
T: (03) 9486 9600
Toll Free 1300 658 873
E: info@dsav.asn.au
W: www.downsyndrome.org.au/vic

Queensland

Down Syndrome Queensland
T: (07) 3356 6655
E: office@downsyndromeqld.org.au
W: www.downsyndrome.org.au/qld

South Australia

Information Service South Australia (Down Syndrome Australia)
T: 1300 344 954
E: infoSA@downsyndrome.org.au
W: www.downsyndrome.org.au/sa

Western Australia

Down Syndrome WA
T: (08) 6253 4752
E: admin@downsyndromewa.org.au
W: www.downsyndrome.org.au/wa

Tasmania

Down Syndrome Tasmania Inc.
T: 1300 592 050
E: info@downsyndrometasmania.org.au
W: www.downsyndrome.org.au/tas

Northern Territory

Down Syndrome Association NT
T: (08) 8985 6222
W: www.downsyndroment.com.au

Australian Capital Territory

ACT Down Syndrome Association Inc.
T: (02) 6290 0656
E: admin@actdsa.org.au
W: www.downsyndrome.org.au/act

downsyndrome.org.au

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Australia