

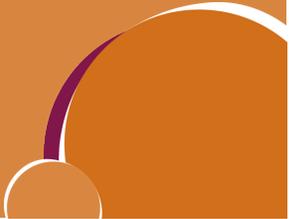


Down Syndrome  
Australia



# Ageing and Down syndrome

# Ageing and Down syndrome



In Australia most people with Down syndrome can now expect to live on average to 55 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 the five key areas of wellbeing, identified by Felce and Perry (1997), and divided the resource into four main sections to help develop and maintain a coordinated approach to support and optimise the well-being of an ageing adult with Down syndrome. (We have chosen to combine Social and Emotional wellbeing)

The key areas which we will look at are:

- Productive wellbeing
- Physical wellbeing
- Material wellbeing
- Social and Emotional wellbeing.

By recognising and understanding the needs in each of the key areas, and working with the person with Down syndrome, better outcomes can be achieved as they age.

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 your local state or territory Down Syndrome Association who are able to assist with the accessing of up to date relevant information.



## Productive Wellbeing

Productive wellbeing is interrelated to the other four areas examined in this resource and is a culmination of all that has happened in the life of the person with Down syndrome. It 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 one's life such as home, work, leisure and education. This resource encourages the productive wellbeing and growth of all individuals with Down syndrome, which then enables them to effectively contribute to their own ageing care and planning 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 show changes with age and therefore present earlier in ageing adults with Down syndrome, these may include:

- hypothyroidism
- Type II 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
- atlantoaxial instability
- obstructive sleep apnoea
- depression
- epilepsy
- dementia – Alzheimer's disease
- immunodeficiency
- arthritis.

Suggested testing or screening regimen:

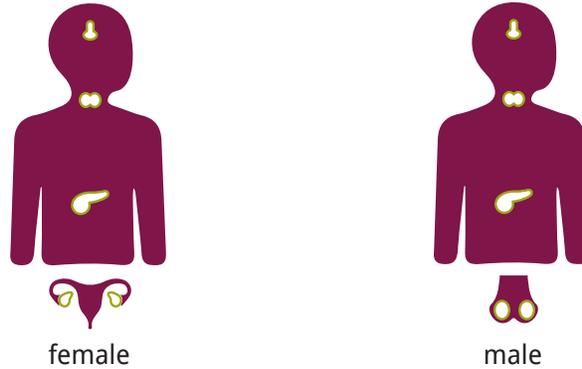
Annual	Blood test for: thyroid function (TSH), full blood count, urea and electrolytes, liver function, cholesterol screening and blood glucose level
Annual	Blood pressure testing Cardiovascular exam which may include echocardiogram (ECG)
Bi annual	Audiology testing and otoscopy (ear exam)
Bi annual	Visual screening by an optometrist for vision, glaucoma, keratoconus and refractive errors
Bi annual	Screening for Coeliac Disease.
Bi annual in women	Mammogram (50–74 year old) along with regular breast examinations 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.
Every 5 years after the age of 50	Haemorrhoids check

Many of these tests are recommended for all adults as they age but have been included in this table for completeness of a medical examination.

It is also recommended that a diary or journal of all doctor's and allied health appointments, tests, scans and test results are kept together 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 closely monitored.

An example of a medical record is shown in **Appendix 1**.

# Endocrine System



## Hypothyroidism

Studies have shown that approximately 40 per cent of adults with Down syndrome will develop hypothyroidism (under activity 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. Over activity (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:

- 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)
- recurring 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](http://www.diabetesaustralia.com.au)**

## **Menopause**

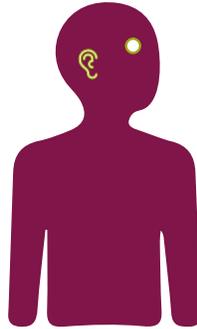
Menopause, otherwise known as 'the change of life', is said to have occurred 12 months after a woman has had her last menstrual period. Menopause is a natural biological process and occurs due to changes in female hormone levels. Studies have indicated that women with Down syndrome have an earlier age onset of menopause, approximately – five to six years earlier than the general population (Esbensen A. J., 2011) – which has implications on their general health. Menopause produces an increased risk for heart disease, depression, osteoporosis, breast cancer (the incidence of breast cancer in women with Down syndrome is reportedly very low) and dementia in all women. Symptoms of menopause may occur at any of the three stages (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 behavioral 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, this may include Hormone Replacement Therapy (HRT) and/or dietary changes as a method to assist in treatment of 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

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 per cent 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 to the optic nerve which gradually affects sight without warning and often without symptoms. Treatment is a regime of drops, prescribed by a doctor, which continue for the rest of the person's life.

## Long sighted (hyperopia) or short sighted (myopia)

Age related longsightedness 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:

- headache
- tired eyes
- frowning or squinting
- blurred vision – 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:

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

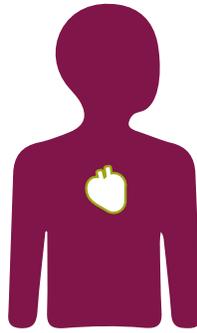
## Ears

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 however thought that medical conditions and recurrent ear infections early in life may influence the ear health of the individual later in life. Hearing aids and ear cleaning (as recommended by a GP) can assist hearing.

Signs to look for:

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

## Heart

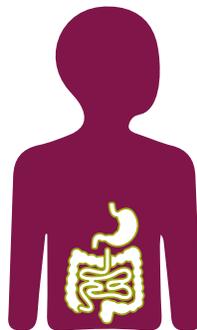


Adults with Down syndrome may have a higher occurrence, than the general population, of cardiac valve conditions, cardiac arrhythmias or pulmonary hypertension which can occur even in those who have had no previous heart issues (Prasher V. P., 1994). An Australian study (Sobey C.G., 2015) suggests there 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 when 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:

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

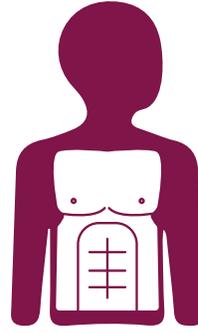
## Obesity

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
- limiting unhealthy foods and beverages, it may be worthwhile speaking with a dietitian
- limiting television time, screen time and other 'sit time'.





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 and makes 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, and 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.

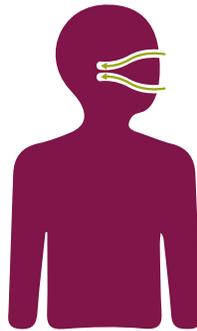
## Atlantoaxial Instability

Degenerative osteoarthritic changes affecting the spine are reported to affect between 22–40 per cent 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:

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

## Respiratory



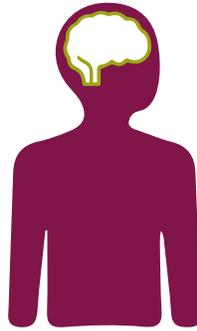
### Obstructive Sleep Apnoea

Obstructive Sleep Apnoea (OSA) is present in approximately 30–55 per cent 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 when asleep called a CPAP machine, along with weight loss and other lifestyle modifications.

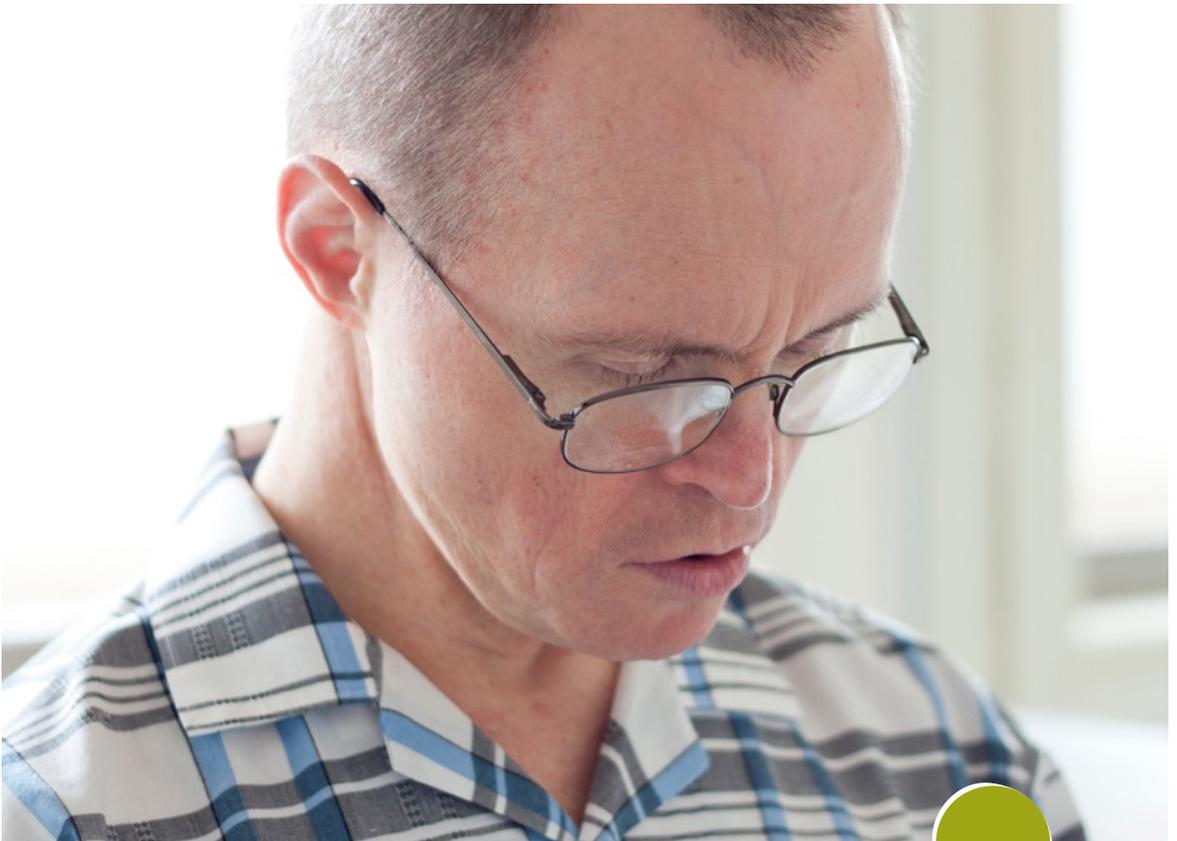
Signs to look for:

- 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).



## Alzheimer's disease

Alzheimer's disease is a progressive degenerative condition of the brain that results in a gradual change, over years, in a person's ability to think, remember and perform tasks of daily living.

In ways that scientists don't yet understand, the extra copies of genes present in people with Down syndrome cause developmental problems and health issues. Scientists think that the increased risk of dementia in individuals with Down syndrome may also result from the extra gene present on chromosome 21. Some studies suggest that 30 per cent of people with Down syndrome aged in their 50's have Alzheimer's disease and more than 75 per cent aged 65 and older have Alzheimer's disease (Barnhart R.C & Connolly B., 2007).

Symptoms of Alzheimer's:

Early Stages:

- reduced interest in being sociable, conversing or expressing thoughts
- decreased enthusiasm for usual activities
- decline in ability to pay attention, learning or recalling new information
- short-term memory loss (difficulty recalling recent events, learning or recalling names)
- behaviour changes
- personality changes
- depressed mood
- lack of motivation
- sleep disturbance.

Middle stages:

- decreased ability to perform everyday tasks and self-care skills
- increased disorientation to time and place – finding their own room/toilets
- worsening mood and behavioural fluctuations
- physical changes such as:
  - new onset seizures
  - urinary incontinence and possibly faecal incontinence
  - swallowing difficulties
  - difficulty with walking and poor depth perception – difficulty with stairs and uneven surfaces.

Advanced stages:

- significant changes in memory
- significant changes in ability to perform daily tasks and self-care
- profound speech loss – understanding of conversations
- full incontinence
- higher incidence of chewing and swallowing issues which can lead to dehydration, malnutrition, aspiration and pneumonia.

### Recognising and diagnosing Alzheimer's Disease

Alzheimer's disease in any individual is considered when a series of changes has been noted compared to their previous 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 when the medical practitioner 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.

Because 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 this assessment and, if required, refer the person to a public or private assessment service.

### After Diagnosis

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

## 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 support team around the person with individuals and environments they feel comfortable and familiar with.

- 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 etc.
- A positive approach should be emphasised and nonverbal 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, visual aides, short concise sentences and deliver information slowly.
- Patiently wait for responses.
- Observe for behaviors that may be interpreted as forms of communication to show frustration, anger and anxiety.

## Resources and contacts

For support and services specific to your state or territory contact your local Down Syndrome Association via [www.downsyndrome.org.au](http://www.downsyndrome.org.au)

Booklet on Alzheimer's and Down syndrome

[www.cddh.monash.org/assets/dsad-booklet-final.pdf](http://www.cddh.monash.org/assets/dsad-booklet-final.pdf)

Alzheimer's Australia

[www.fightdementia.org.au](http://www.fightdementia.org.au) or 1800 100 500

Dementia Behaviour Management and Advisory Services (DBMAS)

[www.dbmas.org.au](http://www.dbmas.org.au) or 1800 699 799

General information on aged care

[www.myagedcare.gov.au](http://www.myagedcare.gov.au)



## 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 necessary to periodically assess their living arrangements to ensure that they are safe, keeping in mind independence, good health and dignity.

Some considerations that need to be thought about are:

- When living at home proactively planning for the event of 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 in accommodation need to take place, 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 who will be able to advise of local services that are able 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.

**[www.downsyndrome.org.au](http://www.downsyndrome.org.au)**

## Retirement

Retirement is a natural progression for any working person and can often bring feelings of loneliness and depression. Planning for retirement for a person with Down syndrome is therefore 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 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](http://www.dss.gov.au)**

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. 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, regarding cessation of medical treatment, 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 appropriate.

[www.palliativecare.org.au](http://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 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 having 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:

- 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 breakup, retirement, menopause or any other external factors.

To assist in overall wellbeing, a Circle of Support, centered on the adult with Down syndrome, can be established, keeping the needs, wants, hopes and dreams of the person who has Down syndrome at the center and the focal point. A Circle of support can occur organically or by being thought about.

## The creation of a Circle of Support

A Circle of Support involves a group of people who are invited to volunteer to come together as a friend and in a deliberate way for the support, and in the interests of, the person with Down syndrome. The group forms a community of friendship and support around the person with Down syndrome and allows the individual to retain control over their life. It is a group that the person chooses to meet together as friends and the purpose is to work with the person on how they want to live in the future and what is important today. The five key areas of wellbeing should be considered when developing a Circle of Support for an adult with Down syndrome.



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

<b>Physical</b>	<b>Social and Emotional</b>
Physical wellbeing	Psychological wellbeing
Mental wellbeing	Social and engagement activities
Nutritional health	Spiritual wellbeing
Palliative and end of life needs	
<b>Productive</b>	<b>Material</b>
Employment	Funding
Activities	Legal
Assistance to daily living	Accommodation
	Safety

Every Circle of Support is individual to the person at the center. 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, others may have an advisory role and others may come and go and be on the periphery, providing emotional support. How often a group comes together, how formal the meetings are and their location, the topics that are discussed also vary depending upon the individual at the center of the group and their changing wants and needs.





Although there are no rules to adhere to, and no two groups are the same, these basic guidelines can assist the success of the circle:

- focus on the person’s strengths and build on those
- celebrate the person’s achievements
- identify negative situations in the person’s life and work to make positive changes
- regular scheduled meetings, which may alter over time (often monthly to begin with and then six to eight weekly as needed)
- the length of each meeting – usually two hours
- where the meetings take place
- someone nominated to lead the meetings
- an agenda for each meeting to ensure the needs and wants of the individual are met
- someone documenting the discussions and listing action items
- someone to maintain the communication to the circle friends
- the team must work with the adult in a coordinated, proactive, holistic and communicative way to plan and achieve the set goals in a timely manner
- meet the changes in needs, wants, and skills gained
- meet external factor changes such as changes in employment or living arrangements.

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.resourcingfamilies.org.au](http://www.resourcingfamilies.org.au)
- [www.mychoicematters.org.au](http://www.mychoicematters.org.au)
- [www.adhc.nsw.gov.au](http://www.adhc.nsw.gov.au)
- [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

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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](http://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](http://www.downs-syndrome.org.uk)

### Ageing and Down Syndrome: A Health & Well-Being Guidebook.

National Down Syndrome Society ndss.

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# Down Syndrome Australia

Down Syndrome Australia is made up of eight State and Territory associations providing support, information and resources to people with Down syndrome and their families across the country. Please contact your local association on the details below for any enquiries, or to contact Down Syndrome Australia directly, email [info@downsyndrome.org.au](mailto:info@downsyndrome.org.au)

## **Down Syndrome Victoria**

[www.downsyndromevictoria.org.au](http://www.downsyndromevictoria.org.au)

(03) 9486 9600 or 1300 658 873

## **Down Syndrome Western Australia**

[www.dsawa.asn.au](http://www.dsawa.asn.au)

(08) 9368 4002 or 1800 623 544

## **Down Syndrome New South Wales**

[www.downsyndromensw.org.au](http://www.downsyndromensw.org.au)

(02) 9841 4444

## **Down Syndrome Northern Territory**

[www.downsyndroment.com.au](http://www.downsyndroment.com.au)

(08) 8985 6222

## **Down Syndrome Association of Queensland**

[www.dsaq.org.au](http://www.dsaq.org.au)

(07) 3356 6655

## **ACT Down Syndrome Association**

[www.actdsa.org.au](http://www.actdsa.org.au)

(02) 6290 0656

## **Down Syndrome South Australia**

[www.downssa.asn.au](http://www.downssa.asn.au)

(08) 8245 4600

## **Down Syndrome Tasmania**

[www.downsyndrometasmania.org.au](http://www.downsyndrometasmania.org.au)

1300 592 050